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Being and becoming a reflective practitioner, through guided reflection, in the role of a spasticity management nurse specialist.

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Abstract

This thesis plots my development as a nurse specialist in spasticity management, a relatively new specialism that has not previously been researched. To address this gap in nursing knowledge this thesis demonstrates how guided reflection developed my individual professional knowledge and how this informed knowledge about nursing and caring when working with people with spasticity and complex disabilities.

I utilised a novel narrative methodology which combined my clinical and research practice. As an organising structure to research and gain insight into my practice I used the six layers of dialogue (Johns 2006). Through this process I explored my experiences by constructing story texts, then reflective texts, culminating in a narrative. Creating story text involved exploring my experiences through regularly journaling. Using a reflective model I developed the texts and dialogued with other sources of knowing such as literature and art forms. To further extend the text and reveal aspects of self that were previously unexplored I would share it with my supervisor(s) and others. To construct the narrative text I assimilated 29 reflective texts into a coherent whole, which represents my unfolding journey, of being and becoming a reflective practitioner.

This reflexive journey has changed my perceptions of situations and my practice approach. Significantly I describe that a person with complex disabilities lives in a precarious harmony; a matrix of highly refined strategies, unique to each person and their family, which allows them to effectively function as a family unit. It can be a fragile state, easily disrupted through life events, health and social care practices.
Implications for practice include that appreciating a person's precarious harmony, is vital to working in relation and towards a therapeutic alliance. Equally, not acknowledging and working with a person's precarious harmony will limit the uptake and ongoing use of novel technologies.
I summarise my practice approach, as the need to sculpt the practice space, tune into the other's wavelength to understand, connect with and flow towards maintaining and improving the balance of the person's precarious harmony.

Abbreviations Key

CJ: Prof. Christopher Johns
DoH: Department of Health
ITB: Intrathecal Baclofen Therapy
IP: Intrathecal Phenol Therapy
MS: Multiple Sclerosis
MSR: Model of structure reflection
NHS: National Health Service
NICE: National Institute of Clinical Excellence
NSF: National Service Frameworks
UMN: Upper Motor Neurone

Preface

My PhD journey and the evolution of this thesis did not start in a conventional mode, I was not considering a PhD scholarship nor had I identified a burning question that I wished to answer through rigorous, intense study. My identification of a gap in knowledge emerged from commencing a new, novel post and subsequently being involved in an action research project.

I was the first specialist nurse appointed in the UK dedicated to the role of supporting people to manage their spasticity. Existing research on spasticity management focused on the effectiveness of drug treatments or strategies for measuring spasticity and had been carried out by scientists, medical doctors and professions allied to medicine. Nurses had been involved with publishing information on safely managing intrathecal services (Gianino et al 1996, Porter 1997), auditing intrathecal outcomes (Jarrett et al 2001, Jarrett et al 2002), highlighting the need to manage spasticity (Ward 1999, Currie 2001) and describing aspects of the nursing role (Porter 2001, Jarrett 2002, 2004), but there was no research on the nurse's role in managing spasticity and hence no knowledge that directly informed me on how to be and become an effective spasticity specialist nurse.

Through my subsequent involvement in an action research study that utilised guided reflection as a method of data collection, I developed individual professional knowledge about being a spasticity specialist nurse. Through discussing and debating my narrative with colleagues in clinical practice, at reflection groups and conferences I realised my insights resonated with their experience. I recognised there was potential to extend this individual knowledge more generally to nursing and caring when working with people with complex disabilities.

Therefore the gap in knowledge that this thesis addresses can be articulated as; showing how guided reflection can inform the growth of individual professional knowledge and secondly how this informs knowledge about nursing and caring when working with people with complex disabilities.
In addition to learning specific things about my role I also learnt about guided reflection as a form of narrative research methodology and how this had a wider impact beyond my own self knowledge and specialism and could influence others considering such a methodological approach. I detail these insights in chapters 2 and 5.

Research paradigms

Denzin and Lincoln (2005) broadly describe four research paradigms: positivist and postpositivist, constructivist-interpretive, critical and feminist-poststructural. I heed their caution that as methodologies continue to develop these boundaries are fluid and may become less distinct. But in an effort to position my thesis methodologically I briefly describe these paradigms.

Positivism and postpositivism are rooted in the scientific method and form the foundations for quantitative research. Both perspectives develop an hypothesis and systematically study and identify links between different phenomena. They also advocate an objective, detached researcher role. The

key difference is the positivist perspective stresses 'theory verification' and postpositivist 'theory falsification' (Ponterotto 2005).

The constructivist paradigm assumes there are multiple realities and that meaning is co-created by the researcher and researched (Denzin and Lincoln 2005). It incorporates the hermeneutical idea that meaning is hidden but through deep reflection can be revealed. The goal is to understand the 'lived experience' (Ponterotto 2005). This paradigm has two main tenets that differentiate it from the positivist and postpositivist approaches; objective reality cannot be studied in isolation of the person and the goal is to understand not scientific explanation.

The aim of the critical paradigm is to disrupt and challenge the status quo, the researcher's focus is toward emancipation and transformation. The feminist and post structural approaches pay attention to the influence of race, class and gender on the real world. Emphasis is placed on representing the 'voices' of oppressed groups.

My approach

Researching self whilst still in practice required a flexible and adaptable methodological approach. I used guided reflection as a process of self-inquiry and transformation (Johns 2006). This methodology is a form of narrative inquiry and philosophically draws on aspects from the constructivist, critical and feminist- poststructural paradigms, this is explored in more depth in chapter 2.

The manner in which I approached my study could be described as a 'bricoleur', a researcher who as the research progresses utilises, as appropriate, different philosophical influences, methods, tools and ways to interpret and represent ideas (Denzin and Lincoln 2005). What this process constructs is described as a bricolage,

'As the scholar-practitioner interacts with others within a community of practice, his or her scholarly practice works with the practice of others to create a bricolage, or composite of methods, materials, actions and experiences, and sensations and perceptions... resulting in a bricolage that is contextually sensitive and which addresses the specificity of the phenomena or problem or decision.' (Jenlink, 2006, p.6)

To represent my 'bricolage' and plot my development as a nurse specialist, I write in the first person and use a story form to maintain a narrative style throughout the five chapters of the thesis. This is congruent with reflection a main tenet of my methodology and method.

To structure my research process I have used the six layers of dialogue (Johns 2006), a dynamic, systematic process of using guided reflection as a mode of self inquiry. I represent my journey as a reflexive narrative. The six layers of dialogue encourage creativity. I have found participating in art workshops, writing poetry and appreciating art, particularly the sculptures of Barbara Hepworth have stimulated my learning and appreciation of situations. Where appropriate in the narrative I include and

reflect on these unique experiences, although their definitive impact can be difficult to articulate, their inclusion demonstrate influences on my development and hence this thesis.

> 'The bricolage highlights the relationship between a researcher's ways of seeing and the social location of his or her personal history.' (Kincheloe and McLaren, 2005, p.316.)

Thesis outline

The first chapter details my background. I use the 'forestructure of understanding '(Heidegger (1962 [1927]) as a framework to situate myself in the context of the research. This is one of the ways in which I creatively use philosophy, albeit in a limited way, to bring out different perspectives of knowing.

In the second chapter I discuss influences from different research methods and situate my approach within the wider body of methodological research knowledge. I detail my methodological journey, including my influences, how I have dealt with issues and overcome difficulties within the process of constructing my narrative. The third chapter focuses on my practice and details the insights I gained, demonstrating how guided reflection informed the growth of my professional knowledge. These insights are developed in the fourth chapter to detail a summation of my approach to nursing people with spasticity and how this can have a wider influence on nursing and caring knowledge. In the last chapter I critically reflect on the methodological process, my conclusions and its possible influence on, and use, by others. To close I consider where I have reached in my transformational journey and possibilities for future narrative research.

The appendices, fact sheets and protocols are included to provide the reader with optional, additional information and technical reference. They were positioned outside of the main body of the text as their initial inclusion restricted narrative flow and I felt obscured meaning.

1.Background

The aim of writing my background is twofold; to situate self within the narrative, clarifying prior influences on my development as a nurse and secondly to enable the reader to interpret and appreciate the impact of my background.

Exploring and revealing

Heidegger (1962 [1927]) in his philosophical thesis 'Being and Time', describes a person as being in and of the world, which shares a culture, history, practice and language. He suggests that appreciating a person's background is vital to interpreting and understanding a person's world. By interpreting, understanding does not become something different, it is revealed as itself.

To explore and reveal my background I utilise the 'forestructure of understanding' which consists of a fore-having, a fore-sight and a fore-conception:

> 'In every case this interpretation is grounded in something we have in advance - in a fore having... In every case interpretation is grounded in something we see in advance – in a fore-sight... Anything understood which is held in our fore-having and towards which we set our sights 'foresightedly', becomes conceptualizable through the interpretation... In either case the interpretation has already decided for a definite way of conceiving it, either with finality or with reservations; it is grounded in something we grasp in advance – in a fore-conception.' (Heidegger, 1962 [1927], p191).

To clarify my fore having, I reveal what I consider to be significant influences on my practice; stemming back from childhood through my professional experience, shaping how I think, feel and respond to everyday situations. To explore my fore-sight, I consider the nature of spasticity, its impact and management strategies.

I detail the service that I provide to people with spasticity to illuminate the context of my practice. Emerging through these considerations is my fore-conception; my interpretation of important values for being a nurse and caring. I articulate these issues in a vision for my practice. I conclude this chapter by summarising my position as I enter the research and the purpose of this thesis. Heidegger shares,

> 'That which can be articulated in a disclosure by which we understand, we call 'meaning'... Meaning is the 'upon which' of a projection in terms of which something becomes intelligible as something; it gets its structure from a fore-having, a fore-sight and fore-conception.' (Heidegger 1962 [1927], p193).

Exploring my fore-structure will contribute to an appreciation (for myself and the reader) of my history, culture, language, skills and activities, which will illuminate influences on how I interpret meaning from my practice interactions.

Childhood Memory - 1974

Six clear-glass boxes line the walls,
each contain tubes and an infant.
The room is hot, smells and is noisy,
bleep, blink, shoooo, sounds of the effort to maintain life.

My sister is here.
As a nurse finishes washing her, she looks at me and says,
'I'm going to go and find her something pretty to wear.'
She returns with an old, washed out,
mustard coloured baby grow.

I turn to my mum and with disgust say,
'That's not pretty, it's horrid!
When I grow up, I am going to be a nurse and
I'll never say I'll put you in something nice when it isn't.'

At home I would intently watch as my mum fed her,
every four hours, day and night.
Simultaneously; food into the mouth, and tummy tube,
Whilst carefully wiping the expelled food,
from the hole in her neck.

She needed lots of clothes.
We were first in the village to get an automatic
washing machine.
One day whilst lying on her back, she was sick,
I turned her and wiped away the sick, like mum
would have done.

When I found mum, I reported what had happened.
Momentarily she panicked but then relaxed.
I remember the glow I felt, when she hugged me
and said how calm and good I was at
being with my sister.

My sisters short life (Katie Jarrett 1974 – 1975),
was the seedling to my work as a nurse.
This thesis is a culmination of my growth to date,
I hope it nurtures, the development
and progress of others.

21/10/06













Fore having
Reflection

The first verse of this poem has lain dormant in my memory for many years, I think it may have made it onto paper once, but I can no longer locate that early attempt. It re-emerged in my thoughts when I was considering how to introduce my thesis and when asking myself, 'why am I a nurse?' The subsequent verses flowed from the first with seemingly little conscious effort of thought or subsequent alteration of text.

Just after writing this poem I attended a workshop[1]. We discussed how poignant old photographs and in particular a family album can be, but how often they only contain happy pictures, suggesting an idealisation of the family. The workshop participants considered the realities of photographing a funeral and one person shared how he treasures the photographs he took at his mother's funeral. This discussion reminded me of the photographs I have of my sister Katie and the flowers at her funeral. I feel privileged that such intimate photographs of her exist and that my family did not shy away from documenting how she lived.

Considering the photographs I have subsequently seen of newborn babies, images of feeding and bathing are commonly captured, as these do of Katie. The significance of these photographs is that Katie's 'difference' her impairment, an oesophageal-trachea fistula and oesophageal atresia, so hidden to the naked eye, is symbolised in these photographs. Her gastrostomy tube is visible in the bath and when being fed. Her relentless feeding regime occurred in the kitchen, for anyone to witness. My dad made the stand, to make it easier for my mum to both infuse feed via the gastrostomy tube whilst continuing to stimulate Katie's oral taste and swallow development by giving her food by mouth. This oral food was then expelled via a surgically formed stoma in her neck. Her impairment was never intentionally hidden. It was part of her and subsumed into family life. I feel this early acceptance of disability into my family life, as a way of being and living has influenced my personal beliefs towards people with a disability. How this has translated into my practice as a nurse permeates my narrative.

Behind words – isolating hidden meaning

The words used in the poem convey the impact of my sister's life on my own development. In the first six verses I write from my perspective as a child using non-medical language, however rereading the poem there are several strong images that resonate with my experience of healthcare and being a nurse. Intensive care units remain stark and are noisy, often with a heady mix of human and antiseptic type smells. The use of technology is even more evident as health care professionals increasingly depend on it, although it could be argued that individual pieces of equipment are smaller, sleeker, have alarms that can be silenced and that the range of technology available is vast and growing, allowing for more choice. I feel sometimes this is at the expense of nursing skills. My

[1] Facilitated by photographic artist Kay Goodridge at Luton University (25th October 2006)

ongoing practice of palpating a pulse to judge its quality is often questioned by nurses running off to find an electronic monitor, surely we just need to know the number they claim. Words such as slow, quick, 'thready', 'booming', faint and intermittent are fast becoming part of nursing folklore when monitoring a pulse.

The words of the nurse about the clothes she chose for my sister were probably not intended to cause offence. However each time I remember the moment, I shudder, as I recall the impact of what I thought were careless words. This memory highlights the power of language and reminds me of the need to carefully use words, and to clarify how others interpret them.
Observation is an important attribute as a nurse. The poem captures how I observed and role modelled the actions of my mum. When Katie is sick, I don't shout for help, but put into action what I have observed. I deal with it on my own, yet know help from my mum is nearby if needed. This resembles the way that nurses who, although they would claim to be part of a team, often work in isolation. I ponder what 'teamwork' really means?

I 'report' the incident to my mum minimising my emotions as I feedback the incident in a perfunctory way. I remember not wanting to raise her anxiety. This resembles the oral culture of nursing that I have predominantly been involved in; provide the facts with little emotion, to give an air of being in control.
I bask in the feedback from my mum on my action and progress. I need to remember the 'glow', or 'feel good factor' I felt and the importance of touch, my mother's hug, to confirm the sentiments of her words. These memories remind me of the importance of feedback and the manner in which it is done. They cue me to consider how I communicate with others and remain sensitive to their feelings.

My role development

I have worked within neuroscience nursing since I qualified except for one year where I worked on a general surgical ward. My career and post registration education is summarised in a timeline (Figure 1.0).

Dates	Clinical area	Academic Courses
1985 -1988		Training and qualification
1988 -1991	Neurosurgical wards and ITU D and E grade staff nurse	
1992	General surgical Ward E grade staff nurse	
1993 - 1995	Neuro -rehabilitation E grade staff nurse F grade team leader	Diploma in Health studies incorporating neuroscience course
1995 -1999	Neurorehabilitation G grade sister	Degree in Rehabilitation
1999 - 2000	Nurse practitioner ITB H grade	
2000 - current	CNS spasticity management H grade / Band 8a	Commenced MPhil, an action research study to evaluate the implementation of clinical supervision.

Figure 1.0: Career timeline.

What attracted me to neuroscience nursing is its variability and unpredictability. Subtle alterations in a neurologically compromised person can indicate that significant neurological changes maybe occurring. To detect and effectively manage these signs requires intense observation and prompt action. This can involve not just recording their vital signs but vigilance on how the person is behaving and interacting.

Neurosurgery (1988 –1990)

My first three jobs were in neurosurgery. One of the consultant neurosurgeons when inducting new doctors to the ward would state, 'It's a foolish doctor who chooses to ignore the concerns of a neuro-nurse however junior she or he may be.'

His rational was that nurses spend significantly more time with patients than doctors do and often notice changes that neurological examinations never pick up. I thought it might have been just a pep talk for the nurses, until one night when I was not happy with Cyril. Earlier that day Cyril returned from theatre having had a craniotomy and partial removal of an astrocytoma. All his neurological observations were unchanged but he seemed different. Sufficiently concerned I summoned the courage to ring the Doctor in the middle of the night and said, 'Cyril is not right – but I have nothing concrete to go on, his 'neuro obs' show no change.'

I remember a large sigh from the Doctor, but he did come to the ward and within the hour Cyril had a huge bleed and was back in theatre. The Doctor thanked me for acting so quickly. I could not identify what cued me to know Cyril was unwell. I could only ever articulate 'he wasn't right'; somehow I had learnt through my experience. I was developing the skill to read the 'whole' pattern and the confidence to act on my intuition, not just on changes in the rules or in this case waiting to observe a difference in his neurological observations. Benner (1984) describes such a transition as moving from proficient towards expert practice in her 'Novice to Expert' model of skill acquisition in nurses.

Value of Teamwork

It is rare for a single discipline to manage the outcome and impact of neurological changes; the input of different disciplines is required necessitating effective teamwork. Working as part of a neurosurgical team required relentless observation and an interdependence, this resonated with how my family worked together to care for my sister, Katie. I learnt that effective teamwork includes respect, honesty, humour and open communication; set against an atmosphere of working with each other rather than for someone, for example the doctors.

Neuroscience knowledge is continually evolving and in some aspects remains poorly understood, so as with Cyril, his care and subsequent intervention relied on my intuition. I am mindful of power differentials between health care professionals and the dominance of doctors but I feel the gap is smaller in neuroscience than other health care specialties. I believe there is a reliance on the intuitive skill of colleagues to maintain safety of care and this requires a greater interdependence between

disciplines and respectful interdisciplinary working relationships. I appreciated having a role within the team that other members respected.

Neurosurgical intensive care (1990-1991)

From the wards I moved to neurosurgical intensive care (ITU). I remember wanting to overcome a fear of technology. Although I was not conscious of such an influence at this time, it is possible my experience of Katie in ITU had left me with a negative image of technology.

I didn't flourish. I struggled to gain job satisfaction caring for someone who was sedated and ventilated. I missed verbally communicating with them, having to rely instead on their family and friends to achieve an awareness of who the person was.

During a shift so many machines bleeped and burred to court my attention. The rigidity of recording neurological and ventilation observations governed my timing and interactions with patients. My practice became routine and controlled. Whilst I was part of a team the work was very isolating, each nurse would essentially be responsible for one or two patients and their respective bed spaces. There was an air of competitiveness to maintain the neatness of your allocated area. I do not thrive on competition and resented this being a primary aim as opposed to direct patient care. There was some joint working, for instance to turn patients, but it was minimal.

My skill acquisition was predominantly related to managing technology. I occasionally observed the interpersonal skills used by senior nurses and doctors when discussing the sensitive issue of organ donation with the relatives of brain dead patients. However, this work was often done in private so opportunities to observe and develop skills in this area were limited.

My ITU experience was always tinged with the threat of violence either from patients coming off ventilation or to patients who required police protection for their safety, often from the perpetrators of their head injuries. I will never forget Steve being weaned from sedation and the ventilator. He was angry, shouting, hitting out at everyone and ripping out all his intravenous lines. He thought he was still being attacked and was continuing to fight his assailant. Trying to get away, he fell out of bed not knowing his body now had a permanent left sided weakness. He was unaware four weeks had passed during which he had endured masses of neurosurgery to repair his severely wounded brain following the removal of an axe from his skull.

I didn't enjoy working with the potential threat of managing violent behaviour.
ITU was a valuable experience not least for illustrating to me the aspects of nursing I enjoyed. I realised I thrived on interacting with patients, acutely observing them and responding to changes without necessarily being reliant on machines. Although I liked to work independently I missed the opportunities for teamwork and I wanted to work in an environment with a reduced threat of violence.

I became disillusioned with neuroscience and wondered if it was the right speciality for me, I moved to a general ward that specialised in pancreatic surgery.

General surgery (1992-1993)

Unexpectedly this experience rekindled my passion for working with people with neurological changes. Having moved from a highly controlled environment for serious head injuries I was exposed to the potential mismanagement of patients with mild head injuries who were briefly admitted to general surgical wards. A majority of these people had sustained their head injury whilst under the influence of alcohol and most were homeless. Nurses did not view these people as popular admissions. I noticed how the care given was minimal and often judgemental. The nursing team preferred a brief stay often just overnight. I found the early discharge back to the streets without considering the potential of neurological damage brutal and uncaring.

Positively I was invited to join a working party of senior clinicians to participate in writing a multidisciplinary policy for the management of people with mild head injuries admitted to general wards. I was able to use my neuroscience nursing skills to influence the resulting policy and I received positive feedback on the value of my input from the multidisciplinary members involved. This encouragement led me to reconsider neuroscience nursing. I applied for a Diploma course[2]. This modular course included placements on neurology, neurosurgery, intensive care and neurorehabilitation.

Neuroscience diploma (1993)

During my neurosurgical placement I witnessed pioneering surgical procedures that were being carried out on people with existing complex disabilities. I struggled to prepare people for the extent of the surgery they were to endure. I did not address the high probability they would become more disabled or die, rather than improve. I shudder as I reflect on how poorly I met their information needs. Whilst they consented and could articulate the risks of the surgery, communication was difficult and I wrestle with whether they really did understand the risks involved. I do not believe the team or I ever really addressed their true intentions and hopes for proceeding with surgery.

At the time I discussed my concerns with my tutor. She shared how she had a similar experience during her neuroscience career. For her the surgical operation had been the insertion of ventricular-peritoneal shunts. I was shocked; this is now a routine neurosurgical operation. Despite her support, I was uncomfortable with how people with disabilities were (not) being involved in treatment decisions. They were being worked *on* rather than in partnership *with*. I feel this experience helped to shape my vision of working with people with complex disabilities.

[2] Diploma in Health Studies at the National Hospital for Neurology and Neurosurgery.

In contrast the practice of the multidisciplinary neurorehabilitation team demonstrated a partnership model of working with people. This felt more in tune with my developing values so after the course I moved to work in rehabilitation.

Neurorehabilitation nursing (1993-1999)

I sensed from my neuroscience course and ward experiences that rehabilitation was seen as the least desirable area to work for a neuroscience nurse, being physically demanding, unglamorous and slow pace. Despite encountering this negativity I was attracted to join the rehabilitation team as it had strong leadership. The nurse manager and specialist nurse were aware of its negative profile and that nursing within the multidisciplinary rehabilitation team was oppressed. They were working towards raising the profile of nursing. I knew from my neurosurgical experience that nurses could be vital team members; I joined the effort to demonstrate the role and value of nurses in rehabilitation.
I wonder now if the negative attitudes I encountered towards rehabilitation were in fact an extension of negative political and societal attitudes towards people with disabilities. Such negativity is still clearly expressed in the foreword of a recent report arguing for collaborative participation to challenge 'disabilism' within society,

> 'Disabilism exists in the under-resourcing of and low status accorded to disabled people and their organisations; they are left off the policy-making agenda. In all areas of social and political life disabled people are typically seen as person's requiring charity and services, not as human beings with full civil rights.' (Hurst and Manwaring, 2004, p12).

In contrast to neurosurgery, the focus of neurorehabilitation is not just about controlling symptoms; it also involves supporting individuals to plan their future lives managing the consequences of a major illness. In neurorehabilitation this often involves incorporating the work of managing a complex disability into their daily lives. Rehabilitation deals with 'life' issues in all their complexity. I found it physically but equally emotionally demanding.
The rehabilitation nursing challenge came from being with people at the raw edge of learning to live with complex disability. I was exposed to the harsh realities of sudden and gradual disability, of patients' struggle to refashion a lifestyle and master daily tasks previously taken for granted. I saw lives being radically changed.

In neurosurgery I could delay managing emotional issues by projecting them to the future. For instance, whilst I was aware that pursuing investigations could provoke anxiety, I would deal with this by providing information about the procedures and the process. I would avoid their emotions by saying, 'Let's wait to see what your diagnosis is before we try to plan for the future.'

I used the process to always look forward resisting the current reality and the need to manage difficult emotions. In doing this I also resisted dealing with my own emotions; I kept them at a distance. Rehabilitation was different; the focus was managing symptoms and merging them into a new life structure for the person and often their families. I no longer had the pursuit of a diagnosis and investigations to hide behind. The demand was to work within the current reality.

First Degree (1996-1999)

My neurorehabilitation knowledge developed further, notably through completing a degree in rehabilitation.[3] The course was instrumental in introducing me to the Disability Discrimination Act (1995) and literature that challenged my attitudes and practices towards people with disabilities (Swain et al 1994, French 1994, Morris 1996). Perhaps because of my family's positive approach to Katie's disability I had not fully understood the degree of discrimination levelled at people with disabilities. I started to appreciate how disabled people were marginalized, both in society and health care.

Examining my experiences was both unsettling and rewarding. I started to challenge the paternalistic approach I was using in my rehabilitation nursing practice. I recognised how I had not always listened to disabled people or engaged them in decisions about their care, ignoring their wishes and knowledge of their own body. Significantly I remember watching a sketch performed by members of the degree course in which they acted the same scenario in two different ways. The focus was a teenage girl with moderate disabilities getting ready to go to school to sit some exams. She was nervous about the exams and worried about being late. In the first sketch the carer verbally acknowledged all the girl's fears but encouraged her to dress independently. This was a slow process exacerbated by the girl's increasing anxiety about being late. In the second sketch the carer listened to the girl's worries and helped her to dress so as she was not late. I saw myself in the first sketch, proud of being what I would have termed a 'true' rehabilitation nurse, but this sketch poignantly demonstrated it was not always an appropriate way to practice.

The value of walking

When working in neurorehabilitation people strove to walk, often at a cost of reduced independence than if they chose to use a wheelchair. I believe they were driven by negative, societal attitudes towards disability (Swain et al 1994, French 1994, Morris 1996) where the wheelchair remains a powerful symbol of disability, despite its potential to be liberating and to promote independence (Sapey et al 2005).

The English language is littered with metaphors that reinforce walking as dominant to other forms of mobility. Lois Keith (1995) captures this poignantly in the following poem:

Tomorrow I'm Going to Rewrite the English Language

Tomorrow I'm going to rewrite the English Language.
I will discard all those striving ambulist metaphors
of power and success
And construct new ways to describe my strength.
My new, different strength.

[3] A multidisciplinary rehabilitation degree run by Oxford Brookes University

Then I won't have to feel dependent
Because I can't stand on my own two feet.
And I'll refuse to feel a failure
When I don't stay one step ahead.
I won't feel inadequate if I can't
Stand up for myself
Or illogical when I don't
Take it one step at a time.

I will make them understand that it is a very male way
To describe the world.
All this walking tall
And making great strides.

Yes, tomorrow I'm going to rewrite the English Language
Creating, the world in my own image.
Mine will be a gentler, more womanly way
To describe my progress.
I will wheel, cover and encircle.
Somehow I will learn to say it all.

(Lois Keith, 1995, p57)

I was shocked at the power of these everyday words and phrases. Not just by the negative impact they could have on a person who uses a wheelchair, but also how insidiously, such words may inform societal opinions about people with disabilities.

The impact of Lois Keith's poem continues to motivate me to be sensitive in my practice to the power of words. For example I always challenge the use of the descriptor 'wheelchair bound' commonly used in health care communication when describing a person who uses a wheelchair. This terminology does not suggest the freedom and increased social and physical interaction that a person using a wheelchair may experience; it merely suggests they are tied to their wheelchair.

Oliver (1993) strongly suggests that it is the rehabilitation professional that promotes walking as the ideal and wheelchair use as negative. He states an individual who chooses to use a wheelchair and not to walk threatens the power and existence of the rehabilitation movement. I can appreciate the perspective that Oliver (1993) describes and now realise that towards the end of my time working in rehabilitation I was finding it increasingly difficult to work within the rehabilitation model where, despite attempts to work in partnership with the individual, the professional and societal view dominated.

The degree incorporated a specialist practitioner award that required me to reflect on my practice and learn from my experiences. To achieve this I commenced clinical supervision with the specialist nurse.

My involvement with clinical supervision

Before 1994, I had no experience of clinical supervision but as part of my diploma I completed an introductory module on clinical supervision. The emergence of clinical supervision within general nursing was set against a background of a new political culture. The conservative government reformed the NHS structure, resulting in a significant strategic change; the implementation of the 'internal market' into the health care system (DoH 1989). A business culture was promoted where healthcare was required to pursue efficiency and cost effectiveness. General Practitioners became fund holders and purchasers of health services whilst hospitals became providers. Managers would lead on strategic direction and manage budgets, no longer just providing a supportive function to clinical teams. There was a push toward individual practitioners being accountable for their practice, which was highlighted in the nurse's revised code of conduct (UKCC 1992). Clinical supervision was suggested as a mechanism to develop and sustain the practice of nurses (Butterworth 1992, Butterworth et al 1997). The NHS Management Executive in their development of the white paper: *Vision for the future* (DoH,1993) advocate clinical supervision and offer the following definition:

> 'A formal process of professional support and learning which enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice and enhance consumer protection and safety of care in complex situations. It is central to the process of learning and to the expansion of the scope of practice and should be seen as a means of encouraging self-assessment, analytical and reflective skills.' (DoH, 1993, p15).

I was keen to explore its use; in 1995 I wrote a feasibility study[4] to explore options for implementing a system of clinical supervision into nursing practice on the rehabilitation unit. From this study and in collaboration with the nurse specialist, we developed and implemented a system of clinical supervision that we hoped would be practical and meaningful. This involved group supervision for the F, E and D grade nurses and one-to-one sessions for me; the specialist nurse facilitated these sessions.

One of my supervision sessions became the trigger for my degree dissertation. I had struggled to support Cynthia a woman with multiple sclerosis (MS), who had repeated admissions for rehabilitation. Her disease progression was relentless, continually challenging her to make adjustments to her life. She had only short periods of stability or none at all before her body altered again. I was influenced by the work of Corbin and Strauss (1991) who suggest that a chronic illness trajectory goes through various linear stages of crisis, acute, stable, comeback, unstable, downward and dying. However I felt the process was cyclical where individuals could jump back and forth between stages interjected with periods of wellness (Jarrett 2000). I carried out a literature review to explore if the concept of transition was useful in describing the experience of living with chronic illness. From this review I devised a model of coping: the transitional process of living with chronic illness (Jarrett 2000, Appendix 1). The main tenets of this transitional model are,

- *The concept of transition can be used to describe the experience of living with chronic illness (Adaptation, adjustment and mastery can describe ways in which individuals move in their transition process of coping with chronic illness, but they are not definitive endpoints that have to be achieved before an individual can be considered as well).*

[4] Dissertation to obtain a Diploma in Health Studies

- *A chronic illness trajectory is cyclical and includes periods of wellness, where symptoms may be absent but the person is described as 'at risk' of symptoms reoccurring.*
- *The management of chronic illness can be a lifelong process and is chiefly carried out by the individual or families and carers in the home.*

My experience of clinical supervision was significant in my development. A subsequent critical incident demonstrated how it was supporting the nursing team.

1998: Managing the aftermath of an extraordinary incident through clinical supervision

Death is a rare event on a rehabilitation unit yet in one day we had two cardiac arrests where both people died. The rehabilitation unit was not situated on the main hospital site and doctors were not available when the incidents occurred. The nurse's only support was via the emergency ambulance service. One of the ambulances crashed on route to the unit; together with a colleague I resuscitated a person for 45 minutes. The emotional affect on the team, the patients and myself were considerable.

The system of supervision had been in use for 18 months, the nurses were comfortable with its purpose and format. To debrief the nurses requested additional sessions. These were successful as the format was familiar and we didn't feel threatened even when sharing painful aspects relating to these situations. The team felt the outcome was so powerful that we should share it with other nursing colleagues; the scenario was presented at the national rehabilitation nursing conference later that year.[5]

The effort to maintain leadership

My first degree helped me to clarify my role in rehabilitation and challenged my perception of disability. I continued my transitional journey from 'working on disabled people' towards 'working with people with disabilities', appreciating their life contexts and how they incorporated illness into them. In parallel to this my management skills of leading a team were being constantly tested.

Nursing forms the largest population within healthcare disciplines and I believe has the greatest diversity of cultures, range of intent for work and educational abilities. Whilst these aspects can contribute to the richness of what nursing can offer and can be a positive challenge for any nurse manager, by the end I was exhausted and no longer wanted to manage nurses. I did not like disciplining staff, but during my time I had to deal with racism, aggression, competitive infighting, long-term absence, sickness and unauthorised absences. These issues were emphasised when I realised that my peers from other disciplines only had to deal with a fraction of such issues and were consequently less stressed. Professions allied to medicine tend not to have the diversity of culture and ethnicity that nursing offers, therapists tend to be predominantly white, female, middle-class and degree educated.

[5] Johnson J and Jarrett L (1998) Implementing Clinical Supervision in a Neurorehabilitation Unit. Platform Presentation. RCN Rehabilitation Conference. Harrogate. UK

I still enjoyed the clinical work, wanted to lead and influence others but managing the team subsumed these aspects of the role. To survive, I went out of my way to treat people equally, to listen and allow all to contribute. To maintain a sense of equality I withdrew from having friendships with team members out of work, I found it very isolating. Despite having a supportive manager I was battle weary from trying to lead a team whilst maintaining the rules of the organisation.

More and more my administrative duties were taking me away from patient care. I tried different ways of compartmentalising my work between the administrative and clinical, where possible sharing and delegating responsibilities, but I got to a stage where my clinical input was no longer effective. Perhaps this was more vivid working in rehabilitation than if I had worked in another speciality. The changes people make on a day-to-day basis can be very small. Continuity of care is required to notice these changes, to give positive feedback to the individual and to have the confidence to support them to progress further and take risks. This maybe as small as encouraging a person to only use one hand to steady themselves, while standing at a sink, so as they can start to work towards independently brushing their teeth.

I missed continuity and effectiveness in my clinical input and was keen to move away from managing a team.

Moving to specialise

In 1999 I started a new role as a nurse practitioner; the impetus to create the post came from the advent of new technologies to manage two neurological symptoms; Intrathecal baclofen therapy (ITB – Fact sheet 1) to manage spasticity and thalamic stimulation to reduce tremor.
This post was attractive as I could transfer and further develop my rehabilitation skills. It involved multidisciplinary teamwork but no staff management responsibilities. Initially, because of my previous ITU experience, I was concerned about pursuing a role where technology played a prominent part. I knew the judicial use of technology could assist a person's transition to wellness but I viewed it as only part of an overall treatment plan. Discussing this with the nurse manager and specialists who developed the role revealed they were keen that the person employed developed the nursing aspects of the role and did not just concentrate on becoming an expert in the technology.

During the first year I worked with five people who used stimulators only one person experienced a transient positive effect on their tremor. The surgery was invasive with significant recovery periods and seemingly little gains. As a result the professor decided to stop offering stimulators as a potential treatment. Meanwhile I was expanding my role to work not just with people using ITB but people with spasticity in general. By the end of 2000 I became the first nurse specialist appointed in the UK dedicated to support individuals to manage their spasticity.
During my first year as a specialist nurse I did not have regular clinical supervision; I missed the support and development it had previously afforded me.

Re-establishing my involvement with clinical supervision

At the beginning of 2001 I attended a meeting convened by an assistant director of nursing to explore options for training clinical supervisors to improve the provision of supervision to nurses across the Trust.

Journal entry- January 2001

In the packed room of senior nurses from across the Trust I hear myself say,

> *'Whatever system of training clinical supervisors we choose we have to consider ways of evaluating the system. We need to learn why supervision has previously been embraced and maintained in some areas and not others.'*

In this meeting I mentioned three times the need for evaluation. Professor Christopher Johns[6] (CJ), invited to the group to share his expertise on clinical supervision and potential training options, suggested that an action research study could run parallel to the method of training he was proposing. The trainee supervisors could become co-researchers and evaluate what promotes and constrains their efforts to implement supervision. Such a piece of research could form part of a Masters degree programme. This sparked my interest, a year had passed since I completed my first degree and I was considering the options for a higher degree.

Seizing the opportunity

Clinical supervision had previously been integral to my nurse experience, education and development and it seemed a logical step to facilitate an action research project on clinical supervision. I was particularly driven by the prospect of receiving supervision again. With a minimal knowledge base for spasticity nursing that consists mainly of reviews (Gianino et al 1996, Ward 1999, Currie 2001, Porter 2001), I saw the opportunity that regular reflection and supervision could afford me to develop skills in my new role, plus to appreciate what a spasticity nurse is and could be.

The action research study

I agreed to facilitate the action research project. I registered on a Master of Philosophy program at City University in October 2001 and Professor Sally Glen became my second supervisor.[7]

The focus of the action research study was to evaluate the implementation of supervision across the Trust. Data was collected through focus groups and individual supervision sessions and reviews. One aspect of the evaluation design was for trainee supervisors to feedback their experiences of receiving supervision. I began a supervisory relationship with CJ. We arranged to meet every six weeks for approximately one hour and agreed to be committed, confidential and honest throughout the process.

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[6] Formerly from Luton University now Bedford University

[7] Throughout the duration of my research Prof. Sally Glen regularly reviewed my written work and we spoke on the telephone or met to discuss my progress on a three monthly basis In my final 18 months (2007 - 2009) Dr Paul Godin from City University joined my supervision team to ensure I had continued support from City University as Prof. Glen moved to Wolverhampton University.

It was my responsibility to bring a story to discuss and we agreed the structure to record our supervision sessions (Figure 1.1). My first session was in March 2001.

Session:	*Date:*
Progress on action plans and key points fed-back from supervisor on written text.	
Integrate significant issues discussed in this session into the text.	
Summarise significant issues that emerged from the discussion/written description.	
List literature discussed	
Summarise actions to consider or take before next session	
Reflections on how it felt to be supervised.	

Figure 1.1: Structure for recording the outcome of each supervision session.

Action research outcomes

Twelve course participants (out of a total of 45) volunteered to be co-researchers but only seven actively participated; these represented individuals who had volunteered for the course. The success of action research depends on the intent of the co-researchers to be involved in the project and their commitment over time (Hart and Bond 1995). The other less committed and forthcoming co-researchers and had been sent on the course by their managers which may have contributed to their lack of involvement.

The active co-researchers did suggest solutions to the problems we encountered, contributed to the development of a Trust-wide strategy and raised the profile of clinical supervision in their respective areas, but the amount of data collected was low which only allowed superficial analysis. The main findings are summarised (Appendix 2) and highlighted below.

The term 'supervision' is a significant barrier to nurses trusting and becoming involved in the process. They view the term and hence the process as suspicious and similar to what Gilbert (2001) suggests in his review, as a form of surveillance. To overcome this barrier some co-researchers adopted different terms such as 'guided reflection'.
Finding the time for supervision was another significant barrier. The co-researchers felt there was scope within their clinical areas to incorporate supervision but it would require a review of how time was effectively used and a reconceptualisation of how supervision or guided reflection is perceived, however this theme was not pursued in detail.

Considering my previous experience of clinical supervision, a surprise finding was that nurses rarely used supervision to discuss their skills and interactions with patients, preferring to discuss conflict resolution with colleagues or preparation for promotion.
The chief nurse's response to these findings was directive; nurses across the Trust should discuss their care of patients when in supervision. Mantzoukas and Jasper (2004) suggest the potential of reflection to liberate and raise the consciousness of individuals was seen as a threat by powerful others, (doctors, senior nurses and managers). To minimise this and maintain their own power; knowledge gained from reflection is advocated as inferior to that obtained from a positivist approach (Carper, 1978, Mantzoukas and Jasper, 2004), or more simply reflection is belittled as a tool of

development. These issues suggest a tension between clinical supervision being used as a professional tool to support and develop individuals, versus an organisational tool to protect and monitor standards of care.

Related Political Backdrop

In 1994 Beverley Allitt a nurse working in England was convicted of murdering children in her care. An inquiry into this shocking story emphasised the need for maximising patient safety when being cared for by nurses (DoH 1994 - *Clothier report*). Following this report a succession of significant papers stated that clinical supervision could potentially safeguard standards of care (DoH 1994b, UKCC 1996). This moved the purpose of clinical supervision away from the development of the individual nurse as outlined in the previous definition (DoH 1993, p15), towards the protection of patients and the organisation. In our action research study it appeared that nurses were ignoring the organisational needs and choosing to focus on their needs of conflict resolution with colleagues and career advancement.

In 1997 the newly elected labour government started to plan to modernise the NHS with less emphasis on the internal market. A detailed framework was published; *A first class service: quality in the new NHS* (DoH 1998), it included three main initiatives. Firstly, evidence for practice was to be appraised through a newly formed department the National Institute of Clinical Excellence (NICE). Secondly, how patients should be cared for throughout an illness trajectory was to be mapped through National Service Frameworks (NSF's), this included a NSF for long-term conditions pertinent to people with neurological conditions and disabilities. Thirdly, there was an emphasis on monitoring the performance of Trusts both centrally (Commission for Health Improvement) and locally through clinical governance strategies. To compliment these initiatives the nursing, midwifery and health visiting contribution were outlined in the document *'Making a Difference'* (DoH 1999). This document emphasises commitment to lifelong learning and development of clinical excellence; valuing the contribution from reflection and clinical supervision to achieve this;

> 'The learning that takes place at work through experience, critical incidents, audit and reflection supported by mentorship, clinical supervision and peer review can be a rich source of learning.' (DoH,1999, p30).

Whilst this acknowledges the value of experiential learning, the undercurrent of monitoring outcomes and safe guarding standards to protect the organisation persist.

I ponder the challenge I face of accommodating a model of supervision or guided reflection to learn about self and develop my clinical practice in an environment focused on outcome, such as the NHS is today. The subsequent chapters will explore this and the tentative idea from the action research study that nurses need to conceptualise clinical supervision differently in their daily work. Moving towards using reflective practice as a way of 'being' a nurse in day-to-day practice.

A change in focus: From action research to narrative

With completion of the Trust strategy and the sharing of the outcomes across the Trust the co-researchers decided to end the action research process as we collectively felt we had met our original aim of evaluating the implementation of clinical supervision.

Initially I only viewed my supervision sessions as part of the overall action research design. However the aspects relating to my development took on a life of their own. At my second university annual review meeting in 2003, I presented the existing data and collectively the reviewers, my supervisors and I agreed it was insufficient to pursue deeper understanding of the impact of clinical supervision and with the lack of further co-researcher involvement had limited scope for development. However it was agreed that my individual reflexive work did have the potential for development to PhD study.
A fundamental aspect of action research is group collaboration towards effecting social change (Winter and Munn-Giddings 2001, Waterman et al 2001). In only developing my involvement from the original design I was moving away from the group collaboration principle of action research. I needed to concentrate on an individualistic methodology and moved to develop a narrative approach. A narrative approach retains elements of action research in that it involves social action.

> 'Narratives are socially constrained forms of action, socially situated performances, ways of acting in and making sense of the world. Narrative researchers often write in the first person, thus 'emphasising their own narrative action. ' (Denzin and Lincoln 2005, p.641).

I discuss my approach in detail in chapter two.

Summary

Throughout my career I have not followed a master plan to reach my ultimate job. I have been keen to develop and progress but also to master the job at each level, so I have only ever looked toward the next potential post, for instance as an E grade I worked towards being an F grade. I have seen nurses who although were promoted quickly never consolidated their skills and were ineffective in their senior jobs; often they became disillusioned and left the profession. I am keen to maximise my experience to avoid disenchantment.

The following poem summarises my career and how in particular I have moved from requiring visual cues that I am a nurse to no symbols and a reliance on self. I felt an earlier version of this poem was too descriptive and took more of a narrative than poetic form. Inspired by an article on using 'haiku' a Japanese form of poetry (Biley and Champney-Smith 2003), I rewrote the poem. The haiku form only allows 17 syllables in a pattern of five, seven and five syllables in the first, second and third lines respectively (Cobb 2002). It should also contain a seasonal element and an image or picture that 'attempts to say something without saying it' (Biley and Champney-Smith, 2003, p40).
Whilst my poem is not true to the Haiku form, I have tried to follow the sequence in each verse and a sense of change is suggested through my career progression. My images are too obvious to suggest an alternative meaning. I feel though the discipline of being concise has added a dramatic flow to the verses. The poem acts as a metaphorical springboard from which I dive into discussing in detail the nature of spasticity and the context of my current role.

Towards *being* a nurse

My first uniform
Odd colour turquoise
But, oh the excitement

Tools to personalise,
attached every day
scissors and forceps,

Badges and fob watch,
ownership displayed by
'patient' name bands.

'Medi-swabs' clean,
deep pockets to store,
how the bugs grow.

Qualification,
my buckle is my symbol,
I am a staff nurse.

Bugs still grow
Angst of Infection Control,
Teams proliferate.

New protocols, rules,
No regalia now,
Harbours infection

Uniqueness gone
no tools to hide behind,
except my navy dress!

Patients distant.
Dress halts all talk
not asked to care,

I still want to nurse
My core purpose thwarted.
Unexpected gift,

Lifting and handling?
New guidelines, no dresses
Must be trousers.

Status not visual.
I wear the same uniform,
I'm in a team again

With less symbols
that I'm a nurse,
I need to use self.

Rehab is brutal.
No diagnosis to mask,
or overnight stays.

It's lengthy work,
facing harsh realities,
but I can still hide.

Solving problems
or setting goals.
I must look beyond.

Next step specialism,
people with complex
disabilities.
Health not illness.

No uniform now
or regalia to attach
just my name badge.

Working *with* people
I'm rule bound but freer.
I am just Lou.

On my journey
I have learnt 'how to do'
Now to develop self

I must work at my
core skills and vision
of *being* a nurse.



Foundation stone on wall of rehabilitation unit (1897)
For the benefit of a class of patient inadmissible to any other convalescent home in the kingdom

Fore sight

Previously spasticity management has been subsumed into the roles of rehabilitation nurses, disease specific or pain management specialist nurses. My reflexive narrative will explore what it is that I do and need to do, to be an effective nurse specialist in spasticity management. As a foundation to this evolving knowledge I will outline the nature of spasticity, its consequences and potential treatments. To put this in context I will outline the service and my current role. As this is a young service its development and associated protocols throughout the research period have always been in a state of flux and transition, the most up to date are provided for technical reference (Fact sheets 1-6, Protocols 1-7).

What is spasticity?

Spasticity is a neurological symptom and may be experienced by people with multiple sclerosis, cerebral palsy, stroke, brain or spinal cord injuries. It may also feature in less common conditions such as tropical or hereditary spastic paraparesis (Thompson et al 2005). The true nature of spasticity remains unclear. The most common definition used is:

> 'A motor disorder characterised by a velocity- dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks, resulting from hyperexcitability of the stretch reflex, as one component of the upper motor neurone syndrome' (Lance, 1980, p485).

A European working group, EU-SPASM[8] (Pandyan et al 2005) who collaborated to review spasticity measurement have challenged the Lance definition specifically in three areas:

- Limb stiffness is not only as a result of neural changes as normal visco-elastic properties of soft tissues also contribute (Dietz 2003).
- Spasticity is not solely a result of hyper-excitable stretch reflexes. Activity in afferent, supraspinal pathways and changes in the α motor neurone are also important.
- Spasticity is not just a 'motor disorder' as cutaneous and proprioceptive afferent activity is also involved.

(Stevenson and Marsden 2006)

A new definition was proposed, spasticity is:

> *'disordered sensori-motor control, resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles'.* (Pandyan et al, 2005, p5)

More simply spasticity can be described as stiff muscles that resist passive movement and is one component of the upper motor neurone (UMN) syndrome, which can occur as a result of acquired damage to any part of the UMN in the central nervous system (Greenwood 1998). Several symptoms can be associated with the UMN (Figure 1.2). Pain can also be present with these symptoms but not always. A possible description of why spasticity occurs is outlined in fact sheet 2. The ongoing need to review the definition I feel shows that both the clinical and scientific community continue to develop their knowledge on the aetiology of spasticity. The nursing perspective is critical to this debate and threads through my narrative.

[8] I was a member of this group

Often an individual will have a combination of the UMN symptoms, health care professionals routinely use 'spasticity' as an umbrella term to represent a person's unique presentation of these symptoms. Throughout the narrative I use the term spasticity predominantly to refer to its specific meaning of stiffness, however occasionally I use it more generally such as when referring to my job title, nurse specialist in spasticity management.

Positive (Additional motor activity)	Negative (Reduced motor activity)
Spasticity (Limb and trunk stiffness) Spasms (Involuntary movements of Limbs and trunk.) Clonus (Repetitive muscle movement often associated with feet tapping on wheelchair footplates) Associated reactions Positive support reaction Brisk tendon reflexes Extensor plantar responses	Weakness Reduced dexterity Reduced postural responses

Figure 1.2: Features of the upper motor neurone syndrome (Adapted from Stevenson and Marsden, 2006, p4)

Spasms and weakness

The main challenge to managing spasticity is it can co-exist with spasms and weakness it is their interaction and subsequent impact on a person's functional abilities that can make management so challenging (Sheean 2001, Stevenson and Marsden 2006). Spasms are sudden involuntary contractions of muscles that can cause gross limb and trunk movements (Figure 1.3). These can produce three different patterns, flexor toward the body and extensor away from the body or adductor where the legs pull towards each other (Stevenson and Jarrett 2006).

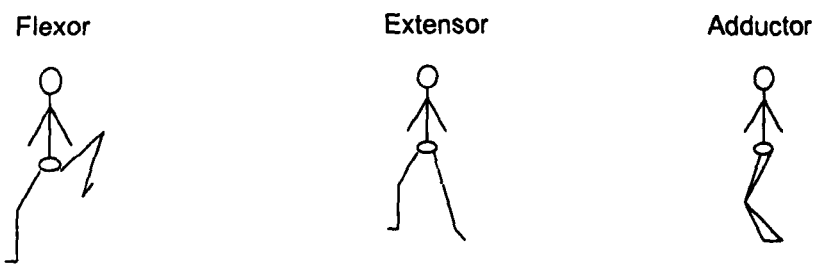


Figure 1.3: Different presentation of spasms

Spasms of the trunk can cause a person to arch off a bed or away from the back of the chair. These movements can be very powerful and cause a person to fall out of their chair or result in injury to carers. Positively some people can use their extensor spasms to walk or transfer.
Muscle weakness can also be a feature, which seems paradoxical that some muscles are stiff and others weak. These symptoms result from changes to different descending tracts, the dorsal reticular spinal tract (spasticity) and the corticospinal tract (weakness). These tracts are anatomically situated

close together; a negative effect on one often results in changes to both resulting in the co-existence of stiff and weak muscles[9].

For some individuals effectively treating their spasticity with medication exposes the previously co-existing but now unopposed weakness. For some the impact of this on their function can be more adverse than the presence of spasticity and weakness together. For instance minimising a person's painful spasticity may expose the extent of their weakness and they are no longer able to walk. The choice becomes living with pain, spasticity and able to walk or being pain free, weak and unable to walk. Managing spasticity and spasms is an ongoing balance between maintaining function, whilst minimising the effect of weakness and other symptoms related to the UMN syndrome.

Biomechanical changes

As well as the neural component of spasticity and spasms, if muscles, tendons and connective tissue are not regularly moved changes to their intrinsic properties can occur (Carr and Shepherd 1998). These changes can also contribute to the feeling of stiffness felt when passively moving a limb and can significantly affect function (Dietz 2003). These bio-mechanical changes can lead to the development of fixed postures of limbs known as contractures. These can be prevented but once formed are notoriously difficult to treat and can cause further problems with function or comfort (Thompson et al 2005).

Consequences of Spasticity

The degree of spasticity and spasms can vary from person to person, day to day, hour to hour and can impact on many daily activities. For instance it can affect physical activities such as walking, transferring, washing, dressing, picking up objects and sexual activity (Thompson et al 2005). Safety in sitting and lying can also be compromised due to spasms or persistent poor positioning (Jarrett 2002). The ongoing presence of spasticity and spasms can have an emotional impact on for example, mood, self-image and motivation (Ward 1999, Porter 2001, Currie 2001, Thompson et al 2005). The occurrence of spasticity and its associated symptoms can span the trajectory of an individual's neurological condition and its management tends to be ongoing over time; for some this will be a significant amount of their lifetime if not all.

People with spasticity can range from having no visible impairment to complex disability. They can span the trajectory of being totally independent with no mobility restrictions to being total bed users not able to sit in a chair, with significant cognitive impairment and dependent for all care. Despite my post being specialised in the management of one symptom, how people present and the degree of competing needs they can have is diverse. My rehabilitation experience is vital to help people manage spasticity within the context of their disease process and lifestyle.

[9] The exact mechanism of this continues to be debated but the reality remains spasticity and weakness can coexist.

However spasticity and spasms are not always detrimental and they may even be positive in improving vascular flow and assisting in transfers and walking (Losseff and Thompson 1995). From my experience in rehabilitation I feel walking remains the most valued form of mobility in society - despite this view being challenged by leaders of the disability movement (Oliver 1993) - and hovers in the background of my spasticity management practice. I need to be mindful in my future practice that 'to walk' can be a goal or dream even for individuals who have not walked for years, or who have contracted legs. Therefore the treatments of spasticity need to be carefully selected and reviewed over time within the context of an individual's aims and aspirations.

Management and treatment of spasticity

There are two fundamental management strategies that need to form the ongoing basis of any spasticity management plan. These are the management of trigger factors (Figure 1.4) and ongoing physical activity including active or passive movement of joints through their full range (Jarrett 2006).

Cutaneous stimuli	Visceral stimuli
• Altered skin integrity — Red or inflamed skin — Broken skin — Infected skin — Pressure sores — Ingrown toenails • Tight fitting clothes or urinary leg bag straps • Uncomfortable orthotics or seating systems	• Any systemic or localised infection • Bowel dysfunction for example constipation, over flow or diarrhoea • Bladder dysfunction for example infections, retention or incomplete emptying • Deep vein thrombosis

Figure 1.4: Cutaneous and visceral stimuli, which can aggravate spasticity and spasms (Jarrett 2006).

Management and treatment strategies can be viewed on a continuum from mild to severe spasticity (Figure 1.5). Often the available drug treatments are not used in a linear progression but are used in conjunction with each other (Figure 1.6).

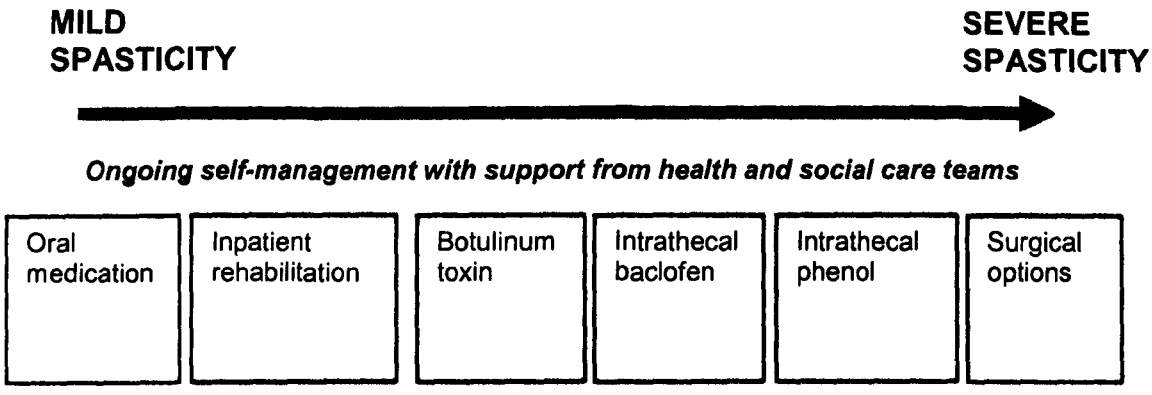


Figure 1.5: Options for spasticity management (Jarrett 2006).

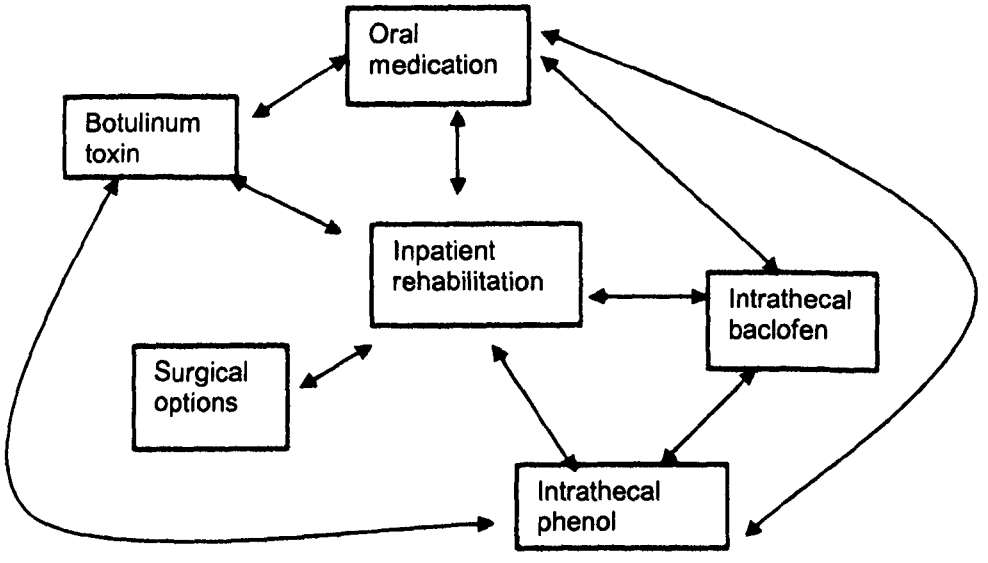


Figure 1.6: Spasticity treatments are often used in conjunction with each other (Jarrett 2006).

Current Service

An outline of the core team and the evolution of the service is summarised in fact sheet 3. The service has distinct pathways for treatment following assessment in the multidisciplinary clinic. I am involved predominantly in the assessment clinic and lead on the intrathecal baclofen (ITB) and phenol (IP) pathways (Fact sheets 1 and 4).

Intrathecal therapies

My role has involved developing and maintaining a robust clinical governance framework, where elements of risk are clearly identified and structures are in place to minimise problems whilst maximising the benefit of intrathecal baclofen and phenol drug treatments. This has required facilitating different disciplines to develop appropriate protocols. For instance skilled nursing care for

the trial periods is extremely important and for this reason I developed specific care plans and nurse specialist competencies to ensure the individual is managed appropriately to minimise risk. To meet a national demand for these protocols they have recently been published (Jarrett 2006a).

Each treatment has a similar pathway that my role extends through; clinic assessment, in-patient assessment, measurement, trial, treatment, ongoing management and troubleshooting if problems occur. A typical weekly job plan is as follows:

	Monday	Tuesday	Wednesday	Thursday	Friday
Am	Answer help-line queries: Clinic preparation: Liaison with community teams				
	Assess and measure person admitted for trial	IP or ITB trial	ITB trial Surgical implant of pump	IP treatment	Pump clinic Assessment clinic IP outpatient clinic Surgical implant of pump
pm	Assessment clinic Surgical implant of pump	Team review of person with spasticity. Education and support of person	Team review of person with spasticity. Education and support of person	Team review of person with spasticity. Education and support of person	
	Answer help-line queries				

Essence of my role

The two main aspects of my role include supporting individuals in their use of intrathecal treatments over time and managing the service (Protocols 1-7). The latter involves the organising of clinics, management of equipment, participating in the writing of business cases to develop the service, audit, lecturing locally and nationally, the education of medical and physiotherapy staff rotating through service and more recently the management of a second nurse specialist post.

With regard to the clinical aspects of my role I lead on the education of the person, supporting them through the process of considering and having an intrathecal treatment. These are not trivial decisions for a person to make.

Intrathecal Baclofen Therapy

Intrathecal baclofen therapy (ITB) involves spinal injections, surgery, and adjustment to living with an implant, frequent hospital appointments and responsibility for acting promptly if symptoms persist or if side effects occur (protocol 3, 4). The pump is implanted by a neurosurgeon. I go to theatre to prepare the pump for implant and importantly to record the length of catheter implanted. This is vital information for the accuracy of future drug calculations and to prevent overdose. Once the person is awake in recovery a medical registrar and I program the pump to commence treatment.

The pump design requires the reservoir to be refilled regularly; this is routinely done in an outpatient setting. I organise this clinic and run it together with a neurology registrar. At each clinic appointment

a spasticity management review is completed, the pump refilled, dose adjustments made and any further education with regard to tone management discussed (protocol 5).

Intrathecal Phenol Therapy

Intrathecal phenol therapy (IP) also involves spinal injections but is destructive in nature (fact sheet 4). A person suitable for IP will have a complex disability involving both physical and cognitive issues, it is vitally important that I appropriately pace the education to ensure the individual and or their carers have enough time to assimilate what is being proposed (protocol 6). After clinic I maintain regular telephone communication with the individual or, if they are unable to verbally communicate, a nominated contact person. I have designed our service so as repeat injections can be given with the person attending as a day case. This causes less disruption to their daily routine and complex care regime (protocol 7).

Teamwork

I also lead the provision of a 24-hour hospital based advice line to support individuals using intrathecal treatments and their community teams. My intent is to always engage with the individual's primary care team as early in the process as possible and to maintain contact throughout. This encourages their involvement in the decision making process and allows a sharing of information and knowledge between us. The team can include the general practitioner, district nurse, community physiotherapist, occupational therapist and wheelchair seating service.

Fore conception

The previous section focuses mainly on the technical side of spasticity management. It is the knowledge I routinely use when asked to describe spasticity management, and is included to contextualize my narrative, yet I know it doesn't adequately reflect what I do as a spasticity specialist nurse. It reflects my technical position as I enter this research to explore what spasticity specialist nursing may be.

By reflecting on my career to date, my fore-having, I recognise the importance of technology but view it as an adjunct to nursing and caring. Watson (1999) in her theory of nursing describes that Nursing consists of,

> '...knowledge, thought, values, philosophy, commitment and action with some degree of passion....As such, human care and caring is viewed as the moral ideal of nursing.' (Watson, 1999, p53-54).

Mayeroff (1971) suggests, 'To care for another person...is to help him grow and actualise himself.' (Mayeroff, 1971, p1).

These perspectives suggest a human response to nursing and caring rather than just the technical aspects I have so far portrayed as spasticity nursing. So how would I articulate my understanding of nursing and caring as I enter this period of research?

First supervision session: March 2001.

CJ looks at me intently and asks, 'What is your vision and values as a spasticity nurse specialist? What do you aim to accomplish?'
A hot feeling spreads across my body, my mind is racing, and I feel unable to articulate my views. As I strive to articulate my vision and values, I feel passionate and realise these issues are important to me yet I have never considered them before. I am challenged, finally stumbling over my choice of words and rambling I summarise:

My role is to lead on the safe administration of intrathecal baclofen and phenol drug treatments (Fact sheets 1 and 4), supporting people with spasticity in their use over time.
My vision is to work with the person with spasticity, their family and carers, jointly sharing our knowledge, expertise and experience to maximise the positive impact of spasticity on the person's lifestyle.
I value working with people over time getting to know them, respecting their experience and knowledge of living with what is often a complex disability and understanding their chosen lifestyles. I appreciate giving support, advice and my skilled input actively communicating and being part of a team with a common purpose to help others. Within relationships I value, honesty, transparency, openness, humour and collaboration with both people living with spasticity and colleagues.

Research and people with complex disabilities

I am passionate about working with people with complex disabilities and including them in my research. Tee and Lathlean (2004) and Gelling (2004) suggest that often people with complex disability are excluded because research designs are paternalistic and restrictive or the research environment is inaccessible. I believe individuals should have the opportunity to be involved in research. I do not want to exclude people because of their degree of cognitive impairment or because they are unable to physically sign consent forms or read information sheets. These people are at the core of my practice, it is my interventions with them that I want to explore and excluding them would not give a true representation of my practice context. Their input is vital to understand what I do or need to do. I feel conventional qualitative methodological approaches that utilised interviews or focus groups would prevent them from participating and could therefore limit uncovering what is significant in my spasticity nursing practice. Guided reflection as a research methodology is inclusive in that it allows me to reflect on my interactions with people with complex disability.

I recognise the values I bring to this research include; working *with* people rather than *on* or *for* and *I* appreciate that people living with neurological conditions are often in a lifelong process that fluctuates between periods of wellness and illness.

Reading the words of Blackwolf and Jones the importance of appreciating my values is strengthened,

> 'Identify your values. Come to know what you believe. Come to know what is most important to you. Come to recognise when your values are tested. Only when you stand up to the test, are your values truly validated and confirmed.' (Blackwolf and Jones, 1996, p13).

I recognise my narrative as a way of 'testing 'and refining my evolving values.

In summary this study will address how guided reflection can inform the growth of individual nursing knowledge and secondly how this informs knowledge about nursing and caring. To close my background I have summarised the key steps in my development and the attributes which I believe are important for successful communication with others. These issues have influenced my vision and role development to my point of entry into the research (Figure 1.7).

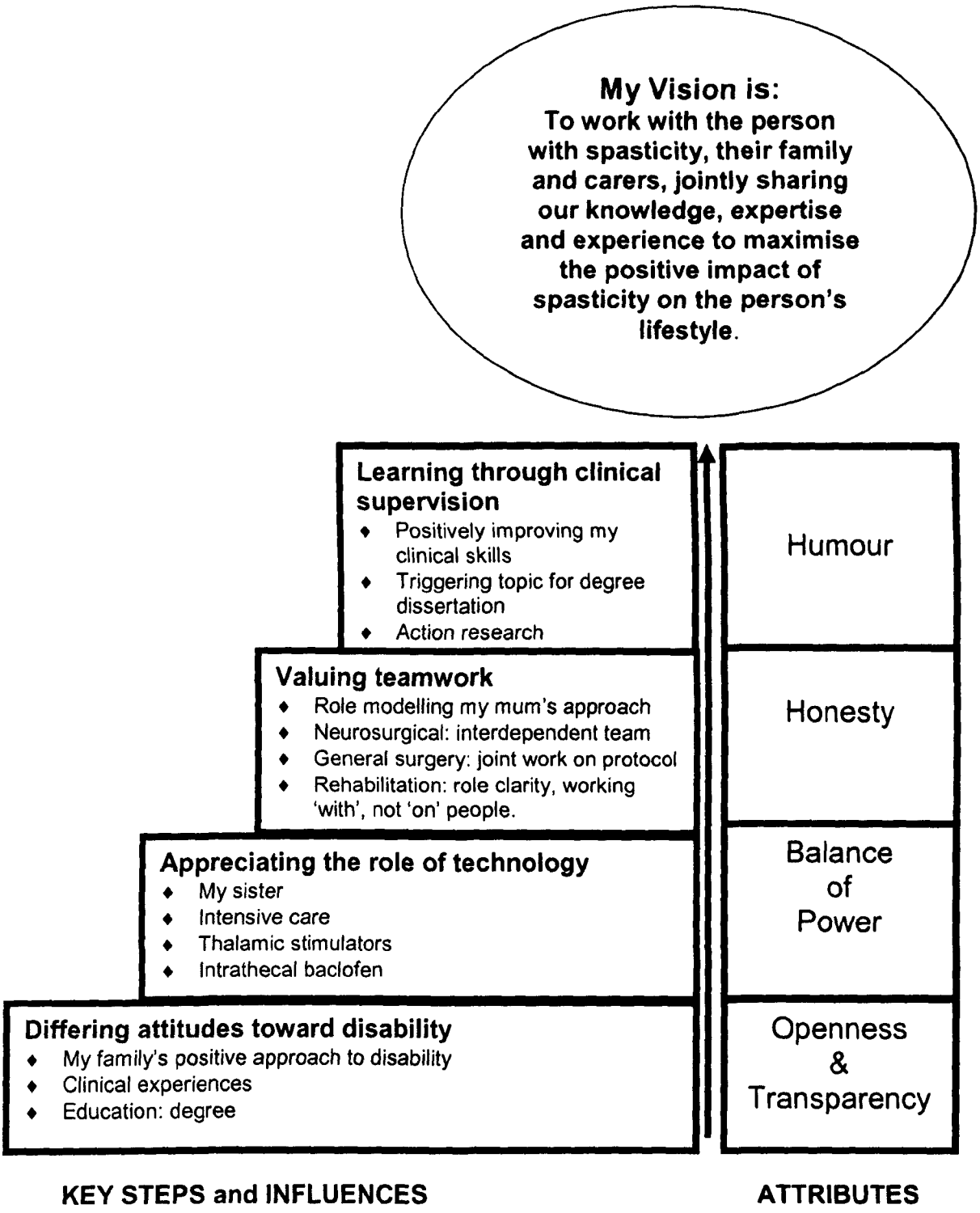


Figure 1.7: Key steps, influences and attributes towards developing my vision as I enter this research period.

2. Constructing a reflexive narrative.

In this chapter I present a reflective account on how I constructed this thesis as a coherent and reflexive narrative. I weave together issues of methodology and method illustrating my use of reflection as a process of self-inquiry and transformation. Whilst ideas guided me, I had to find my own way, for as Clandinin and Connelly (2000) emphasise, there are no prescriptions or formulaic approaches to narrative.

The methodological approach

My methodology is guided reflection as a journey of self-inquiry and transformation towards realising my vision of spasticity nursing as a lived reality. This journey of being and becoming is represented as a coherent and reflexive narrative that adequately plots my transformation and an analysis of those factors in practice that have constrained me.

This approach to narrative as self-inquiry and transformation is grounded in the work of Christopher Johns, which spans twenty years of continuous research and development. In 2002 he published his research book 'Guided reflection: advancing practice' in which he first set out his methodological template for guided reflection as a process of self-inquiry and transformation.

In constructing his methodological framework Johns explored and integrated diverse philosophical influences', seeking to weave these ideas coherently into the wholeness of his approach. He stresses the point, as do Clandinin and Connelly, that narrative is a broad idea that has no formula for doing it (Johns 2006, Clandinin and Connelly 2000). At its core, John's approach is grounded in a critical social science (Fay 1987) with influences from reflective theory (Schön 1987 and Meizrow 1981) and hermeneutics (Gadamer 1975 and Heidegger 1962 [1927]). He favours a pragmatic approach to hermeneutics, one that moves towards finding meaning in reflective text rather than becoming involved with the deep philosophical roots of hermeneutics (personal communication 2008). As I detail under method (p64) this pragmatic approach is fundamental to the second level of dialogue and moving from identifying significance to insight in my texts.

Johns has also been influenced by feminist writers (Woolf 1993[1929], Cixous and Clément 1986), evolutionary consciousness (Wilber 1998, Newman 1999) and empowerment theory (Friere 1970 and Kieffer 1984). Later in this chapter and in the subsequent narrative (Chapter 3) I pick up how some of these writers have influenced me.

John's ideas continue to evolve, but a revised template (Johns 2006 - Figure 2.0), was the most influential to my methodological framework. It was my starting point to appreciate the philosophical influences that have informed the development of this form of narrative methodology.

Critical social science and Empowerment	**Hermeneutics and Dialogue**	**Narrative Inquiry**
The feminist slant	**Guided reflection as a process of self inquiry and transformation**	**Ancient and spiritual wisdom**
Auto-ethnography	**Reflective theory**	**Chaos Theory**

Figure 2.0: Methodological influences grid (Johns, 2006, p56)

Developing my Bricolage: My philosophical influences

Reading Johns's approach to narrative I was inspired to approach my own research from this perspective. This was for several reasons; it meant I could stay in practice yet research self through my experiences shared in clinical supervision. The process combined support and development for both my clinical and research practice. Through the use of a methodological grid and six layers of dialogue it offered a systematic approach to self-inquiry beyond other narrative approaches, that also lacked a vital emphasis on transformation for example the narrative approach described by Clandinin and Connelly (2000) and the autoethnographic approach described by Bochner and Ellis (2002).
As I began to dwell within the narrative approach I began to formulate my own unique approach, just as Johns advocates, each practitioner must find their own way to travel this journey (Johns 2002).
As discussed in the preface, this careful selection of different influences towards creating a methodological framework resonates with the process of constructing a bricolage (Denzin and Lincoln 2005) and with the following description of contemporary narrative inquiry;

'...an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches and traditional and innovative methods – all revolving around an interest in biographical particulars as narrated by the one who lives them.' (Chase, 2005, p651).

My interpretation of these philosophical texts was unique because of my fore-structure, skills and intent. I entered this research from my own exclusive position and needed to pay attention to the specific ideas and texts that resonated with and informed my research process, as Koch (1995) suggests:

> 'The philosophical assumptions that underlie a 'method', and whether those assumptions are consistent with the researcher's own view, seem to me to be the necessary starting point of inquiry.' (Koch, 1995, p827)

Similar to Johns, my methodological approach is situated within narrative inquiry and is heavily influenced by reflection and critical social science perspectives, with other approaches such as autoethnography, hermeneutics and chaos theory being blended into the whole of my approach. Unlike Johns, my application of this methodology is only minimally influenced by feminism and not at all by ancient wisdom.

The Johns methodological grid anchored me to a process but didn't stop me from appreciating other influences. I want to emphasise the significance of aesthetics in influencing the expression of my text and insights, notably sculpture and poetry, I represent this as 'Aesthetics' and personalise the grid by positioning it alongside (Figure 2.1). Johns does not suggest that the influences have a hierarchy but in my interpretation some have been more significant than others. In the grid I have used descending font size to denote the heavily influential to the least.

Critical social science and Empowerment	**Auto-ethnography**	**Narrative Inquiry**
The feminist slant	***Guided reflection as a process of self inquiry and transformation***	Ancient and spiritual wisdom
Hermeneutics and Dialogue	Reflective theory	Chaos Theory

Aesthetics

Figure 2.1: My Methodological influences grid (Adapted from Johns, 2006, p56)

Narrative

Narrative research has been gaining popularity in nursing over the last twenty years, particularly in the areas of nursing education (Diekelmann 1993, Benner 1996, Lindsay 2006) developing nursing competencies (Benner 1984) and as a key feature in professional and scholarly debates on nursing (Benner and Wrubel 1989, Benner et al 1996, Johns 2006). Narrative is a broad term that encompasses different approaches and has roots in different disciplines for example education (Dewey 1963 [1938], Clandinin and Connelly 1994, 2000), anthropology (Bateson 1994) and psychology (Polkinghorne 1988). Ideas from these authors influenced the narrative approach and I have drawn on specific issues in my appreciation of narrative methodology.

Dewey suggests that experience has both a personal and a social perspective. Although people need to be understood as individuals, they have to be viewed in relation to a context, with others and their environment. In addition, experience has continuity, experiences beget experiences, leading to each moment being influenced by a lived past and an imagined future. This back and fore movement that forms the continuity of experience resembles how I have presented my background in chapter 1, where I detail my entry into this research influenced by the Heideggerian idea of a forestructure. Polkinghorne (1988) highlights the temporal nature of experiences within an evolving narrative that has a beginning, middle and end. He also suggests that narrative needs to demonstrate an awareness of causal connections between events, so as the experiences become more meaningful to the person, thereby promoting their future agency. This strengthens my appreciation of paying attention to the temporal position of my texts and how they interrelate. He also highlights the importance of a story line or plot that links the seemingly disparate aspects of the texts together. I recognise that providing the reader with such a focus provides one way for them to make sense of my narrative.

A key issue I take from Bateson (1994) is that as a person engages in writing their own narrative they change, both as an individual and how they understand the world they live in which is also under perpetual change.

These ideas contribute to the need for reflexivity in narrative (Johns 2002, Guba and Lincoln 2005, Murray 2008). Etherington (2004) suggests there are many ways to interpret reflexivity within social science research. She summarises that reflexivity is;

- A dynamic process of self awareness between the researched, the data and researcher at all stages of the research process.
- '... a circulating energy between context of researcher and researched' where both have agency' (Etherington, 2004, p36).
- '...not the same as subjectivity...it opens up a space between subjectivity and objectivity that allows for an exploration and representation of the more blurred genres of our experiences' (Etherington, 2004, p37).

I interpret reflexivity as appreciating connections between past and present reflections, projecting to the future possible forms of effective interaction. I expand my appreciation of reflexivity in a subsequent section when I discuss the process of constructing my narrative (p86 and 97).

Practice is narrative

Chase (2005) describes narrative as '... retrospective meaning making – the shaping or ordering of past experience.'(Chase, 2005 p656).

As I have developed, my appreciation of narrative has deepened and narrative has become very much a way of my being rather than merely being a retrospective meaning making process. Mattingly (1994) describes that 'healers' (in her study an occupational therapist), shape therapeutic interactions by organising them according to an evolving plot that is part of a larger narrative structure.

' The notion of therapeutic emplotment offers one way to examine the social construction (and reconstruction) of illness and healing as a fluid, shifting process influenced not only by molecular condition, institutional structures and cultural meanings but also by the exigencies of the concrete situation.'(Mattingly, 1994, 811-822).

Mattingly (1994) concludes that any clinical encounter is narrative, likewise Clandinin and Connelly (2000) state narrative inquiry,

'... is the best way of representing and understanding experience...narrative thinking is part of the phenomenon of narrative...narrative is both the phenomenon and the method of social sciences.' (Clandinin and Connelly, 2000 p 18)

These views could be summarised as, 'practice is narrative' and resonates with how I have evolved to view my practice as a narrative unfolding.

Doing Narrative

A key feature in the theoretical texts is that narrative theories do not detail ways to do narrative inquiry, they do not prescribe method. Narrative researchers instead describe the processes they have engaged in and from this draw out issues to consider relating to method (Clandinin and Connelly 2000).

To promote a systematic approach to my inquiry I have engaged in the six layers of dialogue (Johns 2006). As I detail my experience of this process in a subsequent section I will describe the influence of narrative themes. In summary, threads from narrative theory that permeate my thesis can be summarised as, appreciating context (Dewey 1963 [1938]), reflexivity (Johns 2002, Guba and Lincoln 2005, Murray 2008), plot (Mattingly 1994, Polkinghorne 1995, Murray 2008), agency (Polkinghorne 1995, Chase 2005, Murray 2008), temporality (Polkinghorne 1996, Clandinin and Connelly 2000, Chase 2005), effective writing and appreciating the influence of guidance and feedback (Clandinin and Connelly 2000, Bochner 2001).

Reflection

Reflection is a term readily used in general conversation and has been incorporated into nursing discourse through processes such as clinical supervision (p25).

Schön (1983) challenged the epistemology of knowledge, when he suggested that the problems most important to individuals and wider society were not addressed by the dominant research approach, technical rationality, where scientific theory and technique is applied to solve problems. He reinforced the value of learning by reflection, as a particular form of professional knowing that, although was

personal, contextual and situational, extended practice knowledge and was the knowledge most readily used by professionals in practice.

Mezirow (1981) discussed the need in adult learning for a critical reflection that leads to emancipatory action or what he describes as perspective transformation.

> '...of becoming critically aware of how and why the structure of psycho-cultural assumptions has come to constrain the way we see ourselves and our relationships, reconstituting this structure to permit a more inclusive and discriminating integration of experience and acting upon these new understandings.' (Mezirow, 1981, p 6)

Reflection can have different layers of interpretation, in my work I adopt the Johns (2004) definition, as opposed to any other, as I find it the most helpful and the one that closely resonates with my practice and philosophical approach. Johns (2004) describes reflection as:

> '... being mindful of self, either within or after experience, as if a window through which the practitioner can view and focus self within the context of a particular experience, in order to confront, understand and move towards resolving contradiction between one's vision and actual practice. Through the conflict of contradiction, the commitment to realise one's vision, and understanding why things are as they are, the practitioner can gain new insights into self and be empowered to respond more congruently in future situations within a reflexive spiral towards developing practical wisdom and realising one's vision as a lived reality. The practitioner may require guidance to overcome resistance or to be empowered to act on understanding.' (Johns, 2004, p3).

Mezirow (1981) situates critical social science at the core of reflection and Johns has emulated this in his definition of reflection. Being mindful of self relates to the idea that reflection always takes place in the present moment, even when reflecting back on experience (Johns 2006). Being mindful involves being discerning with previous knowledge so as one can appreciate a situation for what it is, whilst considering how best to respond.

Reflection and Critical Social Science

A main tenet of critical social science is to stimulate people to reflect on their circumstances and to change those practices and policies that cannot be justified (Fay 1987). It encourages people to improve themselves, similarly through my research process I am striving to improve my practice by working toward desirable practice.

However in my situation I have to hold the nature of 'desirable practice' in tension as I do not know what desirable practice is in spasticity nursing, as it has never been written about before. I therefore work towards a vision, informed by my fore structure and different sources of knowing but one which is tentative, open to challenge and ready to be adapted as my appreciation and understanding of my role evolves.

Contradiction

Reflection highlights contradiction between one's actual and desired practice; understanding my current reality is a basis for change. As I strive towards realising my vision, a vision that requires

perpetually refining, contradiction provides a source of energy to understand and improve my future practice.

This parallel's Senge's (1990) idea, that the gap between our current reality and our vision, can be viewed as creative tension or a source of energy to take action (Figure 2.2).

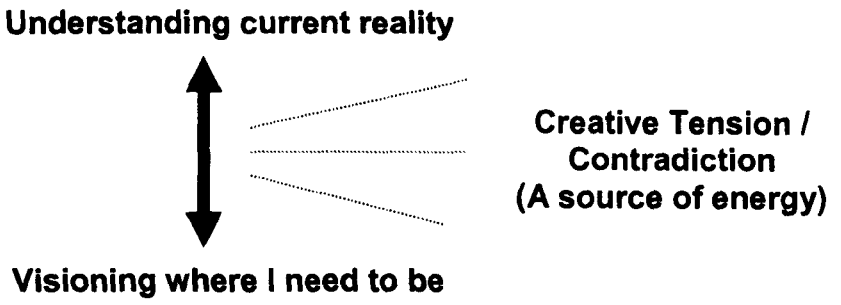


Figure 2.2: My visual representation of contradiction as a source of energy

This process requires me to be open to change, and may require me to confront difficult issues, or those I have been unaware of before. To maximise and convert this source of energy I have used my supervisors, as catalysts to guide my process. For instance, I have discussed the struggle I had to verbalise my vision (p44). Through guidance I was able to articulate embodied moral values that I felt were important when working with people with complex disabilities. Fashioning these into my vision I am better able to recognise when my practice is in contradiction with my desired outcome.

Transformation

Guided reflection as a process of self inquiry and transformation encourages a systematic approach to promoting an individual researcher's agency and transformation, in my case towards being and becoming an improved and effective nurse specialist in spasticity management. To transform is a cornerstone in critical social science as Fay (1987) suggests, to bring about social change a person needs to move through three different stages;

- *Enlightenment*, understanding why things are as they are.
- *Empowerment*, having awareness, the ability and courage to take appropriate action towards change.
- *Emancipation*, the realisation of change towards transformation.

These stages are implicit in Johns (2004) definition of reflection and how I interpret it in practice.

Guiding reflection

To work towards my vision and realise desirable practice, I reflect on my practice, identify contradiction and start to appreciate why things are as they are. Becoming enlightened or revealing self can form a basis for change, but it can be difficult to do, a guide can be invaluable to explore

strategies to act and consider the potential consequences of my actions. In the process of enlightenment a guide is imperative to reveal self,

> 'Critical social science is committed to discovering a coherent pattern at work in the affairs of people, albeit a pattern which lies beneath the surface of social interaction, hidden from the social actors themselves' (Fay, 1987, p69).

Through my research process guidance was critical to pursuing my vision and co-creating meaning I discuss my experience in a subsequent section (p78-81).

Having explored action to take in future situations I feel empowered. As I start to incorporate these into my actual practice I become emancipated and move forward in my journey to become the practitioner I want to be.

> 'The emphasis on being acknowledges the existential moment of the unfolding moment, whilst the emphasis on becoming acknowledges the transformative nature of reflection.' (Johns, 2002, p9)

However, Fay (1987) also identified that people do not change rationally; their progress toward transformation is often impeded. He described these as 'limits' and refers to three in particular; embodiment, force and tradition (Fay 1987). Fay stresses that in order to understand ourselves we need to address these limits.

Embodiment encapsulates both physical and emotional aspects of self that are developed through conscious and unconscious influences. Force is a type of power appropriated by people for self determination (Fay 1987), Johns uses the term power as he feels it is more liberating (Johns 2008- personal communication). Gadamer (1975) discusses authority rather than force and notes,

> 'That which has been sanctioned by tradition and culture has an authority that is nameless, and our finite historical being is marked by the fact that the authority of what has been handed down to us- and not just what is clearly grounded- always has power over our attitudes and behaviour.' (Gadamer, 1975, p280)

Constructing chapter 1 not only situated my thesis in a context it helped me to consider aspects of my 'tradition' that influence me. Fay (1987) suggests,

> 'Human beings are forever set within particular traditions which, in being appropriated, partially define their identity. They, of course, are not passive sponges in this process; they affirm some of their inheritance and they reject other parts of it; they cultivate and they transmute; they embrace, they recombine in novel ways, they create. But all of their activity always involves the appropriation of materials given to them by their tradition; it is the very stuff out of which their development and change is made.' (Fay, 1987, p164)

Embodiment, force and tradition are influential in the way that I view my world; I use guided reflection to explore these issues. My thesis analyses the factors that constrain me, detailing what limits my practice space and realising my vision.

Hermeneutics

Heidegger's (1962 [1927]) idea of 'background' influenced the way I shaped my background in chapter 1. By setting out clearly where I, the researcher/ practitioner is coming from, enables the reader to position me contextually and subjectively as the writer.

Hermeneutics involves the reading and interpretation of texts. It is about discovering and understanding meaning, not just in parts but a deepening appreciation of the whole (Gadamer 1975). The interpretation of a text can be limited if there is distance between the author and reader in time, social background and culture. However, if the context of a text is known the reader will reach greater understanding (Fjelland and Gjengedal 1994). Finally, Gadamer's (1975) ideas about co-creation of meaning is fundamental to Johns' perspective on guidance (discussed on p 105) and hence my experience of it.

Dialogue

As I practice and create my texts the idea of dialogue is vital, Bohm (2000) describes this as, '...a *stream of meaning* flowing among and through us and between us.'(Bohm, 2000, p6). Johns suggests that, 'Dialogue is the flow of guided reflection.'(Johns, 2002, p32). Bohm (2000) describes that being in dialogue, is to be concerned with meaning and appreciating experiences in detail, it involves actively listening, and paying attention in interactions. It requires a sensitivity, detachment and suspension of assumptions.

Tufnell and Crickmay (2004) capture the creativity and temporality of dialogue in the following description,

'Creating becomes a conversation when we enter into dialogue with whatever we are doing. In this conversation we are drawn along in the moment by moment flow of sensation, interchange and choice, rather than flowing a predetermined intention or idea. Conversations grow as we listen and explore – a constantly shifting process of discovery that changes in momentum, rhythm, clarity or chaos as we work.' (Tufnell and Crickmay 2004, p41)

My texts need to capture my dialogue and when reading and rereading them I need to be open to the potential of new meanings. This continues as I dialogue with other sources of knowing and my guide, to the extent the intent of our dialogue is to fuse our horizons[10] and co- create meaning. Co-creation does not mean that I accept all that CJ suggests, the process is about jointly sharing ideas and influences towards new meaning. My narrative does not depict the intricacies of all these dialogues but does represent my co-creation of meaning from these interactions.

Some reviewers of my work have asked for specific examples of when I changed the perceptions of CJ. My intent is not to chart change in others. I engage in intentional dialogue to co-create meaning, to further my understanding of events and to gain a greater awareness of self. Co-creation occurs

[10] Horizon is a metaphor used by Gadamer (1975) to represent a person's normal vision and understanding

through dialogue, by the sharing of ideas the perceptions of those involved are shaped, leading to new understanding and appreciation. My narrative depicts how co-creation has influenced my transformation. To appreciate CJ's individual growth would necessitate a dialogue with him or his respective narrative. The following extract from my narrative shows an episode of co-creation as CJ and I strive to capture my evolving vision. The dialogue echoes the above quote from Tufnell and Crickmay (2004) as we are, '..drawn along in the moment by moment flow...'

July 2007: Revisiting my vision

I share with CJ my reworked vision,

> **To tune in and flow with a person's experience; appreciating their ever evolving life pattern whilst we work together to integrate spasticity management strategies, the use of drugs and technology to promote their health and widen their life space.**

We talk in a poetic form as we discuss the insights that have led to this rewording of my vision.

I muse,
Tension between chronic illness and the medical model
Nature of relationship with the person
Shaping space

CJ takes the flow,
Sensing the connection with the whole
Positioning self
Finding the wavelength

I interject,
Sensing the wavelength

CJ responds,
Touching the wavelength
Flowing with the wavelength
Mindful of expectation
Poise threatened by the carelessness of others
Shaped through ignorance

I continue,
How do I move boulders that litter our journey?
Tripping not just myself but also the precarious harmony that people with spasticity seek to grasp

CJ summarises,
Lives in balance easily rocked

From this we expand my vision,

> **To tune in and flow with a person's experience and precarious harmony with wellness, where wellness is an ever shifting phenomena carefully crafted through experience; appreciating their ever evolving life pattern whilst we ethically work together and with other colleagues to integrate spasticity management strategies, the use of drugs and technology to promote their health and widen their life space.**

Narrative, the development of expertise and co-creation

The work of Benner (1984) and her colleagues (Benner et al 1996) has been highly influential in the development of nursing and in particular, has underpinned the ready acceptance of narrative as a way that expertise can be identified in nursing, however Nelson and McGillion (2004) feel this acceptance has largely been uncritical.

Analysing the method used by Benner et al (1996), they suggest the structured approach used to gather narratives and the way in which the nurses were prepared or 'coached' led to only certain types of narratives being shared. These tended to either depict a confessional perspective from the nurse or situations where the nurse is a hero figure and the patient a mere accessory. Nelson and McGillion (2004) suggest the claims from first person accounts should not go uncontested.

The process of co-creation used in guided reflection as a process of self inquiry and transformation, could be thought to similarly 'coach' a specific type of narrative to be formed, but in my experience it has answered the claim from Nelson and McGillion that first person accounts need to be contested. During my research process I have developed a style of writing my narrative that allows me to interpret self, within a framework of dialogue with wider sources of knowing and co-creation with others. Co-creation is not about being coached to say or do things in a particular way, but is intentional dialogue to appreciate different perspectives of a situation, which in its process creates new awareness and understanding in all participants the guide and guided.

There is a continuity of flow where the self is continually questioned or 'contested'. Further, whilst there is structure in the process of reflection, from using the model of structured reflection, this is loosely applied for guidance rather than being a rigid process to follow. The situations that I have reflected and written about are my interpretation of events and behaviours from which I strive to learn from to improve my future practice. I do not feel this is a process of confession to self or others, but an appreciation of self and whilst I learn from both positive and negative situations I am not motivated to learn through depicting myself as heroic, but by appreciating self as being in that moment, in that situation. My text in chapter 3 demonstrates my interpretation of being in the moment.
A further challenge to this form of research came from a colleague who suggested that, 'The process seems like a sort of shared self indulgence.'

I responded, 'The process is not merely to share information but is intentional to co-create new understanding of self and situations. The intent is that this appreciation informs my future actions, hence transforming my practice and positively impacting on the immediate or future experiences of those I engage with.'

Self Inquiry - Autoethnography

Pinar (1981) suggests that ethnographic studies provide detailed descriptions of events and what happened when, but 'fail to describe *lived* experience' (Pinar, 1981, p176).

Pinar suggests that in ethnography what people are thinking and why they behave in certain ways is lacking, further there is little regard to the position of the text in relation to wider social issues such as politics. Whereas these issues are addressed in an autobiographical method, which,

'... cultivates the specificity of ourselves, the particularity of self and situation.' (Pinar, 1981, p186).

For Pinar whilst autoethnography may lead to greater understanding of self and this in itself will lead to change in the person, the main focus is for greater understanding of self rather than change.

'We write autobiography for ourselves, in order to cultivate our capacity to see through the outer forms, the habitual explanation of things, the stories we tell in order to keep others at a distance.' (Pinar, 1981, p184)

In June 2007 whilst discussing this chapter and my philosophical influences, Paul Godin[7] asked,

'What are the similarities and differences between your approach and auto-ethnography?'

I replied,

'They are both similar in strongly exploring self-inquiry but different in that the intent of auto-ethnography is to describe one's own situation whereas my approach is to transform self.'

To some extent I still believe this, although autoethnography like guided reflection is not a static process and is continually evolving in the quest for appreciating experience and being. Bochner and Ellis (2002) describe the potential for autoethnography to evolve and blur boundaries between different approaches, in particular social sciences and literature and in doing this lead to change in self and others. Holman Jones (2005) moves autoethnography to be considered as,

'... a politics committed to creating space for dialogue and debate that instigates and shapes social change.' (Holman Jones, 2005, p763)

Extending the work of Pinar, these authors suggest that autoethnographic texts are not just to stimulate thought and change in self, but also in others. Denzin describes that autoethnographies,

'...move from the inside of the author to outward expression while working to take readers inside themselves and ultimately out again.' (Denzin, 1997, p208)

Some authors have suggested criteria for reviewing autoethnographies (Denzin 1997, Richardson 2000, Bochner 2001). Holman Jones (2005) integrated and extended these and I summarise those that I have found pertinent to consider when constructing my text.

- How well do I depict the participation, responsibility and obligation of others in the formulation of my text?
- How well do I document my dialogue with other sources, showing my partiality and reflexivity?
- Does the text create a space to engage others to dialogue?
- Do I critically analyse self within the narrative?
- Does my text evoke action in self or others?
- Does my text demonstrate political and or social change?

Aesthetics

In their book on reflective writing Winter et al (1999) discuss that the creative process is an act of 'self-exploration', that can be both enlightening and therapeutic. They draw on the work of Dewey (1958[1934]) and propose a direct link between aesthetics and reflective practice.

'...we possess a general capacity for effectively representing our experience in artistic form; we suggest that in order to realise our capacity for reflection we can (and should) draw upon our intuitive grasp of aesthetic processes as well as our capacity for conceptual and logical analysis.'(Winter et al, 2005, p180)

I am using the term 'aesthetics' to frame my appreciation of art and its influence on my narrative construction. I have found certain pieces of art instrumental, either to help me determine meaning from my situation and past events or to re-energise myself to progress with my study. Tufnell and Crickmay (2004) suggest that images and metaphors can be an effective way to discover aspects of self and reveal hidden meaning.

> 'In this world of connections or image comes the complexity of our feelings holding together the otherwise fragmented field of our experiencing. In the images we make or find we discover hidden, neglected and forgotten aspects of our lives. These images give shape and form to what we sense but cannot fully see...Through our images we discover not one, but many (often conflicting), layers of meaning, meanings revealed slowly as we explore the details of what we have made.' (Tufnell and Crickmay, 2004, 119)

This resonates with how when I struggled to express myself orally or in prose, I interpreted sculptures, a painting or wrote poetry as a way of explicating my feelings and current understanding of situations. This was often spontaneous although as I began to appreciate it as an aspect of my method I became more intentional (such as visiting the monoliths in Cornwall p190).

Whilst I include 'my art' at junctures in the narrative where it was most useful and I try to explain its influence, the actual process of moving towards 'meaning' and a greater appreciation of the particular situation does not always feel conclusive.
'Works of art leave us with a sense of something understood but never fully or finally.' (Winter et al, 1999, p204)

Chaos theory

Practice is chaotic and indeterminate, even with intent I don't know what is going to unfold. The essence of narrative theory is to create order of my past experiences into a reflexive whole, to reveal patterns of my practice. Chaos theory and its claim that understanding often emerges from a sense of disorder (Prigogene and Stengers Cited in Wheatley 1999) has been instructive in helping me to appreciate the complexity of the process. Holding this idea, that there is an apparent order in disorder, helped me to remain engaged and work through situations that felt in disarray. This has contributed to the shape and form of my narrative.

Feminism

Influences from feminism have not been overt in my methodology and method, except with regard to the coherence and authenticity of my writing (Belenky 1986, Woolf 1993[1929], Lather 1986, 1993) which I discuss in the following section (p83-86). Although, it is possible subtle hints of feminism have been at play, as I strive in my contribution to knowledge, to make visible in my practice that which is invisible or to:

'...light a torch in that vast chamber where nobody has yet been' (Wolfe, 1945, p76).

In trying to uncover the hidden nature of caring, its subtle nuances I have needed to find space to express myself in a health care world still dominated by patriarchal values and empirical research. This links with the critical social science aim of transformation and emancipation.

Ancient and spiritual wisdom

Aspects of ancient and spiritual wisdom such as how Native American teachings emphasise the importance and value of the environment they live in (Jones and Jones 1996) are influential in my narrative but not overtly in my methodology or method.

Why this methodological stance?

My application of this methodology was formed to address the gap in nursing knowledge that no text has previously explored; spasticity nursing from the perspective of the practitioner. To date only technical aspects of spasticity management have been previously published (Gianino et al 1996, Porter 1997, 2001, Ward 1999, Currie 2001, Jarrett et al 2001, Jarrett et al 2002, Jarrett 2004). This thesis not only constructs new knowledge but develops existing knowledge and draws together other forms of knowledge.

Criticism towards guiding reflection is largely levelled at it being used as a powerful influence to constrain or shape the development of an individual rather than to enhance and allow individual agency.

Gilbert (2001) in a critical review argues that both reflective practice and clinical supervision can be viewed as powerful management tools that exercise surveillance and constraint, as both processes encourage practitioners to make their practice visible by detailing how they work. Rolfe and Gardner (2006) state reflection and clinical supervision are,

> '...at best a form of repressive self-surveillance, and at worst a deliberate managerial strategy to produce a docile and compliant workforce.' (Rolfe and Gardner, 2006, p 594)

Rolfe and Gardner (2006)[11] define two strands of reflection; ontological and epistemological. The aim of the ontological approach is personal growth through use of an enlightened guide and they cite the work of CJ (Johns 2004, 2005) as an example. The epistemological approach is concerned with an exploration by practitioners of their own ways of thinking about their practice. Rolfe and Gardner (2006) suggest that the latter approach does not involve a confessional and is therefore not seeking power, so is not at risk, like the ontological approach, of exerting power over the supervisee. They state,

[11] Drawing on the work of Foucault

> 'The epistemological project of reflection is concerned only with improvements to practice, and makes a very clear distinction between the person and the actions of the practitioner.' (Rolfe and Gardner, 2006, p599)

Relating these issues to my experience of guided reflection I felt CJ used his power in an emancipatory way to liberate my own power rather than in a forceful or coercive way to shape my views. Rather than becoming or remaining docile, I was able to use my guided reflection space to recognise any docility and plan strategies to rise above it.

Rolfe and Gardner (2006) make an assumption that, who a person is can be detached from and explored separately to who they are as a nurse. I disagree, in my experience both aspects contribute to the whole of my being and have value in being viewed as interrelated. As my narrative unfolds the tensions between my practice and vision dominate the texts, for instance in the very first reflective text (p107-111) if I merely looked at the behaviour and actions of the characters involved, I may not have admitted or exposed my negative attitude towards nursing homes. Yet I believe this realisation about myself, was crucial in learning about how I was behaving as a nurse and the subsequent influence of this insight on my nursing practice threads through the narrative. If I had not addressed this I would not have been working toward an aspect of my vision, of being *with* people.

Maintaining ownership of my thesis

Undoubtedly I have been heavily influenced by CJ's work and approach; my readers might argue my thinking has been shaped to uncritically accept his way of thinking. However throughout the research period I have been conscious of this potential criticism being levelled at my work and have therefore strived to be discerning and to determine the content of my narrative. For example, CJ felt that it was important to capture interactions with my colleagues to provide a wider sense of the context in which I was working, whereas I felt a greater sense of learning and development when I concentrated on my interactions with people living with spasticity. We compromised that I would predominantly focus on my interactions with people with spasticity, presenting only minimally my interactions with colleagues, to provide a flavour of my working environment.

CJ opened a methodological field for me but did not constrain my exploration of it. He guided me to shape my own field, at every turn mindful of his influence. Once we settled into a regular routine of supervision I felt the relationship was balanced and congruent. I felt able to work at my pace and to exert control, for instance I would often terminate our sessions when I felt saturated and unable to extend my thinking any further.

As this is a new and evolving methodology, when considering the best way to present my thesis I did take a lead from CJ; although, through co-creation I could still influence the process. This occurred particularly when we reviewed sequential versions of the narrative, which I had written in different formats, to consider how best to present my insights.[12]

[12] p98-100

CJ has never directly observed my clinical practice; the experiences I have shared were my interpretation of events. He has no vested interest in my practice per se but is interested in the way I shaped and applied my methodological grid as a method, seeking to learn from this research relationship. I believe this focus has contributed to me feeling in control and not under surveillance in my practice. I was able to use guided reflection to appreciate and overcome any docility I may have had.

Method

As outlined in chapter 1 my narrative has evolved from an action research study to evaluate the implementation of a system of clinical supervision (p30-32). As part of this study CJ became my clinical supervisor, between 7/4/01 and 16/7/04 we met for 29 sessions and I wrote structured records from these sessions (p31). In these guided reflection sessions I have shared experiences, CJ has challenged and supported me to see myself and beyond myself, to visualise new ways of being in practice.

Since these sessions we have continued to meet every eight weeks, to deepen my insights within the texts and to construct my narrative through a continual dialogical relationship. Together we have dialogued towards co-creating meaning, represented as a reflexive narrative (Figure 2.3).

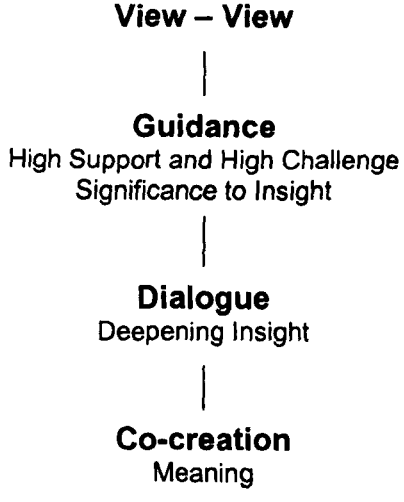


Figure 2.3: The dialogic process of co-creation

Using the six layers of dialogue (Johns 2006)

In 2006 Johns published the six layers of dialogue (Figure 2.4), a structure that seeks to integrate reflection as a systematic journey of self-inquiry presented as a reflexive and coherent narrative. The practicalities of Johns' philosophical influences are woven into the six layers of dialogue. I have used this structure to construct my narrative.

1st Layer: Dialogue with self as a 'naïve' or spontaneous story to produce a story text (that reflects dialogue with persons and self within the story itself);	Story Text ↓
2nd Layer: Dialogue with the story as an objective and disciplined process (using a model of reflection) to gain insight producing a reflective text;	Reflective Text
3rd Layer: Dialogue between the tentative insight and other sources of knowing in order to inform and frame insight within the wider community of knowing;	↓
4th Layer: Dialogue between the tentative insight, guide(s) and peers to develop and deepen insights through co-creation;	↓
5th layer: Dialogue within the evolving text to further deepen insights and weave the narrative into a coherent and reflexive pattern that adequately plots the unfolding journey, producing a narrative text;	Narrative Text
6th Layer: Ongoing dialogue between the narrative, self, others and future experiences within a continuous and deepening reflexive spiral.	

Figure 2.4: Six layers of dialogue (Adapted from Johns 2006 p 36 - personal communication)

Johns (2006) proposed the six layers as dynamic and non-linear, a constant interplay between the wholeness of experiences and parts within it, in the quest to gain meaning and insight within a reflexive spiral of being and becoming. Johns appropriated the idea of the hermeneutic circle to represent this dynamic interplay.

Dreyfus (1995) in his interpretation of Heidegger's (1962 [1927]) work 'Being and Time', describes that the hermeneutic circle,

'... refers to the fact that in interpreting a text one must move back and forth between an overall interpretation and the details that a given reading lets stand out as significant. Since the new details can modify the overall interpretation, which can in turn reveal new details as significant, the circle is supposed to lead to a richer and richer understanding of the text. (Dreyfus, 1995, p36).

In practice, and when I write I feel continually in motion, circulating back and forth between the layers, striving to move my experience through story, to reflective and narrative text.

My experience of using the six layers of dialogue
1st layer: Dialogue with self as a 'naïve' or spontaneous story.

Learning to journal.

The first layer of dialogue involves writing and describing experiences in a journal. I write paying attention to detail, drawing on all my senses to capture the nuances and subtleties of my everyday practice. Not just what happened and who was involved, but was the environment hot or cold, noisy or quiet, public or private. Street (1995) suggests that novice writers tend to write in a 'truncated shorthand form', which lacks detail. When the writer rereads it they are unable to derive value from it, so they think it is worthless. She states:

> 'The challenge is to provide enough detailed description of practice to stand back and critically examine them as if they were an account of the actions of someone else.' (Street,1995, p148)

In the throes of a busy, full-time job I struggled to maintain a daily journal. For the first six months I battled to include journaling into my daily practice. Naïvely in my guided reflection sessions,[13] I relied on recounting stories from memory or brief notes without detailed written descriptions. After a supervision session on the 1/6/01 I record in my journal:

> 'CJ felt that the description was again lacking detail. It was difficult for a reader not in this area of health care to understand potential benefits and problems with each treatment. Further it was difficult to follow the time sequence of events.'

The struggle to write

During my supervision sessions I frequently discussed my journaling and writing style. Writing is my weakest form of communication. I struggle with sentence construction and the use of grammar. Thinking and talking about my actions seem easier than writing about them.
Similarly, Street (1995) suggests that it can be a painful process to write about self and to see it on paper. I was not conscious of this, in fact I was motivated that by reflecting and writing about experiences I could potentially understand them better. I did feel pressurised by a lack of time to record descriptions. When I did write, I would rush it, randomly throwing down key words to remind me of the story. However it rarely had a logical flow and often did not make sense. Street (1995) highlights that finding time, is the first major hurdle for people to resolve when starting to incorporate reflection into their practice.

January 2002 Supervision

I summarised, that I was struggling to find the time to keep a journal and to write detailed, coherent accounts. CJ asked me to consider why I needed to keep a journal, was it just to prepare for supervision sessions?
I started to appreciate that the discipline of regularly journaling was to assist me in becoming more aware of my practice and to collect data for the narrative. As a core tenet of narrative inquiry I needed to consistently write in detail about my daily practice to uncover its essence as a basis for learning.

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[13] See p31 for structure

Although I was clearer about my intent, I remained frustrated about how I was going to develop my writing skills and manage my time effectively.

CJ suggested that I bullet point, three positive aspects and three negative aspects that occurred each day at work. I was sceptical that this would be helpful, as Street (1995) suggests, writers often don't see the value in accounts that lack detail. However I decided that on my train journey home for five consecutive days, I would note three positive and three negative aspects that had occurred in my practice that day. The exercise was quite a revelation; I could not believe what I had been missing in my daily practice. I had never acknowledged the positive aspects of my work, always looking for problems to solve, or focusing on negative aspects.

My initial stories triggered by pessimistic feelings focused only on negative incidents that stood out in my practice. Heidegger (1962 [1927]) discusses that aspects of 'being-in-the-world' can go unnoticed until a 'disturbance' causes a person to take notice of the situation. Perhaps this reflects the culture in the current National Health Service (NHS), that what we do is taken for granted unless it breaks down.

Paying attention to positive aspects of my practice I realised their rich learning and empowering benefit. I felt liberated to pay more attention to positive aspects of my practice, such as positive feedback from people with spasticity and my work colleagues that previously I had not acknowledged.

Journal entry 22/1/02:

> 'I was asked to see Ruth a week ago, she was being treated for spasticity, but I felt she had neuropathic pain not spasticity. I was nervous to feedback my findings to her medical team. A nurse challenging a medical diagnosis! However I did and they were receptive and changed her medication. I went to review Ruth today; she was really positive and said she was very glad that I had questioned her so deeply about what she was describing as 'spasm'. Without my detailed questioning and analysis she felt she might not have ended up on the right treatment. She now has no pain, feels able to participate in rehabilitation and is ready to discuss her diagnosis and its impact with the multiple sclerosis nurse specialist.
> This experience emphasises the importance of careful assessment, listening to the patient and the need for specialist knowledge. I feel good.'

It was vital that I took time with Ruth to assess and analyse exactly what symptom she was describing. This not only improved her care but also led me to realise the significance of unravelling terminology. When I asked Ruth why she used the term 'spasm' she said she had overheard the term being used by a doctor and felt it captured beautifully what she was experiencing. I have subsequently highlighted the need to clarify terminology used between people with spasticity and health care professionals in lectures to both professionals[14], people with MS[15] and when writing

[14] 15/11/05: The use of intrathecal therapies to manage complex spasticity. MSTrust International Conference. Blackpool.

[15] 28/2/04: Managing spasticity it's a team effort. Devon MS Society Study Day. Exeter.

information leaflets (Jarrett 2006). Acknowledging the positive outcome with Ruth I was able to dispel my doubt about whether it had been right to challenge the initial medical treatment.

Developing the discipline to maintain a journal.

Since February 2002 I have regularly used the bullet point approach, recording notes as close to the event as possible and developing them into a reflective text when I have dedicated time. Sifting through my day and isolating the main events encourages me to review issues that may have just merged into the script of the day, otherwise lost, never to be remembered. It helps me to unravel the complexity of my daily practice. I edit what is significant, from which I later write a more detailed and flowing story.

Key to incorporating journaling into my daily practice was identifying a time 'to journal'. I capture insights about this on the 15/10/02:

> 'The bullet points are helping; I am making at least 2-3 entries a week which covers reflections on most days at work. This meant I had two burning issues to discuss in supervision this time! Using my 30-minute train journey to and from work gives a regular time to journal.'

Learning to pay attention to detail

As I paid more attention to detail in my journaling so I paid more attention to my practice, it was as if one fed the other and vice versa. I explored mundane issues as well as the more dramatic ones. As a consequence of my rich descriptions, my work became more satisfying. This fuelled my commitment to maintain a journal.

2nd layer: Dialogue with the story as an objective and disciplined process to gain insights.

Having written a text I needed to think more deeply about it and move into a subjective-objective relationship with it. I chose to use a model of reflection to enable me to move systematically to reveal meaning.

Choosing a model of reflection.

There are a number of models available to guide reflection (Mezirow 1981, Boud et al 1985, Gibbs 1988,). On my diploma[16] course I used Gibb's reflective cycle (1988), for my degree[17] I used the Model of Structured Reflection (MSR) (Version 10, Johns 1998).
In this study I chose to use the MSR version 12 (Johns 2000, Figure 2.5) because it was familiar, understandable and easily applied in practice. In addition it is comprehensive, prompting the user not just to look at self, but the actions and feelings of others, plus it cues consideration of environmental factors that may have had an impact. I found other models tended not to be as extensive.

[16] Diploma in Health Studies Southbank University, London 1995.
[17] Degree in Rehabilitation Oxford Brookes University, Oxford, 1998.

Johns originally constructed the MSR in 1990 through analysing the pattern of dialogue within guided reflection. He then framed this pattern within Strauss and Corbin's paradigm model in grounded theory research (Strauss and Corbin 1990).

In questioning how learning through reflection could be adequately framed Johns appropriated Carper's (1978) four ways of knowing; empirical, aesthetic, personnel and ethical when constructing the MSR.

Looking in

- Find a space to focus on self.
- Pay attention to your thoughts and emotions
- Write down those thoughts and emotions that seem significant in realising desirable work.

Looking out

- Write a description of the situation surrounding your thoughts and feelings.
- What issues seem significant?
- Aesthetics
  - What was I trying to achieve?
  - Why did I respond as I did?
  - What were the consequences of that for the patients/others/myself?
  - How were others feeling?
  - How did I know this?
- Personal
  - Why did I feel the way I did within this situation?
- Ethics
  - Did I act for the best? (Ethical mapping)
- What factors (either embodied within me or embedded within the environment) were influencing me?
- Empirics
  - What knowledge did or could have informed me?
- Reflexivity
  - Does this situation connect with previous experiences?
  - How could I handle this situation better?
  - What would be the consequences of alternative actions for the patient, others and myself?
  - How do I *now* feel about this experience?
  - Can I support myself and others better as a consequence?
  - How 'available' am I to work with patients/families and staff to help them meet their needs?

Figure 2.5: Model for structured reflection – 12th edition (Johns, 2000, p47)

Ways of knowing

Empirical knowledge; 'is systematically organised into general laws and theories for the purpose of describing, explaining and predicting phenomena' (Carper, 1978, p14). It includes the traditional approach to science and is 'ultimately aimed at developing abstract and theoretical explanations' (Carper, 1978, p15).

Carper (1978) describes aesthetic knowing as the art of nursing, it is concerned with 'grasping' and understanding a situation from the perspectives of all those involved.

Jacobs-Kramer and Chinn (1988) suggest that aesthetic knowing creatively explores context specific experiences, as stories unfold; the integration of different patterns of knowing can be appreciated. This process

'... will move nursing away from a quest for structural truth and toward a search for dynamic meaning.' (Jacobs-Kramer and Chinn, 1988, p138).

Personal knowledge is learning to know self, Carper states,

'Personal knowledge is concerned with the knowing, encountering and actualising of the concrete, individual self. One does not know *about* self; one simply strives to *know* the self.' (Carper, 1988, p18)

Personal knowledge considers not just how one is positioned in relation to oneself but also to others. It involves engagement not detachment and requires an appreciation that others have the '...freedom to create themselves and the recognition that each person is not a fixed entity, but constantly engaged in the process of becoming.'(Carper, 1988 p19).

Ethical knowledge addresses the moral aspect of nursing knowledge. This includes an awareness of ethical codes even though these do not always have the answers to moral dilemmas that nurse's face. Carper (1988) suggests a need to develop processes for being ethical in practice. Johns (1995) relates to this by suggesting that,

'To act ethically is a process of deliberation within the specific situation. It is not possible to merely adhere to or apply ethical principles. As with empirical knowledge, ethical principles serve only to inform the situation.' (Johns, 1995, p230).

The four ways of knowing are interdependent towards gaining an overall understanding of a particular situation. Chinn and Kramer (1991) suggest that viewing these four ways of knowing collectively can assist people to make sense of their practical experiences and enhance their personal knowing. Johns (2000) identified reflexivity as an additional way of knowing. Reflexivity involves looking back to discern patterns that have unfolded within the continual flow of experiences.

Whilst the MSR cues (Figure 2.4) relate to discrete ways of knowing, they are interrelated within the whole experience; viewed collectively they give a greater awareness of the whole experience rather than viewing each cue or part independently. White (1995) extends the Carper model by including sociopolitical knowing. She feels the context of situations need to be understood to allow full appreciation of the other forms of knowing.

'The other patterns address the 'who', the 'how' and the 'what' of nursing practice. The pattern of socio-political knowing addresses the ';wherein'. It lifts the gaze of the nurse from the introspective nurse-patient relationship and situates it within the broader context in which nursing and health care take place. It causes the nurse to question the taken-for-granted assumptions about practice, the profession and health policies.' (White, 1995, p81).

White (1995) suggests that the aesthetic mode of knowing can be developed creatively by 'cumulative experience' by engaging, interpreting and envisioning and including the 'artful enfoldment' of the other ways of knowing (White 1995, p81).

Through use of the MSR, I have systematically explored self and hence these ways of knowing, moving from appreciating significance to realising insights.

Significance to insight

During my research three new versions of the MSR (Latest edition 15a, 2007, Appendix 3) were developed. This reflects the continuous pattern of development Johns' undertakes to test the model through his ongoing practice.

Most significant from the 15th edition was viewing reflection as a spiral moving from identifying significance to gaining insight (Figure 2.6). [18]

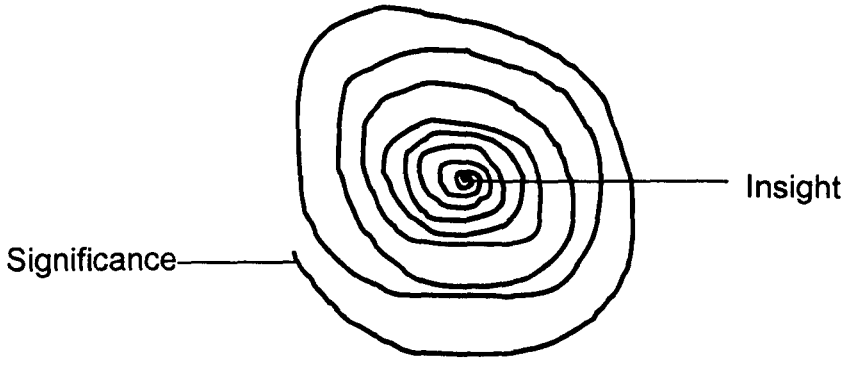


Figure 2.6: Reflexive spiral of significance to insights

Significance is defined as importance or noteworthiness whereas insight is penetration into character or circumstances with understanding, intelligence or wisdom (Concise Oxford Dictionary, Sykes, 1985). Drawing out significance and insight can move through three layers,

- Obvious significance
  - Less obvious significance
    - Insight
    -

Significance by its nature can be obvious; it can lie on or just under the surface of the experience, and is often what prompted me to reflect on a particular incident, whereas insights required deeper consideration such as, use of the MSR, repetitive readings of a text, an elapse of time between readings, dialogue, guidance and patience.

By responding to the MSR cues I deepened my understanding of superficial significances by building up an appreciation of the wider aspects of the story. The cues helped me to structure my move along the spiral (figure 2.10) towards gaining insight. Guided reflection further deepened my understanding. Appreciating significance can lead to cognitive changes whereas insights lead to a change in perception that can influence future action (Johns 2007, Personal Communication).
These issues could be viewed diagrammatically (Figure 2.7).

[18] I shared these insights at the 13th Reflective Practice Conference: Platform Presentation 'Significance to Insights.' June 2007. Aalborg, Denmark.

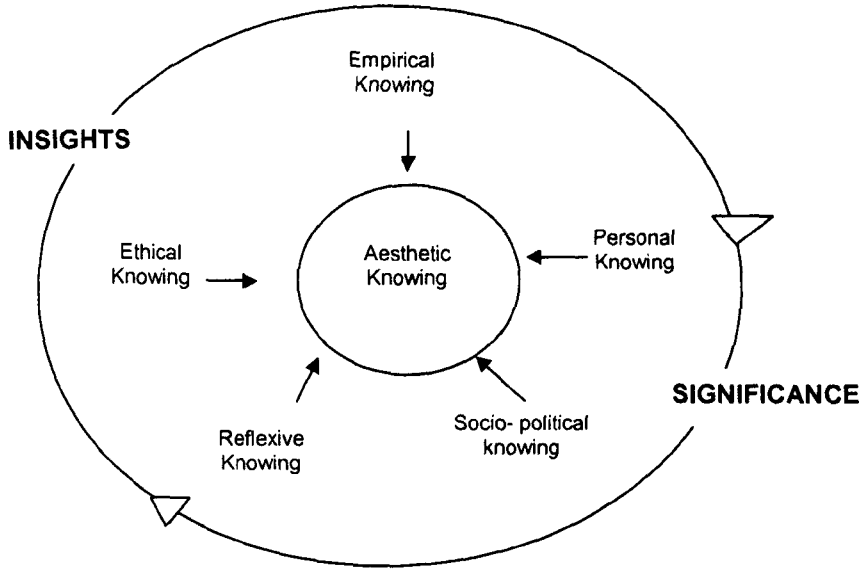


Figure 2.7: Integrating ways of knowing and moving from significance to Insights

Developing insight: Supervision April 2006

CJ and I discussed the work of Jeanette Winterson (2001), particularly the following quote (cited in Johns 2006) where she uses an analogy of reducing computer screens to find significance:

> 'There are so many lives packed into one. The one life we think we know is only the window opened on the screen. The big window full of detail, where the meaning is often lost among the facts. If we can close that window, on purpose or by chance, what we find is another view.
> This window is emptier. The cross references are cryptic. As we scroll down it, looking for something familiar, we seem to be scrolling into another self- one we recognise but cannot place. The co-ordinates are missing, or the co-ordinates pinpoint us outside the limits of our existence. If we move further back through a smaller window that is really a gateway, there is less and less to measure ourselves by. We are coming into a dark region. A single word might appear. An icon.' (Winterson 2001 pg. 103)

Isolation of a single word points towards insights. For example, this resonates with reflective text 13, 'Am I numb?' (p183), the writing of which was triggered by my consideration of whether I was 'numb' to the impact that severe disability could have on a person and their family. Inspired by the idea of 'scrolling down' a computer screen to look beyond the familiar... I remove from my conscious thoughts familiar practice images for example the multiple ways spasticity can 'hold' a body into different shapes. This clearing of images allows an icon, one word to stand out, 'numb'. Exploring this was a route to the core of what I was feeling; it was a move toward new understanding, of gaining insight.

Using the MSR

Initially, I diligently worked through the cues, writing my responses. Over time, I needed to pay less attention to the cues, they had become internalised (Johns 2002, 2006), I was able to dialogue with my story and start to write a reflective text without needing to directly refer to them. I developed my use of the MSR to prod my thinking rather than as a rigid framework to follow; this prevented me from writing individual responses to the cues and breaking my story into parts, thus developing my story as a whole.

My use of the MSR - 12th Edition

Looking in

So much of what we do is a reflection of who we are; this first section of the model involves creating the right environment to 'look in' at self. I am reminded that to develop my story into a reflective text is an action-orientated process that requires time, concentration and effort. I need to approach reflection with intent, recognising it can be arduous and requires energy.

Looking out

Drawing out significance.

To draw out significance I word processed my story from my journal, editing and rephrasing as I typed. Often time had elapsed since my journal entry which provided the opportunity to reconsider the issues from a fresh perspective. As I moved through the cues the extent of the significance deepens and I moved towards identifying insight. For instance in the story of Ruth, my initial journal entry captures how beneficial I found it to affirm my practice. It was only when the cues; 'Why did I feel the way I did within this situation? What factors (either embodied within me or embedded within the environment) were influencing me?' did I start to question my reticent approach to the medical staff.

What was I trying to achieve?

This practical cue encourages me to focus on what my intent is? Do I have a clear goal? Do I communicate it well to others and what do my actions mean to me, to others? With Ruth I try to appreciate the nature of her pain, resisting the diagnostic labels used by other professionals, I strive to appreciate and understand what she is describing to me, what her experience is like for her. On a deeper level it was respecting her autonomy and humanness.

Paying attention to feelings.

Initially my reflections were triggered by negative feelings such as shock, anger, disbelief and frustration.[19] Boud et al (1985) suggest negative feelings need to be dealt with and cleared so as learning can occur. I disagree. I have learnt from my feelings whatever their nature.

[19] Reflective texts 1 - 5

Nursing is recognised as having to deal with the emotions and feelings of others; James (1989) describes this as emotional labour. Through guidance I recognised the importance of dealing with my own feelings in order not to let them interfere with the emotions and concerns of the person with spasticity and also to manage my vulnerability in developing more intimate relationships with people with spasticity.

Paying attention to my feelings and developing my understanding through reflection nurtures my compassion for others. Likewise concentrating on the feelings of others encourages me to appreciate the sensitivity of the situation from their perspective and this heightens my empathy. Belenky et al (1986) describes this as 'connected knowing', being in relation with others where there is intimacy and equality that allows empathy to develop.

I found the cues that related to my feelings particularly revealing and challenging but crucial to learning about self. However, I do not find sharing my feelings easy. This was highlighted to me by Lea Gaydos[20] whose feedback I requested after my presentation at the 2007 reflective practice conference, where I had read a section of narrative, [18]

> 'Your narrative demonstrated your thoughts, but as I listened I was desperate to know how the incidents made you feel? You didn't disclose your feelings...'

The text I had shared at this conference is the second in my narrative, as my narrative develops so does my focus on my feelings although there is a sense that this is always tentative and difficult to do. Despite this, when I did reflect on my feelings it was cathartic and enabled me to articulate, value and label them and I came to realise that, how I am feeling is significant in my response to others.

Influencing factors.

Considering what influences promote and restrict me from achieving desirable practice requires an awareness of self. Understanding my current reality is not a condition of the environment but a condition of self. Fay (1987) suggests that revealing self can be challenging because we are embodied, conditioned by tradition and force. Johns (2000) identified factors grounded in issues of authority, tradition, embodiment and theory that influenced the way nurses thought, felt and responded within their everyday practice (Figure 2.8). Using the grid was pivotal in leading to an understanding of my current reality. For example, the 'weight of tradition' is evident in my comment,

> 'I was nervous to feedback my findings to her medical team. A nurse challenging a medical diagnosis!'

I started to appreciate the subservient role I was taking and my hesitancy in dealing with issues of authority and power in my everyday relationships. I was reinforcing the stereotype that doctors exert power over nurses (Daiski 2004). Yet the medical team were asking for my opinion, recognising my authority and specialist knowledge. I need to recognise this as positive feedback of my value to people with spasticity and other team members. Such recognition can contribute positively to

[20] Associate Professor, Beth-El College of Nursing and Health Science, Colorado Springs

developing my self-esteem, which Roberts (2000) suggests is required to stop nurses oppressing themselves.

Conforming to normal practice / habit? The weight of tradition	Negative attitudes and prejudice? Racism?	Expectations from others? Need to be valued
Limited skills / discomfort / confidence to act in new ways?	**What factors influenced my decision –making and actions**	Fear of sanction? The weight of authority
Emotional entanglement / over-identification?		Misplaced concern – loyalty to colleagues versus loyalty to patient? Anxious about ensuing conflict?
Personal stuff / baggage? Deeper psyche factors?		Knowledge to act in specific ways? The weight of theory.
Wrapped up in self-concern? Pity? Stressed? Guilt? Frustration? Other feelings?	Time/ Priorities	Expectations from self about ' how I should act' Doing what was felt to be right?

Figure 2.8: Influences grid (Johns, 2006, p45)

Ethical action.

The cue 'did I act for the best?' challenged me to question my practice from an ethical perspective. Every clinical situation is different and knowing what is best cannot be prescribed but must be carefully considered from the perspective of the people involved, informed by ethical principles. I use ethical principles to see different perspectives rather than as a 'recipe book' where I can choose the 'right' action to take. I used 'ethical mapping' to help me explore this cue (Figure 2.9).

The grid helps me to focus on the interrelationships of power and conflict within situations and to consider how decisions are reached.

Patient's/Family's position	Who has authority to act?	*The doctor's perspective*
Is there any conflict of values? If so, how might the conflict be 'best' resolved?	**The situation /dilemma**	What ethical principles inform this situation • Autonomy • Do no harm • Truth telling • The greatest good • Duty
The nurse(s)' Position	How was the decision actually made in terms of power relationships?	*The organisation's position*

Figure 2.9: Ethical Mapping Grid (Johns 1999, 2000).

Applying ethical principles to a situation is described as ethical principlism and originates from the ethical philosophies of the modern era, deontology and utilitarianism. It is argued that only considering

these issues is a traditional way of approaching ethics (Hugman 2005) and is limited at assisting individuals to be ethical in their practice, as the principles can be contradictory (Hanford 1993) and do not consistently provide the practitioner with clear decision-making pathways (Varcoe et al 2004). Hugman (2005) suggests ethical issues implicit within professional contexts need to be made explicit, that individual professionals need to be able to justify ethical action. I rise to this challenge. Through reflection I live and practice ethics. As Fairbairn (2002) states:

> 'Our moral imagination is formed in the lives we lead. It is because our moral understanding is limited that if we want to be ethical in our behaviour and specifically in our professional practices, we need to rehearse decisions reasons and justifications.' (Fairbairn, 2002, p23).

Guided reflection encourages me to consider the ethics of my practice. Varcoe et al (2004) facilitated focus groups with a total of 87 nurses, to explore the essence of ethical practice. They conclude that nurses describe it as both a way of being and of enactment. My journey towards an ethical way of being in my practice permeates the narrative.

What knowledge did or could have informed me?

Clearly to be an effective practitioner I need to draw on, critique and assimilate as appropriate, knowledge in my every day knowing. Initially I tend to draw on neuroscience, chronic illness and disability related literature, for instance with Ruth I readily accessed my knowledge on the different drugs available to treat her neuropathic pain. The strength of this cue is that it continually prompts me to question what knowledge I know but also are there any gaps? Guiding my reflection in this way helps me to consider different ways of knowing as described earlier (Carper 1978)

Knowledge can come in many guises. I need to remain open to influences such as any local or national guidelines, protocols or policies that may have help me make sense of what is happening and assist in my decision-making. The influences and ethical mapping grids (Figures 2.6 and 2.7) can also prompt the need to explore different sources of knowledge. Exploring different ways of knowing and other sources of 'knowledge' at this stage provide a basis, which is extended in the third layer of dialogue.

Reflexivity.

Responses to the reflexive cues link with previous experiences, having looked back I now look forward to consider how I may act in future scenarios. It's important to recognise if I am repeating patterns of behaviour that are not necessarily the best response. This is a vital stage towards transformation.

Alvesson and Sköldberg (2000) use the term reflexivity interchangeably with reflection, this can be confusing but I didn't realise how much until I volunteered to share my experience of reflexivity in a lecture.[21] I interpret the terms as related but distinct entities, however when I started to read around in

[21] Through the looking glass: PhD students' experiences of the research journey. City University Research weekend January 2006.

preparation for the lecture I found the literature contradicting and unclear. I stood back from the literature and tried to clarify my understanding. I found I could visualise it, for me reflexivity:

'Is moving, changing,
encompassing all, altering everything.
It reminds me of the seashore,
never static, constantly moving.
Where everything has an equal place, a part to play,
Everything is interacting, changing, being reshaped...'

The continual movement resembles the ongoing refinement of the reflexive spiral of being and becoming the nurse specialist I want to be. I view reflection and reflexivity as distinct yet interdependent in the process of developing knowledge and my practice.

In subsequent versions of the MSR, CJ has added, 'What factors may constrain me acting in new ways?' So as well as rehearsing different ways of responding, the reflexive questions look at what may restrict realising desirable practice. Although I may not always be able to influence constraints, recognising and understanding them is the first step towards managing them.

At the research seminar[21] I used an analogy to expand my initial visualisation, to try and demonstrate what reflexivity meant to me in practice. Rereading it now I realise I included certain constraints to my practice.

Distinguishing between reflection and reflexivity[22]

Visualise the seashore...

Imagine the rocks represent experience, the sand reflection, the beach reflexivity, the sea the environment or context and I am the beach-comer practitioner.

I am unable to move the large, hard, stationary rocks, but I know if I look closely I may see how they are transformed into small, soft, fluid sand particles.
In the pursuit of desirable practice an experience jars me into reflection, to seek understanding of how each element of the experience interacts to contribute to the whole scenario.

Standing on the rock I can feel secure but it does not mould or shape to accept who I am like sand does.
I can rely on experience, ignoring reflection and reflexivity, just practicing at a certain level of competence, but the risk is I will be stuck in one place and not realise my full potential.

On the rocks I am concerned with watching where I need to hold and step, afraid of falling, being cut, feeling hurt.
Running on the sand is less restrictive, I feel freer, cover more ground...to fall over, feel unstable with all the discomfort of sand in my toes, is just being part of discovering, learning.
It may seem easier to ignore contradiction, how I feel and to avoid conflict but is it as exciting or empowering.

Together the sand particles cover more space and are flatter than the peaks of the rocks.
My reflection changes my perspectives and insights. Any contradictions are laid out, flattened or demystified. I link it back to previous reflections, they become interdependent and my knowledge is broadened as I think how I may practice differently in the present and future.

[22] For an audio and visual presentation of this poem see file on accompanying compact disc (Appendix 4).

The rising tide is more of a threat on the rocks, at first being on high ground I feel safe, but as it rises, its harder to safely get off, will I be battered by waves and washed away?
Will the continual waves of change in the NHS batter my experience until I am burnt out?

Although waves can also batter me on the sand, I have more chance to run, or I can decide to flow with the sea, move to a different place, a new position, to view the horizon and to learn.
Striving for desirable practice though reflection and reflexivity can lead to personal growth, development and improved nursing care even amid constant change.

Reflection, reflexivity is for me a way of being.
Necessary tools for survival and growth as a nurse, in the NHS, researching self.

In layer one I mention how through paying attention to the detail in my journal I became more attentive in my practice, one feeding the other. This gradual layering of awareness through reflection led me toward being able to articulate deeper perceptions or insights and I recognise; Being and becoming is a reflexive spiral where my pattern of unfolding experiences and insights represent my journey towards transformation.

3rd layer: Dialogue between the tentative insight and other sources of knowing in order to inform and frame insight within the wider community of knowing.

Holding my tentative insights I can turn again to the literature, to open a dialogue whereby I can position my insights within the wider community of knowing. Through this dialogue my insights are both challenged and informed. As a consequence my insights shift and deepen, in doing so I critique a relevant literature for its value to inform my insights. Through this process, I assimilate other sources of knowing within my own knowing. Extant literature is not viewed as authoritative but through a sceptical eye (Dewey 1963 [1938]) for its value to inform my insights. Mayeroff (1971) describes such dialogue as 'alternating rhythms',

> 'There are times in caring for a child when I examine an act as a relatively isolated episode, without relating it carefully to what went before and what will follow, and other times when I look at the particular act in its wider connections within a larger framework and can discern trends, long-term effects, and tendencies.' (Mayeroff, 1971, p16)

This resonates with my appreciation of the movement between insights and dialogue to deepen understanding. For instance dialoguing with my insights is illustrated in my narrative when I consider literature relating to chronic illness to extend my appreciation of what it is like living with spasticity and spasms.[23] A further layer occurs when I dialogue with art and art related literature to gain meaning into my practice.[24] Drawing on a theme from autoethnography,

'Good autoethnography is not simply a confessional tale of self-renewal; it is a provocative weave of story and theory.' (Spry, 2001, p711)

Analytical and methodological memos.

[23] For example see my references to Charmaz (1983), p176, 181, 232, 245, 250 or Kralik (2001, 2002) p151, 153, 160, 176, 232, 245

[24] Chapter 3 through three analytical pauses, after reflective texts: 6,p138-145; 10,p168-172 and 17, p211-215.

As I wrote my reflective texts particular issues I wanted to explore further became apparent. To analyse these issues in detail I needed to take a break, metaphorically I needed to stand back, from writing the reflective text. To do this I started a new text where I would write and gather all my related thoughts together.

Those pages relating to the narrative I called analytical memos, a term lifted from grounded theory (Glaser and Strauss, 1967, Manning, 2000). Ideas more related to the construction of the narrative I termed methodological memos (Appendix 5). Through these memos I explored tangents and interrelated concepts. There was no tangible system or logical flow to how I wrote my memos, but this seemingly chaotic approach revealed profound insights. The process reminded me of the theory of dissipative structures (Prigogine and Stengers 1984) cited by Margaret Newman (1999):

> ' The system operates in a rhythmic, predictable fashion for a while until a chance element, some critical event brings about a giant fluctuation that propels the system into disorganised, unpredictable fluctuations, from which the system will eventually emerge at a higher level of organisation.' (Newman, 1999, p37)

Whilst developing my reflective texts through use of the MSR, I was often stimulated to consider an issue in more detail. Constructing memo's focused my attention on these issues and would challenge or 'disorganise' my understanding. I learnt to flow with the unpredictability of this process as I often emerged with deeper insights or a 'higher level of organisation'.

Situating other sources of knowing

The work of Wilber (1998) helped me to appreciate how different types of knowledge can be viewed as an integrated whole. Wilber (1998) posits there are different but partial ways to 'know' truth. To integrate these partial views, accepting their diversity and differing approaches to validity Wilber offers 'The integral vision' (Figure 2.10) to map the different approaches to knowledge generation.
The four quadrants of the map represent individual or collective approaches towards gaining knowledge. The right hand pathway represents objective approaches that are exterior to the individual or group and use third person ('IT') language; methods include quantitative approaches such as randomised controlled trials and organisational theory to appreciate how systems function. The left hand path covers subjective approaches that are interior to the individual or group and uses first person ('I' or 'WE') language. Individual methods include reflection and group methods such as action research. Wilber posits that no approach is superior,

> '...any phenomenon can be approached in an interior and exterior fashion, and also as an individual and as a member of a collective.' (Wilber, 1998, p9).

Historically the objective path has overshadowed the subjective path, with the approaches of empirical science dominating the way to ascertain knowledge (Schön 1983, Wilber 1998). The dominance of the behavioural approach and its impact is still evident in my workplace. In the grading of evidence for the recent National Service Frameworks, randomised controlled clinical trials were given higher scores than experiential knowledge (DoH 2005). Wilber (1998) challenges this dominance,

'...the persistent existence of these four large camps in the knowledge quest is evidence enough that none of them can be totally reduced to the others. Each approach is giving us, as it were, one corner of the Kosmos. Each is telling us something very important about various aspects of the known world.' (Wilber, 1998, p12).

	INTERIOR Left Hand Paths	EXTERIOR Right Hand Paths
Individual	*truthfulness* sincerity integrity trustworthiness Personal experience reflection ***I*** INTENTIONAL	*truth* propositional Empirical forms 'Science' Technology Knowledge observable *IT* BEHAVIOURAL
Collective	***WE*** CULTURAL *justness* cultural fit mutual understanding rightness Patterns of relationships within structures of everyday worlds	***IT*** SOCIAL *functional fit* objective network Systems theory Social systems Organisational theory
Knowledge gain	*Subjective* **Contextual**	*Objective* **Abstract**

Figure 2.10: The Integral Vision (Adapted from Wilber 1998 p10 & 13)

Wilber (1998) suggests each paradigm has a partial view of knowledge with its own methods ('rules of injunction') and criteria for judgement ('truth or type of validity claim'). Misunderstanding arises when the rules from one quadrant are applied to another, for instance in objective studies variables are controlled, in subjective studies they are embraced.

I use 'The integral vision' as a template to position sources of knowledge into specific quadrants. Johns (2006) argues that the rules of injunction for the 'IT' type of knowing have become normative,

> 'As a consequence, the significance and legitimacy of subjective knowing has been oppressed. 'I' knowing is accessed through reflection and provides the only basis for dialogue with other paradigms.' (Johns, 2006 p50)

I use my reflection space to consider the literature within its own specific rules of injunction and truth criteria and assess whether it informs my practice and ways of knowing (Carper 1978). I have been influenced by scientific literature, art workshops, paintings, poetry and sculpture in particular of

Barbara Hepworth.[25] Throughout the narrative 'I' dialogue and assimilate relevant theory meaningfully into my 'aesthetic -knowing', my practice. In this way abstract ideas are contextualised.
'The creation of personal knowing may be enhanced through the use of art, poetry, literature and storytelling.'(White, 1995, p6).

The narrative captures how and when different influences stimulated my learning.
Exploring other sources of knowing was challenging to engage in, caught as I was in a scientific paradigm with its narrow view of knowledge. The following poem written following a supervision session demonstrates my struggle to engage with the literature to expand my reflective texts.

Dialogue with the literature – 27th Oct 2006

CJ states, 'Engage with the literature', use metaphors,
Easier said than done, I silently scream in irony!
I am afraid to change the words of others
I 'quote' so as their construction remains untouched, not adulterated.
I need to shake free from my awe of the written word
To stay within its power, will only lead to self oppression

What do I understand by, dialogue with the literature?
To dialogue is to run free and truly listen to the words of others.
Listen, read, listen, read. HEAR the words and the 'in-betweens',
albeit through my own 'veil' of understanding and interpretation.
I need to work at understanding my senses, to feel pain in my eyes and ears,
as intently I observe and absorb a cacophony of input.

There is no right or wrong, let the words speak.
What do the sentences say to me, not others, to ME?
Do they help my understanding and develop meaning?
If so then isolate that thought so as it can crystallise.
Then work with it, insert it and allow its position to shape and
be shaped by the story it is now co-creating.

Blocks may occur or be predicted.
Embrace them, if ignored I could be subtly defending my own views, ideas
and not truly 'listening'.
Feel able to alter original words, change direction,
Flow with the meander, always carve my own route.
This is my story, my reflections, eventually my narrative will emerge[26]

Johns (2002) used Wilber's four quadrant model to emphasize that the practitioner can only meaningfully dialogue with extant literature from a position of personal experience - asking such question as 'how does this theory / research inform the particular situation', in contrast with viewing the literature in an abstract way. As I shall elucidate in the 4th layer of dialogue this dialogue is enhanced through guidance.

[25] http://www.modernbritishartists.co.uk/hepworth_biog.htm accessed 10th February 2006
[26] Influences: Bohm (2000) and Johns (2004)

4th layer: Dialogue between the tentative insight, guide(s) and peers to develop and deepen insights through co-creation

Throughout the research I was guided within the supervisory relationship towards becoming reflective, gaining and deepening insights and finally, in shaping the narrative.

Why guidance is needed

Johns (2006) acknowledges that there can be limitations when reflecting independently and advocates that guidance is required to enhance learning through reflection. In summary guidance is a balance between high support and high challenge. It is also a two way active process; it is not a system where one person passively receives advice and information from another person, who could be judged as having more experience, knowledge and hence power. It involves active dialogic engagement to learn from and understand each other's perspectives, from which a new way of viewing and appreciating a situation is achieved for those involved. Each person is supported and challenged. The focus is not to uncritically adopt the views of others but to move towards a co-creation of meaning.
Guidance was significant to me for multiple reasons, it has:

1. Challenged my assumptions and insights leading to the co-creation of meaning
2. Opened up my perspectives on how I view individuals and situations
3. Picked me up when I felt demoralised, supporting me to take action as necessary

Challenge

Contradiction between my practice and vision has not always been easy to appreciate; it was through guidance that it was often revealed. Strategies to guide or prompt my learning have been identified in the 2nd layer such as the influences grid (Figure 2.6). Whilst I have found these strategies helpful they demand self-discipline. When deeply involved in an experience I have been blind to certain perspectives, struggled to be honest with self and to identify ways to move forward. Guidance from others, which involved challenging my perceptions, was crucial at this stage, to develop my awareness and the emerging text.

Contradiction in my actual and desirable practice became apparent as early as session one; I had a negative attitude towards the work and care that occurred in nursing homes. Although uncomfortable with this feeling, I was able to acknowledge that I did have such a belief. With guidance I was subsequently able to develop a more positive attitude as is reflected in later experiences.[27]

[27] Reflective text 7, p146-149

Dialogue and Co-creation

Guidance enabled me to see my embodied self, how I was being influenced and the impact of my work environment on my practice. Gadamer (1975) suggests that to understand we continually have to test 'all our prejudices',

> 'An important part of this testing occurs in encountering the past and in understanding tradition from which we come. Hence the horizon of the present cannot be formed without the past...Rather understanding is always the fusion of these horizons supposedly existing by themselves...
> In a tradition this process of fusion is continually going on, for the old and new are always combining into something of living value, without either being explicitly foregrounded from the other.' (Gadamer, 1975, p 306).

As CJ and I dialogued with my evolving texts and I tested my 'prejudices'. In a reflexive spiral moving from significance to insights we revealed understanding, 'our horizons fused' and meaning was co-created.

For instance the idea of an individual with spasticity living in a 'precarious harmony'[28] emerged through my sequential supervision discussions.[29] From the seemingly distinct yet related texts I recognised a pattern of coping, relating to the impact of living with a complex disability. Wheatley (1999) discusses that order is inherent in chaos, when this occurs in systems, computer images can be mathematically generated that trace the system's evolution,

> 'The chaotic movements of the system have formed themselves into a shape. The shape is a 'strange attractor' and what has happened on the screen is the order inherent in chaos' (Wheatley, 1999, p116).

My label of 'precarious harmony' is the pattern or 'strange attractor' from these sequential texts. I describe 'precarious harmony'; as a highly refined coping strategy unique to each person with a complex disability and their families, which often is put into jeopardy when a person is taken out of their normal living environment such as being admitted to or even just visiting a hospital.

Support

At the root of guidance is being able to listen to others and to be listened too. Being heard in my guided reflection sessions helped me to consolidate my understanding of events. Listening to the challenges from CJ enables me to see my practice and explore new ways of being and responding. The following paragraph from my journal relates to a period of time where team members were in conflict over the development of a new therapist post, having the opportunity to 'be listened to' helped me to move forward:

> 'I was glad I discussed this issue I was finding it too complex to unravel myself. I was unable to clearly see my position in it. Now I can see how useful it is to start from the perspective of my vision as a way of then ranking the importance of other issues. My vision is to improve services for people with spasticity. The best way for me to do this is to work at my individual relationship with the clinical specialist team so as the impact of the new role can be assessed as fully as possible. This will hopefully than impact on the quality of the service provided to people.

[28] Reflective text 9, p 155-161 specifically p159.
[29] Reflective texts, 1,2,3,6,8.

This scenario has been in the background of my practice for some time, probably weighing me down, draining me of energy. Now I can see where I have to aim for, I do feel lighter and more energised to try and tackle the issues (Session 16 – June 2002).'

Changing nature of the supervisory relationship

The agenda of my supervisory relationship shifted over the research period from an emphasis on supervising my clinical practice to an emphasis on constructing the thesis (figure 2.11).

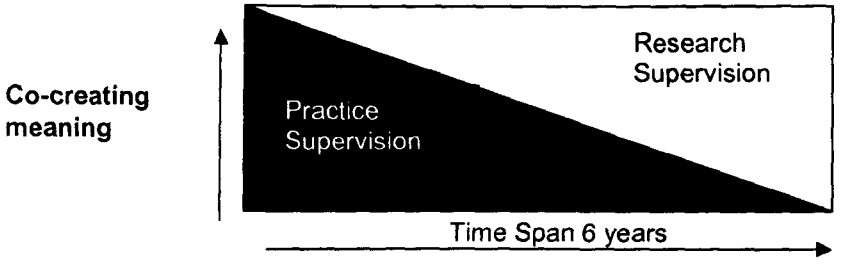


Figure 2.11: Changing emphasis from practice to research supervision

Cherniss and Egnatios (1978) from their research describing supervisory styles identify five types, Didactic–consultative, laissez-faire, authorative, feelings orientated and insight-orientated. Initially as I got used to the supervisory process CJ's supervisory style was didactic and educative, he would offer advice and suggestions as to why people behaved and interacted with me in certain ways. He opened space for me to visualise my practice from different perspectives. As I became more skilled at reflecting, approximately six months into the relationship, CJ traversed between encouraging me to question my emotional response, a feelings orientated style to asking me questions to encourage me to solve issues, an insight orientated style (Cherniss and Egnatios 1978). However the supervisory style was consistent, always prompting me to draw out significance and construct insights within the co-creative process. It was never prescriptive or authoritative I was always reminded it was *my* narrative and the role of the supervisor was to open up and problematise my practice towards being and becoming an effective spasticity nurse.

Trust

Trust is an important attribute between the supervisor and supervisee; I would have found it difficult to expose my practice without respecting the supervisory relationship that CJ and I developed. The foundations of our trusting relationship related to being honest, committed, critical and confidential. Gilmore (2001) in her critical review of studies evaluating clinical supervision in the UK found that trust between participants in a supervisory relationship was an essential requirement for disclosure. Trust is important as discussing and reflecting on experiences can be uncomfortable however supportive the supervisory relationship. Sometimes I felt situations were too emotionally raw to discuss, as the following example from my journal shows.

> 'I didn't want to discuss the conflict I had experienced with my manager. I felt physically drained and emotionally fatigued. Today had been very tough. I was concerned that reflecting more deeply would be depressing and make the situation worse, but on the contrary. CJ guided me to see how being assertive, proactive, taking control and confronting my managers bureaucratic

style had ended in a positive collaborative result. I had been tough on the issues whilst not being drawn into a passive, non assertive, child like mode. Although I cannot change the outcome of this situation this reflection will help me manage future situations.' (Session 22 – July 2003).

Through the process of supervision my negative feelings were acknowledged and I was able to turn my negative energy into positive, which enabled me to move forwards and consider future action.

Other forms of guidance

My interactions and dialogue with CJ were vital to my ongoing commitment and progress but so too was regular feedback from my second and third supervisors. In addition the university's annual review system of my work, publishing, presenting at local seminars, national and international conferences (Appendix 6) have all provided critical review and enabled me to gauge how others perceive my research. This feedback has helped to balance the influence from CJ, shape my subsequent thinking and how I present my work. Although stress provoking, these experiences have developed my confidence and strengthened my commitment to persevere with writing my narrative.

5th layer: Dialogue within the evolving text to further deepen insights and weave the narrative into a coherent and reflexive pattern that adequately plots the unfolding journey.

Narrative form

In total I constructed 29 reflective texts together with 14 analytical and 8 methodological memo's (Appendix 5). In the 5th layer I weave these into a coherent and reflexive whole that adequately unfolds my transformational journey towards realising my vision and desirable practice as a spasticity management nurse specialist.

In constructing a coherent narrative I pay attention to four key issues; the plot, reflexivity, writing and ethical issues relating to my research process.

Plot

The plot is to give structure to the narrative.

'..making a configuration in time, creating a whole out of a succession of events.' (Mattingly, 1994, p812)

It is the plot that holds the narrative together, giving form to the reflexive process. My narrative plot is to reflexively mark my journey of realising my vision of spasticity nursing as a lived reality. As I write I pay attention to the pattern and links between the reflective texts, in particular the movement from significance to insights and the co-creation of meaning. Yet how would I know if I had achieved my vision? This is difficult because my vision is always shifting as I reflexively gain insight into my

practice. Hence I need a broad scheme to frame my insights that can lead to a summative representation of spasticity nursing, I chose the being available template (Johns 1998).

Marking the reflexive journey: The Being Available Template

The being available template was synthesised by Johns (1998) from data captured in reflective practice sessions with practitioners as part of his PhD. It weaves together elements a practitioner needs to consider to assess whether they are 'fit' or available to engage with others in the practice context. I chose to utilise, the being available template (Johns 1998, 2000), simply because it resonates deeply with my practice vision grounded as it is in holistic values. At its core is being in relation with the person, Johns notes that the,

> '...core therapeutic of holistic practice is the practitioner *being available* to work with the person and their family; to find meaning in the health event, to make good decisions about their lives and to take appropriate action to meet their health needs.' (Johns, 2002, p51).

This resonates with my vision; to work *with* the person with spasticity, their family and carers, jointly sharing our knowledge, expertise and experience to maximise the positive impact of spasticity on the person's lifestyle. [30]

Johns identified six inter-related factors that seemed to influence the extent the practitioner could be available. The first five are concerned with the therapeutic relationship with the person and the sixth with the organisation or practice environment.

1. The extent to which the practitioner holds and intends to realise a vision of practice.
2. The extent to which the practitioner knows the person.
3. The extent to which the practitioner knows and can manage her involvement within relationships.
4. The aesthetic response- the extent to which the practitioner can respond to the person with appropriate and skilled responses.
5. The extent to which the individual is concerned for the individual.
6. The extent to which the practitioner can create and sustain an environment where being available is possible.

Vision

Having a vision of practice gives meaning and purpose to my practice and allows me to focus my intent, compassion and action. My vision is a dynamic structure always shifting in response to the insights I gain through reflection. So the challenge has been to continually test and refine my vision in light of what I am learning through my practice.

Knowing the person

Knowing a person involves developing an awareness of their life context; how they position themselves in respect to their health, illness, symptom management and chosen lifestyles. It involves appreciating the life pattern of a person (Cowling 2000), tuning into their wavelength to understand

[30] p44

the meaning they give to their health experiences (Johns 2004). This cue is fundamental in my approach to people with spasticity and complex disability – the need to get to know the *person* and not just to see their disability or disease. Benner et al (1996) state,

> 'Central to expert practice is concern for revealing and responding to patients as persons, respecting their dignity, caring for them in ways that preserve their personhood, protecting them in their vulnerability, helping them to feel safe in a somewhat alien environment, and comforting their family, striving to preserve the integrity of close relationships.' (Benner et al, 1996, p 145).

Concern for the person

Having concern is what motivates people to care and creates possibility within a therapeutic relationship (Johns 2002). I value this cue to focus me on the central tenant of why I am a nurse; that I want to work with and 'care' for others. This perhaps seems obvious but 'working with people' can be lost in current health care systems, when the NHS is so driven to reach government targets. At a recent study day on the latest government initiative (DoH 2007),[31] to facilitate an 18 week trajectory that starts from referral of a patient to a service to the commencement of treatment, the room full of senior clinicians went quiet and the facilitator looked embarrassed when I pointed out that we had discussed this issue for three hours before the patient was mentioned.

Having concern for a person is linked to compassion. Caring for self and others through reflection nurtures compassion, I suddenly see things, by understanding, my compassion flows. Rinpoche (1988) in answer to the question, 'What is compassion?' states,

> 'It is not simply a sense of sympathy or caring for the person suffering, not simply a warmth of heart toward the person before you, or a sharp clarity of recognition of their needs and pain, it is also a sustained and practical determination to do whatever is possible and necessary to help alleviate their suffering.
> Compassion is not true compassion unless it is active.' (Rinpoche,1988, p191).

This factor prompts me to remain active in my concern for others.

The aesthetic response

For Carper (1978) the aesthetic response is about grasping the situation and appreciating the perspectives of all involved. It is to paraphrase CJ (personal communication 2008) the ability of the practitioner to appreciate the situation, make clinical judgment, and respond with skilful moral action as appropriate towards enabling the patient to meet their health needs, and reflect on the efficacy of that response. It draws connections between the present with past performance whilst anticipating future practice.

Within the being available template I interpret the aesthetic response as appreciating the wholeness of a situation. It involves how I integrate the other ways of knowing with having concern for the person, continually evolving my vision, managing self and appreciating the impact of the changing environment. I am concerned with my performance, and in particular pay attention to four elements; appreciating the situation, making clinical judgements, responding with skilful action and judging

[31] www.18weeks.nhs.uk

efficacy. This is the core of my practice, the aspects most evident within my narrative.

Managing self

Johns (2006) describes managing self, as knowing and managing self within relationship, it requires equanimity, poise and being mindful.

In managing self I pay attention to the impact of my interventions, for instance, how is the person responding to my words or silence; actions or non-action, how am I influencing this person? This work contributes to knowing and having concern for a person, it can require a level of intimacy and connection that can expose one's own vulnerability.

Through reflection and supervision I can explore these issues. At times this requires a detailed look at self, this can be painful and include negative aspects of self that are difficult to acknowledge. The guide is essential in this situation to provide maximal support as well as high challenge. This is vital work if I am to remain available to a person in practice, whilst acknowledging and managing any stress.

Creating and sustaining an environment where being available is possible.

My practice environment, situated as it is in an organisational context and influenced by political directives, will promote and constrain the way I want to practice. I need to appreciate these wider influences and cultivate a leadership style, which is in tune with my vision and enables me to work towards maximising the environment to enable desirable practice. Benner et al (1996) state,

> '...expert nurses must develop skills of advocacy, communicating their concerns and designing the system to support caring practices in order to create a supportive public space for their caring practices. This calls for self-respect and independent thinking.' (Benner et al, 1996 p161)

Creating a suitable practice environment also involves managing self within relationships such as effectively managing conflict, oppression and issues of power.

Using the Being Available Template

The process of using the being available template is dynamic and ongoing as it is integrated with my practice. As it influences my practice I am simultaneously testing it to see if it does capture my transformational journey or whether it requires amendments. At the reflective practice conference in 2005,[32] I illustrated this diagrammatically and with the accompanying explanation (Figure 2.12).

[32] Reflective Practice Conference: Enlightened holistic Care: From Research to Practice through Reflection; May 2005, Reykjavik, Iceland.

'I visualise the being available template as a cylinder, spinning on an axis. The axis represents my ever-present but changing practice environment. Thinking about my work environment has led me to appreciate deeper political and cultural processes that can influence my practice arena. The spinning movement represents the dynamic nature of integrating the template into my practice. Through guided reflection I have learnt that assessment or getting to know the person with complex disabilities is an ongoing, process. I represent this in the diagram as building blocks. As I work I ask myself questions; is the spasticity useful to the person? Is it the right time for treatment or should we delay? What are we aiming for? All the time I am building up my knowledge of the individual and their life or getting to know the person. This sparks my concern and I consider, how can I show them my concern whilst respecting their expertise and knowledge? Can I respond skilfully do I need to develop skills or refer to someone else?
This work can be demanding and emotionally draining I need to monitor if I am managing self effectively?
People with spasticity motivate me. Yet they can literally be without voice. I attempt to smooth their journey and get their voices heard, so as jointly we can work towards defining what is desirable in our work together.'

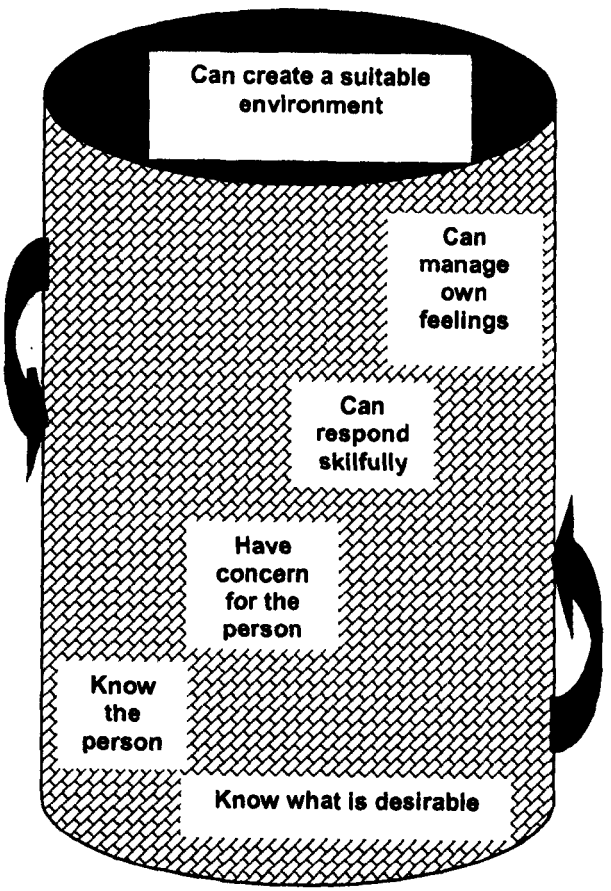


Figure 2.12: My representation of the being available template

Reflexivity

Reflexivity is 'looking back' and seeing myself emerge through a succession of experiences towards realising my vision as a lived reality. It is like a drama unfolding experience by experience. Reflexivity,

'... is the conscious experiencing of self as both inquirer and respondent as teacher and learner, as the one coming to know self within the process of research itself.' (Guba and Lincoln, 2005, p210)

Reflexivity involves engagement with self in a hermeneutic circle of being and becoming, moving back and forth between my texts, and between my texts and my practice. Yet, in this flux, how might my

vision be known as a lived reality? What theory might adequately frame this realisation? I consider whether the 'Being Available Template', with its core therapeutic (p82), which resonates strongly with my intended vision of the way I wanted to be with people with spasticity, is implicit within the text, or does its presence need strengthening to show its congruence with my vision. This requires re-reading and editing the reflective texts sequentially many times, with time in between each reading. I feel the need as Johns (2006) describes to 'dwell' with the texts. This process is important to ensure I grasp the pattern and all its nuances to move towards developing an approach to spasticity nursing, but also to ensure the narrative reads in such a way that the reader can adequately follow my development toward transformation (Figure 2.13).

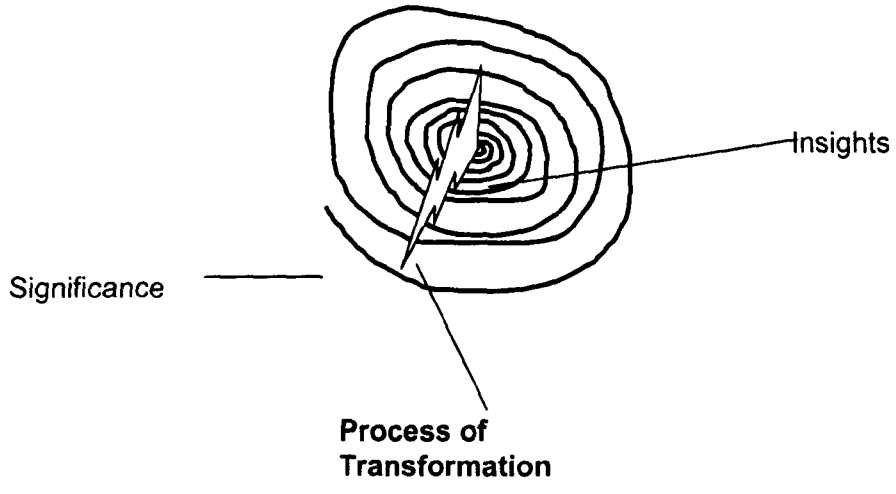


Figure 2.13: Reflexive spiral significance to insight and transformation

As Etherington (2004) suggests,
'Reflexivity enables us to provide information on what is known as well as how it is known.'
(Etherington, 2004, p37)

Writing

Three aspects have been identified that denote a good autoethnography; the writing is well crafted, and would stand up to scrutiny from literary critics as well as social scientists, it must be emotionally engaging and critically self-reflexive (Spry 2001). I have alluded throughout the layers that writing coherently challenges me. As I persevered to construct a thesis worthy of academic judgement the pressure to write well intensified. I listened to advice; practice writing, pay attention to grammar, read and re-read well-written texts or novels and then practice writing again. However my struggle permeates the process. The following example from my journal relates to a supervision session where CJ had given feedback on an earlier draft of this chapter, where he felt I was not writing in a narrative form.

Supervision February 2006

'I feel quite stunned by CJ's feed back; he asks if I am going to cry. I wonder what my facial expressions portray. I don't feel like crying, my head is just so 'full' I am unable to think. CJ asks me to write in narrative form what we have just discussed; I look vacantly at him unable to move.

After lunch against a backdrop of CJ and Jane (another student) in heated debate over aspects of her field notes, nervously I push myself to type. Perhaps witnessing the struggle of Jane is liberating, at least I am not alone. Short sentences stagger onto the page.

At one point I interrupt CJ and Jane and ask why they both include descriptions of nature in their work. CJ said nature is important and can influence our interactions. I'm sceptical that paying attention to nature could help me develop my narrative style. However the interaction took the poem in a different direction and I was glad that only the day before I had written some quotes attributed to Barbara Hepworth in my journal.'[25]

I need to be able to write

I need to be able to write.
What stops me, why am I not able to be free?
I struggle to find words, not sure of sentence construction,
grammar is non-existent, an enigma.

Yet I am able to verbalise what I feel, but do I?
I speak confidently, but what does that hide,
the words momentarily hang in the air, but are then gone.
It's hard to revisit the spoken word.

Whereas the written word is there to be seen
and reviewed over and over again.
I need to practice writing, read exemplary texts, the pressure of time looms.
I hear the words from CJ, be patient, be confident that the skill will come with time.

Style is about setting the scene,
appreciating the environment, paying attention to detail.
Style is individualised, but how can I find it?
Will it really just come with patience, practice and time?

CJ feels nature is important,
I am moved by the sculptures of Barbara Hepworth.
She pays attention to nature, preferring to work with natural materials,
in the outdoor setting and is greatly influenced by the environment.

I was recently struck by the following words that are attributed to her
'One must be entirely sensitive to the structure of the material that one is handling. One must yield to it in tiny details of execution, perhaps the handling of the surface or grain, and one must master it as a whole.'[25]

It feels as if she is talking hermeneutically to interpret the whole you must look beyond the surface and appreciate the parts.
Or how I must handle words, pay attention to each one that I write so as the sentence is coherent and flows.

Does this help me with developing a style?
My current style, is either short punchy statements or long rambling ones?
Different tenses and a blurring of knowing when to use the right tense.
This makes the text disjointed and difficult to read.

My current use of literature also provides interruptions,

I need to be more assertive at how I insert my interpretation of the literature.
I need to smooth the text, make it flow.
Like touching a Hepworth sculpture, smooth, rounded and connected.

I will become more disciplined.
Write, write and write some more.
Perhaps a narrative will emerge,
that speaks what I am trying to write and defines my style.

Writing the poem was my 'aha moment', it cleared my emotions and I used it as a springboard to move forward with constructing my thesis.

The influence of Barbara Hepworth

My search for meaningful images or 'icons' to both intellectually and visually represent my collective insights of spasticity nursing, led me to explore the sculptures of Barbara Hepworth. Her work is dominated by the relationship of the inner and outer aspects of a structure. Often this is symbolised by a hole through the sculpture, with threads, which link the two facades. Similarly in narrative writing everything has to have a place, and the connection between the parts need to be shown, so as the whole is interconnected. Her sculptures (particularly Tides 1, 11 and Pelagos, figure 2.14) represent movement and remind me of the dynamic hermeneutic circle.

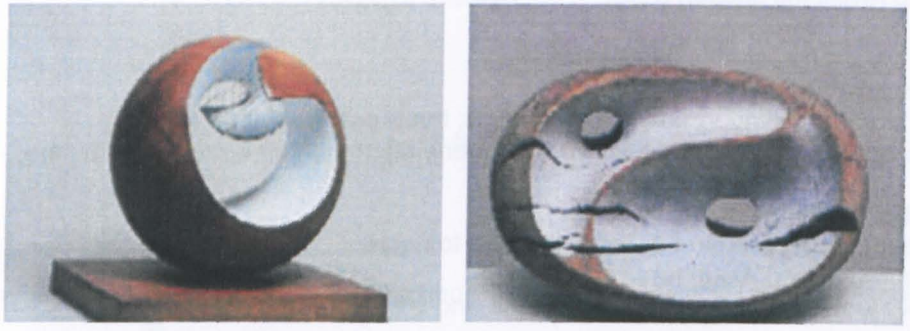


Figure 2.14; Pelagos and Tides 1 © Tate, London 2007

Hepworth states:

> 'In the contemplation of Nature we are perpetually renewed, our sense of mystery and our imagination is kept alive and rightly understood it gives us the power to project it into a plastic medium some universal or abstract vision of beauty.'[25]

She resists copying the beauty of nature. She feels the need to represent its beauty in abstract form, so as we can see it from a different perspective. I feel this is similar to writing a narrative, there is no need to repeat the story, it is in itself a thing of beauty, but by re-interpreting it, new meaning can be interpreted by first the writer, then the guide, then the reader and so on.

Writing poetry seems to free my mind and helps me to find expression. I can write in small sentences and initially disregard punctuation. This is useful when my writing becomes drudgery and I need to spur myself on. Lewis (1951) cited in Holmes (1998) states that poets write poetry as a way of exploring their inner experiences and feelings and it stimulates their relationship with language.

Writing this poem in conjunction with considering Hepworth's sculptures helped me to engage with the process of writing. Okri (1997) states,

'You cannot write well when you have no feelings and no thoughts on the subject. Perhaps when we have to write to order the ill-used creative self, bored with the business of irrelevant and joyless tasks, will simply refuse to come alive when you really need it' (Okri, 1997, p27).

I have for many years enjoyed looking at Hepworth's sculptures, often searching them out in galleries and sculpture parks, but only now am I beginning to appreciate they are significant to me. Appreciating the sculptures and the words of Hepworth help me to see situations differently, my perspective is broadened and my 'ill-used creative self' is stimulated into action. I have assimilated her influence into my evolving approach to nursing people with spasticity and this threads through chapters 3 and 4.

Ethical issues relating to my research process.

Gaining ethical approval

Before carrying out the project I registered and sought approval from the Trust's research and development directorate and the local ethics committee. The original project outline submitted was to evaluate the implementation of clinical supervision using action research. The research directorate gave approval in May 2001. The ethics committee replied in July 2001 and gave approval as long as I dealt with the following point in the co-researcher information sheet:

> 'I think that you should state on the second page that the information being made available to managers and nursing staff of the Trust will be in an anonymous form, and that the participants will therefore not be identifiable. In passing, I think that you will also find this improves the study, as participants will feel freer to co-operate if they feel the information is being kept confidential.'

At the time I took this advice without question and amended the information sheet. The study at this initial approval stage involved colleagues as co-researchers, not patients. Consent was obtained from the co-researchers and I proceeded. However as my reflective texts developed and the potential for the research to be used in presentations, publications and to form the focus of the thesis became evident, I felt I needed to revisit the ethical approval for the study. Johns (2002) states,

> 'Research and developing self in the context of self's own practice demands no ethical approval from others. Indeed it is a mark of responsibility to take self seriously and develop self's potential to realise desirable practice.' (Johns, 2002, p 58).

Fairbairn (2002) suggests that both academics and health care workers state they value highly the privacy of service users and despite being able to articulate how to maintain confidentiality in practice this is not adhered too. He uses the example of overhearing practitioners talk in detail about patients both in a hospital canteen and a pub.

Whilst I am sympathetic to Johns and Fairbairn's arguments and have also witnessed 'loose' talk from colleagues, I felt I had to revisit the ethics of my research.

Revisiting the ethics committee

Whilst the research emphasis is on self and I can decide whether to proceed or not, I was conscious that I was not giving choice to the people with spasticity that I work with. They are a highly disabled group both physically and cognitively, experiencing invasive treatments, which only certain neurology centres in the UK offer and at this time, I was the only nurse specialist in spasticity management in the country. I felt there was potential for individuals to be identifiable in my presentations and texts and this was not addressed in the original ethics submission and hence approval. I felt compelled to remain within the rules of my work environment.

In November 2002 I revisited this issue with my supervisors and the medical professor who supported my application. From these discussions I wrote to the ethics committee with the following two suggestions. To display a poster in outpatients during my clinics and / or to write to individuals once I was sure they were to be used in my thesis or publications to ask for permission to do so. Both methods would inform people about my research, their possible inclusion and importantly if they did not want to be involved it would not restrict their access to care and treatment in any way. The committee replied,

> 'The main ethical consideration that stems from your letter is that patients that you use as illustrations in your thesis may be identifiable, because of the complex nature of their condition. Because of your change in emphasis of the study, there needs to be an amendment submitted. Specifically, you need to produce a patient information sheet and consent form, which specifies that you will be using their case history in a thesis that you are writing, but that all information will be anonymised as far as is possible. The consent form should reflect this.'

I developed the information leaflet and consent form resubmitted them and then began to consider how practically I was going to obtain formal consent. I did not revisit the committee with the challenges that this would pose; I accepted the authority that they held. Although not available in 2002 the revised *Mental Capacity Act* (DoH 2005a) endorses the ethics committee authority,

> 'Research involving, or in relation to, a person lacking capacity may be lawfully carried out if an "appropriate body" (normally a Research Ethics Committee) agrees that the research is safe, relates to the person's condition and cannot be done as effectively using people who have mental capacity.' (DoH, 2005a, p4)

Christains (2005) identifies four codes of ethics which most ethical committees rooted in an empirical frame of working adhere too; informed consent; deception; accuracy; privacy and confidentiality. My concerns have been influenced by this and have been particularly directed towards obtaining consent and maintaining confidentiality.

Obtaining consent

In practical terms obtaining consent is difficult, as the majority of people with spasticity that I work with are no longer able to read or write and have difficulties with comprehension. I did not raise this with the ethics committee; I just accepted I would need to overcome these issues, much as a team we do in practice.

As I practice, my intent is to work with individuals to assess and manage their spasticity in the most effective way that suits their lifestyle. I work as part of a multidisciplinary team, individuals can choose at any time to opt out of what the spasticity service can offer and hence my involvement in their care. Consent for my interventions can be verbal or by implication. For instance people having their intrathecal pumps refilled will arrange their clothes so as I can access the pump without discussing the need to do so. I do not seek written consent for my nursing interventions, although I have a key-educating role in preparing people to formally consent with the medical team for invasive treatments such as intrathecal baclofen and phenol.

Obtaining consent for my research is a change in my practice, whilst it could be argued by researching my practice I am changing the nature of the relationship and need now to apply different boundaries, it doesn't detract from the awkwardness of now having to ask for formal consent for interventions and interactions that have regularly occurred before without such formality.

Primarily my narrative relates to people with spasticity but my stories and reflective texts also include details of colleagues, I will discuss my respective approaches in turn.

My approach to gaining consent from people with spasticity

Gaining the initial consent prospectively was not possible, because until I wrote in my journal I wasn't clear which incident I would develop further and who would feature. Instead I started to talk about my research to people with spasticity that I saw regularly or those who were about to see me for an intense period such as during an in-patient admission. I would drop into general conversation that I was researching my practice. Often this would provide an opening for me to expand and give more detail. Some asked for written information others did not. For those who were visually impaired I changed the font on the information sheets or read it to them.

One useful approach I used was to explore how the person gives consent in other situations. Dewing (2002) suggests in her work with people with dementia, that this is an important strategy to maintain a person-centered approach to the consent process. To manage the complexity surrounding consent she describes 'being with' a person, the need to be connected and engaged with the intent of being in a relationship.

Spending time with individuals is seen as an important strategy when researching vulnerable people. One researcher credited the successful completion of a study to spending two months on a psychiatric ward before commencing data collection; meeting the staff and clients, discussing the research and her role (Koivisto et al 2002). Philpin et al (2005) state simply taking the time to listen and be encouraging is successful in engaging people with communication difficulties. In my situation I think the issue of taking time to be with people, gradually building up their knowledge of my research and having an established work relationship did make it easier to approach individuals and for them to agree to being involved.

I remained alert for situations where I could inform individuals about my research, for instance if I was going on study leave I would detail why, rather than being vague and saying I was going on 'leave' or would not be available. Graber and Mitcham (2004) interviewed 24 clinicians described by their peers and mangers as being compassionate. They found there was a move from detachment, a professional distance, to a more intimate level and sharing of personal knowledge between compassionate nurses and their clients. This resonated with my approach to sharing details of my research with those I work with. Often these were not long explanations about my research; 'I was sowing seeds', which made it easier if I approached them in the future to be included. Christains (2005) stated that in ethnography, research occurs in settings where subjects live, and he quotes Church (2002)

> ' ...informed consent is a process of ongoing interaction between the researcher and the members of the community being studied...One must establish bonds of trust and negotiate consent...taking place over weeks or months – not prior to a structured interview.' (Church, 2002, p3).

Written or Verbal consent?

Once I knew a person with spasticity would feature in a reflective text I approached them for consent. For those people unable to write I accepted verbal consent. Initially I thought I should get someone to witness a verbal consent, however I felt uncomfortable. Surely getting a colleague to hear him or her give consent was only protecting me, but what from, sanction from the ethics committee? The committee asked me to obtain consent, without specifying whether verbal or written however the need to develop the consent form implies they wanted written. The Declaration of Helsinki (http://www.eric-on-line.co.uk/ accessed 14/08/2006) states that a person's consent is preferred in writing. The DoH (2001) concurs with this and also states that there is room for judgment when working with people with learning disabilities they state:

> 'Legally, it makes no difference whether people sign a form to indicate their consent, or whether they give consent orally or even non-verbally...A consent form is only a record, not proof that genuine consent has been given. It is good practice to seek written consent if treatment is complex, or involves significant risks or side effects.'(DoH, 2001 p4).

Requiring a formal written consent I feel indicates to the person that the research is more important than our work together and that I do not trust their verbal response as giving me their consent. Koehn (1994) cited in Hugman (2005) discusses that contracts (consents) between service users and professionals can end trust and work against it developing in a professional relationship. Hugman (2005) also notes that contracts can be seen as a way to protect vulnerable individuals from powerful professionals. It would be difficult to evaluate if only I was benefiting from my research, through improving my practice and gaining a research degree. Indeed it was possible as my involvement with individuals can be relatively long term, often years that they could potentially benefit in the future from my improved practice.

I find this frustrating. My practice and research are a joint entity an ongoing endeavour. I do not do one without the other. It seems inappropriate to run different methods of obtaining consent. As time progressed and I gained confidence in my research approach I became confidant to independently

accept verbal consent from individuals who couldn't write and to fictionalise those who couldn't speak or write.

Fictionalising accounts

Some people were unable to consent or had died before I could obtain consent. The main threads of their stories were retained if I felt I had developed significant knowledge, but their details and the context of the situation were radically changed. In some cases two to three stories were amalgamated into one. This enabled characteristics to be merged into new characters to protect the identity of the person, their family and carers. I created fiction but maintained the meaning that was significant. In the words of Fairbairn (2002) I created a true as opposed to real story.

> 'Real stories are about actual people.' True stories reflect real life situations that people encounter.' (Fairbairn, 2002, p23)

Richardson and Adams St. Pierre (2005) describe the use of fictional writing as a creative analytical process, a new way of writing ethnography. Angrosino (2002) describes how revisiting one of his own ethnographic texts years later he was able to address the subjective aspects of the events and in particular his emotions and feelings through writing a fictional account based on the characters he interacted with. He concludes:

' ...although the story 'fictionalises' my experience, I firmly believe this is the most truthful piece I have ever written about the Indian world of Trinidad, and about my role as an ethnographer therein. It is not of course, for me to say whether I have adequately conveyed that truth through my writing, but I hope the story will at least be accepted in a spirit of reflective dialogue, and in the assumption that such a dialogue is at least a valid a way to deal with 'that complex whole' of culture as are the more objective pronouncements of this particular participant observer.' (Angrosino, 2002, p334)

Continuing negotiation

An ethics committee can only determine the ethical appropriateness of a co-operative research inquiry at a certain point in time, however well planned and written it is. As in practice many certain issues are only revealed as the study progresses (Tee and Lathlean 2004). Documenting the agreement of consent was a single event but maintaining awareness with individuals of what I may include in my texts was a continual process. For instance if something stood out as I practised I would discuss it with the individual gaining their perspective and indicating that I would reflect and write about it later. Negotiating consent or the person's awareness was ongoing (Gelling 2004) and in some cases reciprocal; as Carla's comment illustrates (reflective text 12):

> 'Oh here we go back to the imagery, pulling on my reins again, to slow me down. I think you should put this in your book.'

Ongoing negotiation is also important as a person's cognition and ability to understand can change after consent has been granted (Tee and Lathlean 2004). Pucci et al (2001) explored the retention of information on consent in 70 people with Alzheimers disease and 40 carers without evidence of cognitive impairment. They found individuals with only mild or moderate Alzheimers disease could not recall consent-related information after only a brief period (6-72 hours) and there was a similar finding

in 10% of the carers. This strengthens the need for renewal of consent over time for individuals with or without cognitive impairment.

Involving family members

Another important issue in my work is the need to share the information about my research not just with the individual but their carers or family members too. My work is as much with family members and carers and they clearly feature in the texts. However I did not individually consent them, I accepted one signature or joint verbal agreement as confirmation that 'the partnership' could be included.

English law does not currently allow family members or carers to consent on behalf of a relative or patient for either health care interventions or research. However it is seen as good practice to involve them and they can provide assent. Providing assent does not give permission for the individual to be involved in the research but is affirming that the family member / carer has no objection to the family members participation in it (Gelling 2004, Leyshon and Clark 2005). The recent review of the *Mental Capacity Act* (DoH 2005a), which came into force in 2007, is indicating a more formal involvement of family members and carers in the consent process for those individuals who lack capacity:

> 'Carers or nominated third parties must be consulted and agree that the person would want to join an approved research project.'(DoH, 2005a, p6)

Philpin et al (2005) support this change. In their research on individuals with communication difficulties they state:

> '...there is much to be gained from carer's and partners contributions, given that people's experiences of illness do not occur in a vacuum' (Philpin et al 2005, p299).

In a research group working with people in a vegetative state (Gelling 2004) the involvement of family was invaluable for two reasons; families have an intimate and unrivalled knowledge of their own family members and they are more likely to get a response. Similarly in my work it is vital that I work with family members and carers. They help me to interpret individual responses, plus learn some of the unique patterns of communication that they have developed, so I can, as far as possible engage with the individual. I do this by spending time with the family and the individual, observing and questioning how they communicate and asking them to watch and feedback on how I am managing to interact and interpret responses.

My ethical approach to colleagues

Early in my research journey I presented my approach to colleagues at a departmental research seminar. I emphasised I was exploring my own practice and behaviours but highlighted this would involve reflecting on my relationships with other colleagues. However, anything written would be done so anonymously. Subsequently I have regularly shared aspects of the narrative pertaining to people with spasticity at subsequent research seminar evenings. In addition with the core team as I became more adept at reflecting, I would initiate reflective dialogue as we practised, stating that I would be including our dialogue in my narrative.

Issues around consent

I have not formally obtained written or verbal consent from my colleagues, but have I acted ethically? I have informed them of the project and about their possible anonymous inclusion, this has not been a one off but an ongoing endeavour.

However, I could potentially cause harm to a colleague if I include an incident in the narrative, they recognise themselves and do not like how they are portrayed? To minimise or prevent this is changing dates, names, and their profession or merging stories enough? Should I consider retrospectively obtaining their consent? Potentially they could then want some control on the way they are portrayed, which could change my perspective and how I learnt from the story (although this would fit with the evolutionary nature of narrative). Or worse I could now cause them harm by asking them to recall an event four or five years ago that I classed as conflict, which they may not have done. Maybe these incidents will need to be culled from the final narrative text; yet doing so would deprive the narrative of context and mislead the reader about the nature of my work environment. Perhaps I should take comfort from the attitude of Fairbairn (2002) and concentrate on developing my skills in concealing characters in my writing.

> 'Though the services referred to in true stories do not exist, services with the values, beliefs and practices attributed to them do exist.' (Fairbairn, 2002, p24)

Naturally it's the reflective texts on conflict and differing opinions that concern me the most, yet such interactions are commonplace in health care (Carson 2001):

> 'Sometimes the story is about conflict with a health professional or a patient or the patient's relative...The stories they tell are the kind of conflicts we have all faced in clinical practice.' (Carson, 2001, p200)

So with careful disguise would the characters really be identifiable? Why am I so concerned about breaking the confidentiality of colleagues? I think it is because they are more likely to read or hear me present the texts, than people with spasticity are. Perhaps too I am concerned that colleagues are more likely to exert power, perhaps make me feel uncomfortable or create a difficult work environment if they are unhappy with the text. Alternatively they could read and learn from the text with no concerns as to whether they are in it or not.

Although I made people aware of the nature of my research it did not seem to change their behaviour, for instance, conflicts still occurred. If certain team members had given consent from the outset, would they have been more guarded about their attitudes and behaviours, would it have changed my practice environment? A criticism with not consenting staff to this process is that these texts may not receive depth of analysis in the thesis to preserve the identity of colleagues. Lathlean (1996) describes how when writing an action research project she watered down the representation of her findings to maintain confidentiality and anonymity, but lost essence of meaning. She reflected that her research which aimed to evaluate a new way of working had a high profile nationally; therefore it was predictable that the group participants she was studying would be identifiable. She wished she had addressed this with the research subjects from the outset, who were also disappointed by the

misrepresentation of the final outcome and with hindsight, would have preferred not to be anonymous. Similar to my work it would have been difficult for me to consent colleagues in an informed way from the outset.

Including my texts with colleagues

Only one of my reflective texts focuses solely on my interactions with colleagues, although the presence of my colleagues and our interactions bare significance in most of the stories. This reflects that part way through my journey, I made a decision to concentrate on my interactions with people with spasticity. As these stories were the most interesting and provided a greater learning opportunity. The work was new, exciting and unique, but importantly I could directly influence, improve and monitor my own practice. My experiences with people with spasticity provided a wealth of possibilities for new learning; I could create an environment to be available, where I could continue to develop my skills and knowledge.

Whereas reflecting on incidents with colleagues did improve my interactions and I learnt communication and leadership skills, I was mainly learning how best I could interact with certain individuals and their nuances. Staff turnover was low, old issues of managing conflict, limited resources and power struggles repeatedly dominated and new instances were infrequent. Although I continued to refine and strengthen my leadership skills throughout the research period by using my journal, I stopped expanding them into reflective texts; preferring to concentrate on developing my practice with people with spasticity.

Insight: Developing an ethical approach to practice

My understanding of research ethics was narrow; my initial approach was to satisfy the needs of the Trust, to seek approval. I began to emerge from this rigid understanding; this was not about adhering to rules, getting approval from committees and then doing the research. I needed to develop an integrated ethical approach to both my practice and research that would require continuing negotiation and alertness to monitor for when I may be working outside of ethical principles.
As Quallington (2000) suggests:

> 'Ethics is only of value if it helps to inform and improve our practice...Caring, because of its intimate involvement with others, is by its very nature an ethical enterprise. In order to care ethically it is necessary to reflect on the personal and professional values that we hold.' (Quallington, 2000, p3).

My approach to practice needs to have an ethical component, not to resort to in times of uncertainty and crisis but one that influences how I practice every day, an integral, ongoing ethical approach to my practice (Kidd and Finlayson 2006). My effort towards an ethical way of being permeates the narrative.

The actual process of constructing the narrative form

This layer was the most intense, requiring patience and commitment to complete. I spent three years writing my stories, reflecting on them, identifying significance and insights, dialoguing with the literature and discussing them with CJ; I would amend them and then move onto the next story. Although I was reflexive through this period with individual texts informing subsequent ones and ideas for my approach to spasticity nursing emerging, I needed an intense period of study to revisit all the reflective texts and memos in detail and to weave the narrative. As Margaret Wheatley (1999) notes,

> 'When we concentrate on individual moments or fragments of experience, we see only chaos. But if we stand back and look at what is taking shape, we see order. Order always displays itself as patterns that develop over time.' (Wheatley, 1999, p118).

To see order in my texts required, patience, guidance, an appreciation of literature but not sole reliance on it, a sense of discipline to rewrite and rewrite and importantly time to dwell with the texts. The space to construct my narrative is variable depending on external influences. For instance, my time to write is constrained by my work and personal life. This bounded, but changing space reminds me of 'Ring', a sculpture I photographed by Austin Wright (Figure 2.15).



A. Wright (1969): Ring.
Yorkshire Sculpture Park
Photographed April 2006

Figure 2.15: 'Ring', (1969), Aluminium. Austin Wright (1911 –1996). Yorkshire Sculpture Park, UK: Photographed April 2006.

The aluminium ring takes up such little space to form a distinct boundary, yet the joint delineation of the ring and its shadow form a large, variable space. This space represents the process of constructing my narrative (Figure 2.14). The actual ring represents the space I have to construct my narrative within my current lifestyle. The shadow represents my experiences and vision and how they are continually changing as I refine my insights to develop my narrative. The ring and shadow are interdependent as my practice and research spaces are, but the shadow is transient and variable in nature and continually alters my construction space.

'The sculpture (Ring) serves as a lens to focus the viewer's attention back into nature. The sculpture was seen by Wright as a 'whoop of joy' and is symbolic of his motivation to capture a sense of wonder and love of nature.' (Pheby, Lilley and Hodby 2005).

My construction space is my lens to focus on my practice, both its parts and wholeness, to appreciate its sense of order (wonder) and to work towards the excitement (joy) of co-creating meaning (Figure 2.16).

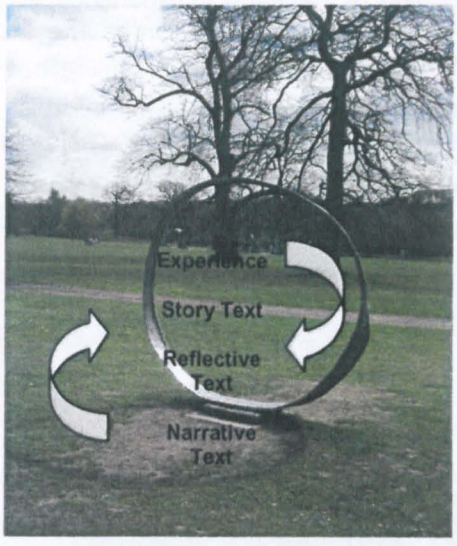


Figure 2.16: My experience of working with the six layers of dialogue.

Shaping the narrative form

It took several attempts to devise a format that adequately captured the essence of my practice. For my first attempt I rewrote the reflective texts, amalgamating similar issues to create 17 reflective texts, within each text I included literary analysis. However, I felt that the essence of the story was lost and I was paying more attention to published literature than the significance and insights within my stories. As Bochner (2001) cautions when considering the virtues of storytelling versus story analysis,

> 'It is difficult to understand how one is being true to (and not misrepresenting) "the fundamental nature of narrative" by slicing, dicing and cutting out what makes a story a story.' (Bochner, 2001, p141).

For my second attempt I separated the stories from the analysis, but this was disjointed and did not have a narrative flow. In November 2006 whilst wrestling with shaping my narrative form, I was flicking television channels when I caught a glimpse of the painting 'Summertime' by Jackson Pollock (figure 2.17).



A section of 'Summertime' by Jackson Pollock 1948 © Tate London 2006

Figure 2.17: 'Summertime' by Jackson Pollock 1948

Influenced by Heidegger (1962 [1927]), Wynn (2006) states,

'Art has the potential to free us from the pervasive grip of technicity by altering or reopening relations that are being programmed, regularized, converted into data, manipulated, or reduced to a mere representation.' (Wynn, 2006, p38)

I was inspired by this quote and how Wynn (2006) describes how she developed a greater appreciation of the nurse's role with dying patients and their bereaved relatives, after spending time in a gallery examining a sculpture depicting a dying man and his wife.

I subsequently visited the Tate Gallery in London to view 'Summertime' and I quote from my journal,

'Initially the picture looks chaotic but after 20 minutes I can start to see the order within its chaotic form. Scanning the picture from left to right, the painting is oblong and paint drips horizontally down the canvas, this resonates for me how my insights are emerging from the different stories over time. There are smaller linking threads, they are significant and give the chaos form.
The picture is more detailed on the left hand side than the right. Does this resemble how my early stories will be more detailed and get less so but perhaps more in depth as the thesis moves along? Some sections are coloured in, as if islands in the painting. These possibly signify space an important issue I want to include in my conceptual model.
To promote my developing understanding I need to draw my own pattern. I must pay attention to what is significant and view each insight as its own coloured thread originating in one story but possibly being repeated in subsequent stories.
I view the picture in sections and recognise the repetition of forms; yet I can see its whole. This is what I need to do with my thesis have different intersecting threads that although layered come together as one. Each story will consist of a pattern of significance and insights and will be part of my whole pattern. My thesis needs to, 'Just be'. Whole.'[33]

Energised from my experience of dwelling with 'Summertime, for my third attempt of shaping the narrative form I removed all the analysis and added a summary of significance after each story, but

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[33] Interestingly the text to accompany 'Summertime' wrote by Professor Richard Taylor a Physicist also likened Pollock's work to defining order within chaos,
'Jackson Pollock declared that he was concerned with the rhythms of nature. But if his swirls of paint represent nature, what sort of patterns would his paintings contain? During Pollock's era, scientists assumed that natural objects such as trees and clouds were devoid of pattern. It wasn't until the 1970's that they detected a subtle form of order, which the natural world called fractals. Fractals consist of patterns that recur at finer and finer magnifications. A small part of the structure looks very much like the whole. My own scientific analysis of Pollock's drip paintings have shown they also have this quality as if he instinctively grasped the principle underlying the patterns of natural scenery. Pollock's genius lay in his ability to paint such intricate fractal patterns so precisely and to do so 25 years ahead of scientific discovery.' © Tate London 2006

this was often repetitive of what was already in the reflective text. CJ highlighted that I was confusing story telling with story analysis. I was masking the insights contained within the story by trying to justify issues with other literature. We moved to consider that, 'the story is theory'.

To reflect this new idea in my narrative construction, I amended each reflective text, to ensure my identified significance and insights were contained within the story. Key references were added back in to strengthen the emergence of my insights. The aim was to maintain the narrative flow whilst demonstrating how some literature had expanded my understanding of the meaning contained within the reflective texts.

I then added three analytical pauses, the first after text 6, the second after text 11 and the third after the final text. These pauses provide a break in the stories where I summarise the significance and insights I have gained up to that point. Their position in the text are not random but carefully considered to reflect how the emerging insights were influencing the evolving ideas about my practice.Their inclusion is to provide an internal logic to the development of my main ideas in relation to being an effective nurse specialist in spasticity nursing. One aim of presenting this logical flow of my ideas was to stimulate the reader to consider their own interpretations. CJ and I feel this form provides greater clarity and provides a platform for understanding how my conceptual approach[34] was formed, taking account all six layers and their respective influences. The narrative started to 'be' and flow similar to my perception of the painting 'Summertime' (Pollock 1948).

6th layer: Ongoing dialogue between the narrative, self, others and future experiences within a continuous and deepening reflexive spiral

The challenge with this layer is to write the narrative so as it is readable, engaging and understandable; to an extent the reader is engaged enough to reinterpret the text and to deepen the reflexive spiral. This led me to consider two questions:
Why would the reader read the text?
Why should the reader believe the text?

Why would the reader read the text?

Readers will approach my narrative with different intent for instance, to improve their practice, out of interest, to appreciate the methodology, to examine or judge it or maybe even to read it for pleasure. Their needs will be different yet they share common issues that I need to consider to ease their reading of the text. In the simplest form this relates to writing well, with appropriate use of grammar and subject headings to lead the reader through the text. In addition Okri (1997) reminds me to capture the reader by letting the drama unfold. A key aim though is to stay true to the story. To represent it as I interpret it. To provide the detail so as the reader can relate to the story.

[34] Chapter 4, p219-234.

Generalisability of findings or Resonance

Johns suggests that insights gained using guided reflection as a process of self inquiry are not generalisable and to suggest otherwise would be an error of judgement (Johns, 2008 personal communication). This idea had been informed by a thread in narrative theory,

'Contemporary narrative researchers occupy a different social and historical location. Under the auspices of the narrative turn, they reject the idea that the small number of narratives they present must be generalizable to a certain population.' (Chase, 2005, p667).

I have found that whilst insights may not be directly transferable, my stories have resonated with others. Resonance can be described as, a striking, moving experience that is deeply apprehended, the 'felt effect' by a reader when reading a text or 'the sudden perception or intuitive grasp of the life meaning of something' (van Manen, 1997, p364).

Insights are by their nature always tentative, through this reflexive research process of using guided reflection as a process of self-inquiry and transformation I have tested and refined my insights, they have evolved and continue to do so. I view knowledge as always unfolding. My intent is not to prompt people to grasp at my understanding as concrete, but for my texts to resonate with their experiences which may prompt their own interpretations.

When presenting my narratives to my immediate colleagues (the spasticity and rehabilitation team) I could sense by their attentiveness and still postures that they were engaged in listening. Afterwards they actively questioned me about my experience, the story and my future practice. This wasn't always at the session, sometimes days later they would talk to me again about a particular issue, demonstrating that they had continued to reflect and synthesise certain issues I had raised. Some clearly stated that listening to my narratives made them think about their own practice. This resonates with a theme in narrative inquiry that,

'Narrative researchers treat narratives as socially situated interactive performances – as produced in this particular setting, for this particular audience, for these particular purposes.' (Chase, 2005, p657)

These colleagues were entrenched in the context and could visualise themselves within the stories. To the extent some thought they were a character in the text when they were not, such did the stories resonate with their experiences.

When I first read narrative text as part of an international conference presentation[32] I was unsure of its relevance to a more general audience. From an action research perspective Greenwood and Levin (2005) argue that knowledge is context specific and to utilise such knowledge requires not only an appreciation of its original context but also the context of where the knowledge is to be utilised. They state;

'...generalization becomes an active process of reflection in which involved actors must make up their minds whether the previous knowledge makes sense in the new context or not and begin working on ways of acting in the new context.' (Greenwood and Levin, 2005, p 55)

After my presentation audience members stated how they could connect with my experience, it meant something to them. One neurological ward sister said that she wished she could transport me to her ward, to repeat the presentation as she felt strongly it would help her staff manage a person currently an inpatient with them.

At subsequent presentations people have reported feeling moved, tearful as they were transported into the story and reminded of specific aspects of their own practice encounters. I quote from an email I received on the 23rd January 2006,

'I didn't get the chance to say to you that I thoroughly enjoyed your presentation!! I was so impressed and you actually made me cry! Thank you so much – it was a pleasure to meet you and I hope to bump into you again.'

These experiences suggest that these listeners to my stories, far removed from my practice context, had also experienced resonance. Receiving feedback on the value and impact of sharing my narratives with others strengthened my appreciation of its worth, at least in prompting them to think about their practice. Which on reflection, is maybe all any research paradigm can claim to do. Research can only ever inform it cannot be applied; therefore knowledge always has to be interpreted for its value in informing a particular situation. I offer this thesis and present my texts in that spirit, to stimulate resonance and trigger the reflexive process in others. As Chase states,

'...any narrative is significant because it embodies – and gives us insight into – what is possible and intelligible within a specific social context.' (Chase, 2005, p667)

To maximise the opportunity of influencing the practice of others I need to 'engage' or 'capture' my readers attention, make my context explicit and take them on my journey in the hope they too will solicit meaning from my text. Gadamer (1975) suggests the reader of a text extends knowledge by interpreting new meaning from the text. Therefore the meaning of the text always goes beyond the intent of the author. In my experience this has occurred with people who listen as well as read my texts. The process can be self-perpetuating if the meaning is reconstructed into new texts, which are then re-interpreted and so on, leading to potentially multi layers of meaning (Figure 2.18).

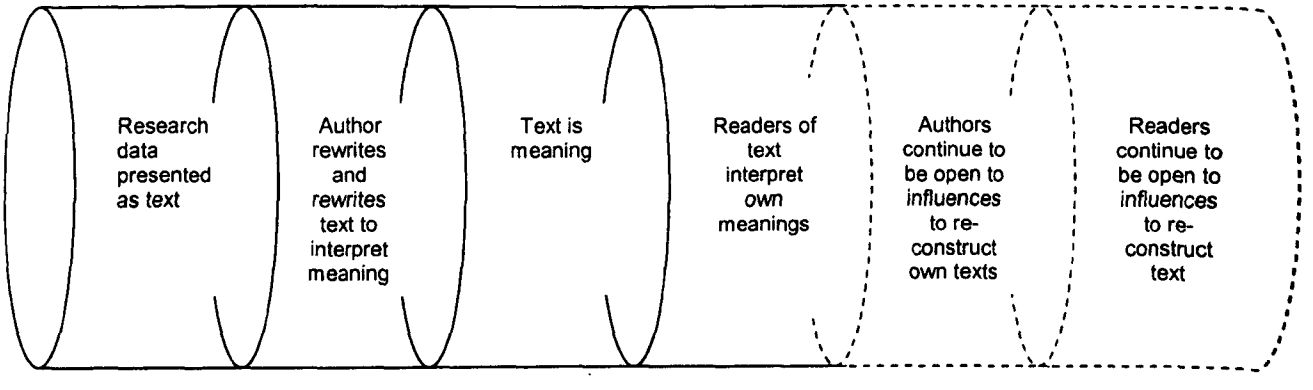


Figure 2.18: Layers of meaning from texts

Why should the reader believe the text?

How do I ensure authenticity of my text or as Wilber (1998) describes the truthfulness of it (Figure 2.8)? Johns suggests that 'a valid narrative should seek to reveal truthfulness' (Johns, 2002, p63). It should be coherent (Johns 2006). He recognises however that what a person discusses in reflection may not be a 'true' representation of what they actually did in practice.

People reflect on the significance of an experience (Johns 2002). Narratives are social constructions rather than truth (Elliot 2006), as Denzin and Lincoln (2005) state,

> 'Lived experience cannot be studied directly because language, speech and systems of discourse mediate and define the very experience one attempts to describe. We study the representations of experience, not experience itself. We examine the stories people tell one another, about the experiences they have had.'(Denzin and Lincoln, 2005, p645).

Woolf (1993[1929]) in her seminar 'A room of her own' shares her view on the importance of disclosing a forestructure and appreciating subjectivity or fiction as a reflection of truth.

'...But in order to make some amends I am going to do what I can to show you how I arrived at this opinion about the room and the money. I am going to develop in your presence as fully and freely as I can the train of thought, which led me to think this. Perhaps if I lay bare the ideas, the prejudices, that lie behind this statement you will find that they have some bearing upon women and some upon fiction. At any rate, when a subject is highly controversial – any question about sex is that – one cannot hope to tell the truth. One can only show how one came to hold whatever opinion one does hold. One can only give one's audience the chance of drawing their own conclusions as they observe the limitations, the prejudices, the idiosyncrasies of the speaker. Fiction here is likely to contain more truth than fact.' (Woolf 1993[1929] p3-4)

Gadamer (1975) like Woolf (1993[1929]) suggests that judgements about the quality of a text should be left for the reader to appraise and that it is the reader that creates meaning. To do this Wilber (1998) shares that the author's interior truth needs to be appreciated,

> '...we are dealing not so much with exterior and observable behaviour but with interior states, and the only way you and I can get at each other's interiors is by dialogue and interpretation.' (Wilber, 1998 p14)

He suggests dialogue recaptures the spirit of the moment and provides context and is best achieved through an approach where,

'...the validity claim is truthfulness, trustworthiness, sincerity...' (Wilber, 1998 p15).

Lather (1986, 1993) identifies four criteria: face validity, construct validity, catalytic validity and rhizomatic validity, which guide me to construct and write my narrative in an authentic way.

Face validity

Face validity requires authenticity of the voices heard in the narrative. I have demonstrated how I established the discipline of writing as near to the event as possible in order to capture dialogue that represents the voices of those that I interact with and present in the narrative.

Implicit within this research approach is to detail how meaning was derived. My narrative demonstrates how meaning was co-constructed through dialogue with self, others, my guide and

wider sources of knowing and in doing so face validity is implicit within in my research process and narrative.

Construct Validity

Construct validity requires the research to be grounded within a wider community of knowledge (Johns 2002). Knowing through reflection is individual, subjective, contextual and uses 'I' language (Wilber 1998). As Johns (2002) asserts it is only through this paradigm that I can dialogue with other forms of knowing in meaningful ways to inform my practice. When considering the impact of other sources of knowing, I use 'the integral vision' to prompt me to consider their methodological approach and how their partial truth claims may or may not inform my work. In my narrative the use of the six layers of dialogue as an organising structure, theoretical framing and analytical frameworks such as the MSR contribute to maintaining construct validity.

Catalytic validity

The aim of my narrative is to demonstrate how I have transformed as I work towards realising desirable practice as a spasticity nurse specialist. Lather (1986) states:

> 'Catalytic validity represents the degree to which the research process reorients focuses and energizes participants toward knowing reality in order to transform it.' (Lather, 1986, p272)

To ensure catalytic validity the research process needs to be visible in the narrative text. For instance this chapter traces how I engaged in journal writing, reflection and dialogue with my guide. In subsequent chapters I strive to demonstrate how meaning was co-constructed and how the conceptual approach to spasticity nursing evolved. The being available template can be a tool to assess catalytic validity, as it helps me to mark my reflexive development and for the reader to follow and assess my progress towards transformation.

Wilber suggests that to appreciate truthfulness in the 'I' quadrant a person's 'interior state' needs to be accessed through dialogue and interpretation.

> 'The validity claim here is not so much whether my statements match exterior facts, but whether I can truthfully report on my own inner status.' (Wilber, 1998, p14).

Through the narrative I detail how specific works of art have influenced my development, to allow the reader access to my 'interior state'. I have used creativity in the form of poems, photographs, collages, a drawing and my appreciation of paintings and sculpture to show their influence on my development. This has been in an effort to make the text compelling, coherent, to more clearly portray my ideas and emerging knowledge. They have also been tools to unleash my writing ability when it became stagnant, often enabling me to see my practice and emerging texts from different perspectives. Aesthetics is closely associated with the philosophy of art but also 'authenticity' (Price

2007).[35] I hope by including my aesthetic forms I have contributed to the authenticity and originality of my thesis. They are my interpretations and are unique representations of my authorship.

Rhizomatic validity

With a rhizome or root system (Figure 2.19), the complexity has evolved as a natural, organic process, yet there is order implicit within its apparent randomness.

Lather (1993) states rhizomatic validity, 'unsettles from within, taps underground...generates new locally determined norms of understanding; proliferates open-ended and context –sensitive criteria; supplements and exceeds the stable and permanent...'(Lather, 1993 p 686).



(http://www.bakewell-trees.org/pictures/roots/(3).jpg accessed 29th Oct 2007. All photography © Michael Judge)

Figure 2.19: An image to represent Rhizomatic Validity.

Narrative is complex, indeterminate and contradictory, like life itself. My stories link together like a complex root system (Figure 2.17). I might leave some issues dangling or pick them up later on, but as a whole my narrative is the closest representation I can get to a lived reality. I interpret rhizomatic validity as the need to take into account all the issues that contribute to the pattern of my practice, its wholeness. I try not to stifle the text by fitting it to a scheme. I only ever cautiously and mindfully apply the being available template as a way of plotting my transformation and never as an explanatory system. Likewise I cannot separate or isolate issues they are interdependent. Appreciating this helps me understand why my narrative didn't read well when I tried to separate my insights from the stories; the stories no longer flowed as part of their integral network had been separated. I had breached its rhizomatic validity.

[35] Reader in the Sociology of Sexual Health. City University Doctoral Conference 2/2/07 plenary lecture Creativity: art and/or science (in the production of the doctoral thesis).

Summary

This section has detailed my methodological approach and process to researching self. Gadamer (1975) encapsulates the spirit of this reflexive spiral when he states:

> 'The discovery of the true meaning of a text or a work of art is never finished; it is in fact an infinite process.' (Gadamer, 1975, p298).

Similarly the conceptual approach outlined in chapter 4 is a representation of desirable practice as I draw the thesis to a close. My approach will continue to develop beyond this, as I practice and continue in my quest for desirable practice. The following section details my practice related narrative.

3: Narrative

Reflective text 1: Simon's story **Supervision session 1 & 2**

Shocked by my own negative attitude towards nursing homes.

April 2001: Pump Clinic
Team present: Tom the neurology registrar and myself

Simon

Simon is coming to the pump clinic today. I look forward to seeing him as we often exchange a jolly, lively banter. He seems to make the most of his three monthly appointments or as he says, 'Trips to the City'; as he enjoys spending time with his father, who always drives him and after their appointment, they go for lunch together in a nearby pub. Simon's wife, Melanie, stays at home with their young son. I have never met Melanie but regularly speak to her on the phone, usually after clinic to confirm or discuss changes to his dose regime. Simon is happy with this arrangement as he often forgets exactly the doses we prescribe. She also phones if she is concerned about his spasticity or she wants me to clarify something with his respite nursing home. They appear to be a close family who work together to help Simon manage his multiple sclerosis (MS).

As Simon drives his electric wheelchair into the clinic room I glance at him,
'Wow look at you, someone's been buying trendy clothes!'
'I am not in the mood for being teased.'
Surprised by his retort I immediately stop preparing the refill kit and look properly at him. His normal pristine appearance is intact but he hangs his head low, he looks tired and drawn. His limbs are being held in a flexed position; his spasticity looks to be increased. As if to confirm my observation he starts to have frequent flexor spasms of his hips and knees his feet involuntarily rising from the footplates. His whole body looks tense; a strong visual cue that all is not well.

Bob scuttles in behind Simon avoiding any eye contact. I return my attention to Simon and ask, 'Hey what's wrong?'
'I am very unhappy,' he pauses and gathers up enough breath to speak.
'You know that nursing home I regularly visit; well I have been put there for good.'
As my muscles tense, I feel a hotness spreading through my body. I query, 'What do you mean?'
'I am staying there now, only going home at weekends.'
He raises his head and sits up as fully as he can to take a deeper breath to angrily force out the words, 'I didn't realise it was going to happen!'

My mind is racing. I feel shock, concern and I silently ask myself: How could this be? Would somebody really be moved without his or her agreement to live permanently in a nursing home? From previous interactions I thought Bob and Melanie cared deeply about Simon, had I interpreted this correctly? I looked at Bob for more information, barely raising his head he whispers, 'It's been under

discussion for a while, but then it suddenly happened, a bed became available. Simon's right, he wasn't totally aware of the situation.'

I feel my concern turning to anger, yet I sense Bob's anguish. I know my facial expressions can depict my true feelings; I take a deep breath and pay attention to my body language. I feel my energy sap, yet know I need to stay engaged with both Simon and Bob if I am going to be available to help this family resolve their conflict.

I focus on the task at hand gather my thoughts and smile at them both as I say, 'Sounds like you have both been having a really difficult time, shall we focus on your spasticity and how it has been through all these changes?'
Simon replies, 'Yes take my mind off it. I feel stiff and I've got spasms. Don't worry though Lou, my pump battery hasn't run out yet, it's because I'm stressed.'
His concern for me makes me smile he returns a grin. Bob looks relieved, and the tense atmosphere starts to ease.

I feel able to bury my feelings and divert the conversation as Simon's pump battery is running low and he is to be admitted within three weeks for his pump to be surgically replaced. I can use the in-patient time to explore with him how he is and consider if I can offer any additional support. In the interim I want to investigate how this situation has occurred.

Seeking the truth but treading carefully

Not wanting to direct my anger towards Melanie during our post clinic telephone conversation, I plan to discuss his drug regime as normal, but also to explore how and why he was moved into the home.
'Hi Melanie, it's Lou, how you doing?'
She sounds distant and tired as she replies, 'He's told you then?'
I startle at her directness, knowing I would ring; Melanie is straight to the point. She doesn't play games.

Melanie, like Simon isn't happy. She explains that it had been getting harder and harder for her to independently care for Simon and their son 24 hours a day, everyday. She did get support from carers but it just wasn't enough, so she had started negotiations with the nursing home. She had mentioned it to Simon, but only once in passing, then suddenly a bed became available and Claire, the nursing home manager advised her to take it. It had been a difficult decision. He was very angry. She stressed how Simon was coming home at weekends and that she wanted me to continue using his home address for hospital correspondence such as appointment dates and she would liaise with the home. Likewise she wanted to carry on speaking to me after clinic so as she knew what was happening with his drugs. We agreed that after each clinic I would inform her and Claire about any changes to Simon's drug regime. I could feel her need to still be involved and retain an element of control in his care. She starts to cry and she sobs as she shares, 'Lou I just can't tell you how hard it is to entrust his care to others after 16 years... but I couldn't go on. The pain in my back was

excruciating; I didn't want to start resenting him...You know, it's only a couple of weeks and my back is already less painful.'

After the call I feel humble. Behind all the jovial banter I have shared with Simon and Bob, I had no idea just how difficult life was for them. For the first time I appreciate that my knowledge of Simon and his family is but a snapshot in the overall reality of their daily lives. Perhaps the clinic visits were more of an escape than I realised.

Later I speak to Claire, she confirms the process of the initial negotiations with Melanie, the unexpected availability of a bed and that she had urged the family to take the opportunity, as she was concerned about Melanie's welfare. She said it had been tough for them all to manage Simon's anger when he realised it was potentially a long-term arrangement. She shares, 'However I find people settle quicker if they are not involved in detailed discussions about permanently moving in. They seem to respond better if they see it as a gradual move, where they still have an element of control and choice and that it is not seen as a final decision.'
I am sceptical. In reality Simon does not have control or choice as everyone around him is viewing it as a permanent option. I am uncomfortable; this paternalistic way of working is at odds with my vision, to collaboratively work with people with spasticity. However I try to remain open and respect Claire's skill and knowledge. I am acutely aware I need to explore the work that nursing homes do.

The revelation

Three weeks later Simon is admitted for his pump replacement. I rush to the ward to see how he is.
'Oh I'm grand Lou - I love living in the home.'
I don't hide my surprise, 'But only three weeks ago you were really upset because you hadn't realised that you were moving there on a long term basis.'
'Yes I know, but if they had told me I was going for good, I wouldn't have wanted to go. I would probably have been very angry and upset, particularly with Melanie and that wouldn't have been fair. But now in the home I always have someone to talk to. I've got a mate Dave and we just hang out together. It's much better than rushing, trying to get ready to go to the day centre each day. Of course I look forward to the weekends, nobody can care for me like Melanie can, but its ok, because she visit's everyday with my son, I feel much more like a father and husband – we are a real family again.'
I share my delight; yet inwardly chide my surprise that living in a home could have such a positive outcome.

Journal reflection

Later I reflect on his words and consider the strain for a family to live apart and renegotiate their roles. The process of nursing home placement has been described as even more traumatic than the actual death of a loved elder (Dellasega 1991). Kellet (1999) suggests that carers need to be supported to reconstruct a valued and positive identity within the context of a nursing home.

I can support Melanie's transition to her new role, which has less emphasis on being his primary carer, by continuing to discuss his drug titrations with her post clinic and to arrange his appointments through her.

April Supervision

I am comforted that for now Simon feels the move into the home is the right option. CJ challenges that this maybe a public image that he wants to portray so as not to cause his family further anxiety. Alerted to this issue I will now monitor for any change in how Simon may feel.

Simon's story illustrates the fragmenting impact of spasticity on family life and my struggle to position myself ethically in such tensions. I realise my interactions fluctuate along a continuum where paternalism and advocacy are at opposing ends (Johns 2000).

I struggled to appreciate the paternalistic stance taken by Claire. Benjamin and Curtis (1986) describe that paternalistic actions can be justified if the person is not able to exercise autonomy to begin with, but it is anticipated that the person will agree with the decision retrospectively. Simon's ability to clearly articulate his feelings when admitted to hospital confirms to me that he could have been involved from the beginning in making decisions about his long-term placement. I feel Simon's autonomy was restricted because the truth was withheld even though he later ratified the move and actions of his family.

Varying my responses along the advocacy- paternalism continuum requires emotional effort and can be draining. James (1989) describes dealing with other peoples 'feelings' as emotional labour, which involves,

> '...hard work, and can be sorrowful and difficult. It demands that the labourer gives personal attention which means they must give something of themselves, not just a formulaic response.' (James, 1989, p19)

Supervision helps me to view the fragmentation of Simon's situation and my position within it. It helps me work through my anger and recover a sense of the whole.

As I discuss the direct communication styles used by Melanie and Simon, CJ introduces me to the work of Thorne and Robertson (1988, 1988a, 1989), whose research explored the understanding of trust in health care relationships. They interviewed seventy-seven people experiencing chronic illness either directly themselves or through a partner they lived with. They derived three stages of interaction that individuals with chronic illness and their families move through with health care professions: Naïve trusting, Disenchantment and Guarded alliance (Thorne and Robertson 1988). Naïve trusting describes a passive interaction where individuals believe that healthcare professionals will work with them in collaborative ways, negotiating and mutually making decisions with their best interests at heart. Disenchantment occurs when the individual and their family realise this isn't going to happen; they become dissatisfied with care and develop adversarial relationships at the cost of their needs not being met. Because of the chronic nature of an individual's illness as their condition changes there is often a need to re-engage with health care professionals. However, the individual and their family have learnt from previous experience and they forge relationships with a 'guarded alliance'; they are streetwise and reconstruct relationships on an informed, not naive level.

Simon and his family would have met many professionals over the years of managing his MS. Simon and Melanie interact with me from a position of guarded alliance, using honest and direct speech. I now appreciate the need to reciprocate this to develop trust and remain available to them.
Considering this further, I enter a person's illness trajectory after they have been in the health care system for many years, perhaps battling to be acknowledged and heard. I rarely encounter naive trusting or disenchantment even when meeting people for the first time. My interactions seem to start at the level of guarded alliance. It's as if the person's previous experiences of health care professionals lead them to view me immediately from the perspective of guarded alliance. It is as if they do not want to risk being let down, so use strategies to protect themselves and so as they are heard.

Following week

I attend an educational meeting held by the MS Trust and discuss Simon's story with a nursing home manager. She shares her frustrations; 'Hospital staff often view the work of nursing homes as the end of the line and not as facilities which can enhance an individual's quality of life.'
I feel my face beginning to flush as I recognise my negative attitude in her comment. She confirms my sense of shock at this discovery.

Whose treatment choice is it?

May 2001: Spasticity assessment clinic
Team present: The neurologist, physiotherapist and myself

Pete

Pete is unable to self propel his customised wheelchair; his mum Pat pushes him into the clinic room. She avoids eye contact with us and seems nervous. In contrast Pete cheerfully greets us with the challenge, 'Hope you can sort my legs out; they've been stiff for three years, spasm all the time and are uncomfortable.'

As we talk Pete's legs alternately flex and rise up, his right knee sometimes reaching as high as his chin line. These are strong and intense hip and knee flexor spasms; they are frequent, every couple of minutes. Pete seems to ignore these gross movements even though they punctuate his speech. He perseveres to engage in the discussion, continually smiling and looking for opportunities to make a joke. The spasms are so forceful that he gradually slides down the seat of his wheelchair, to a point where to prevent him from falling; both the physiotherapist and I jump up and together reposition him. He responds, 'Thanks. Oh yeah I forgot to say, I often 'spasm' out of my chair. I'm battered and bruised and constantly afraid of falling or hurting my carers.'

Pat continues, 'I can no longer reposition Pete and the carers only do it if there are two of them, he spends most of his time on the bed now. It's safer. It's too risky to have him in his chair.'
Pat looks embarrassed; Pete catches her gaze, smiles and breaks the tension as he claims, 'I have always been lazy though mum; you know I like my bed. I'd rather have a lay in, than get up. Not likely to change that now, at the age of 36, am I?'

It's a valiant effort by Pete to support her. She forces a smile, but she looks tired and I sense she is struggling to continue to support and laugh with her son.
Through our discussion it emerges that Pete has experienced physical, cognitive and emotional changes since his diagnosis with multiple sclerosis five years ago. He concludes, 'It's been relentless but I cope by keeping cheerful.'

Pete lives in his own flat; he has a 24-hour care package, provided by a live in carer who rotates every two weeks. He shares that a positive by product of this arrangement is that, 'I get to try 'cuisine' from all over the word, most of my carers are good cooks, I have had Indian, Italian and currently my menu is Jamaican.'

Pat interjects poignantly balancing this positive image: 'I visit every day; to make sure he is getting good care. I don't go on holiday anymore. No I couldn't, I would never relax, and I would be too worried that he wasn't being looked after.'

The team jointly agree there are two treatments that could potentially manage Pete's severe lower limb spasticity, intrathecal baclofen (ITB) or phenol (IP). We are unsure which would be most suitable and suggest to Pete that he is admitted to hospital for a trial of both to see which is most effective. He agrees to this plan.

Forging our relationship

After the team appointment I spend more time with Pete and Pat, discussing the two options further and providing written information. As we conclude, I feel Pete would be suitable for IP but he is favouring ITB. From what I know of Pete's lifestyle I think the work and commitment involved with ITB therapy (Protocol 3, 4 and 5) may add to the stress of his current care situation rather than relieve it. Conversely IP has a more instantaneous effect with less commitment although it is a destructive treatment. At this early stage I acknowledge Pete's preference, but urge him and Pat to read the literature and consider both the positive and negative aspects of each treatment. We agree to speak in a couple of weeks.

May Supervision

The time I spend individually with people after the team assessment evolved to improve the efficiency of the clinic. I share with CJ that I am beginning to value this time as important for me to develop my relationship with the person and their carers. CJ introduces the idea of appreciating a person's pattern (Rogers 1970, Newman 1999, Cowling 2000, 2004) rather than just concentrating on a person's list of symptoms. Newman (1999) in her theory of health as expanding consciousness states,

> 'Disease is a meaningful aspect of health. The shift is from treatment of symptoms to a search for patterns; from viewing pain and disease as wholly negative to a view that pain and disease are information; from seeing the body as a machine in good or bad repair to seeing the body as a dynamic field of energy continuous with the larger field; from seeing disease as an entity to seeing it as a process.' (Newman, 1999, p12)

As part of the team assessment I gain factual information; I subjectively appreciate a person's spasticity and spasms by passively moving their limbs, I start to build up a picture of how they manage their spasticity and live their lives.

Newman's (1999) view that health and disease are integral to the pattern of the whole rather than distinct entities resonates with how people with spasticity have to incorporate management of their spasticity into long-term life plans.

I try to grasp their reaction to different treatment options and advice we may give. Seeing them independently enables me to expand this knowledge. I ask them how they are feeling and what they understand about the options offered? This enables me to gauge both their emotional response and their level of ability to grasp and retain information. Listening to their responses helps me to plan what support and education they need, at what pace and in what format.
The situation is informal and with just me, I assume less intimidating than the clinic. I am often out numbered by family and carers. As they talk amongst themselves I closely observe how they

communicate, from this I can modify my own interactions to maximise their comprehension. Gauging how they are reacting to the idea of ITB, I can target individual concerns and decide what information to share and when. For instance some people want to know about the complete ITB process others want to consider smaller steps so may initially only consider the trial (Fact sheet 1, Protocol 3). During our conversation I keep a prototype pump in my pocket, I only show it to people if they want to see it and I have prepared them for its size and weight. Different family members can react in different ways, Pete chose to see the pump and Pat declined.

Cowling suggests that,

> 'The focus on pattern is an intentional choice of the researcher to go beyond symptoms, diagnostic categories or a problem focus as the primary interest of inquiry.' (Cowling, 2004, p204)

Through reflecting on Pete's story I now value an aspect of my role is to intentionally seek to appreciate a person's whole pattern. This process enables me to develop my communication and trust with the person and their family. I feel gaining an appreciation of a person's pattern is vital to the ongoing success of working with someone, to successfully incorporate intrathecal treatments into their lifestyles to maximise their spasticity management. In addition, I recognise pattern appreciation as an ongoing, evolving process rather than a one off task of completing an assessment and its associated documentation. Knowing a person involves an ongoing appreciation of their changing pattern. Reflecting on this has strengthened my intent to effectively utilise this time in clinic.

June 2001: Quelling excitement

Six weeks later Pete is admitted. When the physiotherapist and I arrive at his bedside to record his measures (Protocol 2), his mood is even more excitable than in clinic, 'Lou I've met a woman who uses ITB, she's so inspiring, the pump has revolutionised her life. I really want one now.'

My heart sinks at the prospect of quelling his excitement, but I know we need to explore how he is relating this woman's outcome to his own situation. Is he aware of potential barriers that may prevent him from achieving the same outcome? I am mindful to remain positive, smiling I reply, 'Well I can see she certainly hasn't put you off!'

We laugh. I continue, 'How did you meet her and what was her spasticity like?'

Without being explicit about my concerns Pete immediately tunes into them, 'I know it's a different situation. She has cerebral palsy and has never 'spasmed' as much as me, but I figure the pump could help me a bit?'

He diverts his gaze and whispers, 'She walks too.'

My thoughts start to race. Does Pete think that a pump may help him walk again? I know I cannot leave this topic I have to confront him, 'Pete, do you hope ITB will help you to walk?'

He looks intently at me but doesn't answer. I probe further, 'When was the last time you walked?'

'It's about 4 years.'

He pauses. I leave the silence but keep eye contact. He continues, 'I know it will take a miracle for me to walk again.'

'Unfortunately Pete, ITB is no miracle, it is just a very efficient, fancy way of administering a drug.' I continue to gently clarify how the intrathecal treatments could help manage his spasticity but would

not help him to walk. I share how for some people ITB can improve their walking but from the team's experience they tend to be walking prior to the treatment or have only recently stopped.
I wonder if I have been too blunt. Will Pete remain engaged in the process? He does and continues to ask questions as we carry out the measures and as we discuss the plan for his stay. Our level of communication feels different though, more intense and trusting.
As we finish the measures the neurologist joins us. Together with Pete we all agree a goal of treatment:

'To reduce Pete's spasticity, the frequency and intensity of his spasms so as he can maintain a safe upright posture in his wheelchair.'

Journal reflection

When discussing the issue of walking I felt as if Pete was testing me to see if I was going to be honest or blur the facts. I acted likewise, testing Pete to see how he handled sensitive and potentially painful information. Similar to my interaction with Simon we were working from a position of guarded alliance (Thorne and Robertson 1988). Thorne and Robinson (1988a) describe that reciprocal trust is an essential component to enable effective health care relationships. Pete and I pooled our knowledge; Pete shared his experience of living with his spasticity and his life context, which allowed me to appreciate his life pattern and I provided information on the treatments and process. We were reciprocally sharing an image of each other's worlds. Thorne and Robinson (1988a) suggest that an individual will develop faith in their own competence if this is acknowledged by the healthcare professional. By listening to Pete, I validated his experience; and hopefully increased his self-esteem and subsequent trust in me.

Thorne and Robinson (1989) identify four categories associated with guarded alliance: hero worship, team player, consumerism and resignation. Each of these conditions is dependent on the degree of trust the person has in the healthcare professional and the trust they have in their own competence (Figure 3.2.0).

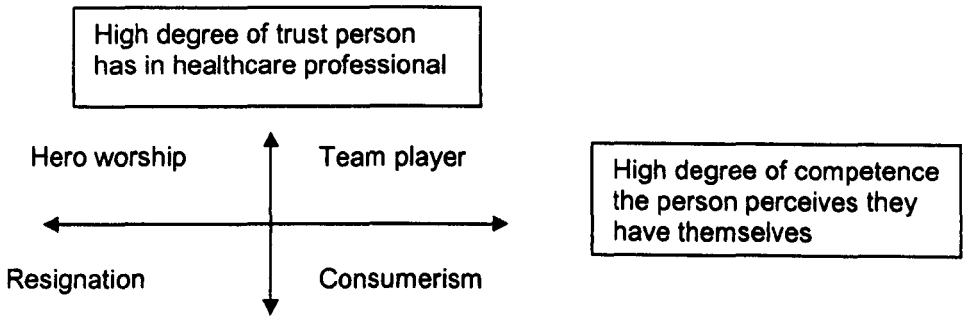


Figure 3.2.0: Model of guarded alliance (Adapted from McGrath, 2001 p77 and Thorne and Robertson 1989)

In the category hero worship the person and their family put their trust in one professional, relying on them for all their information and support. Often the person feels they have little knowledge and competence, so refrain from making decisions leaving it to the healthcare professional. This dependency causes strain, making the relationship difficult to maintain. Resignation depicts

individuals who view all health care professionals as untrustworthy. Having this all-inclusive view spares them from dealing with unfilled expectations. The consumerism category depicts those people who feel they have developed an extensive knowledge of the system and know how to achieve the care they want. They will shop around to achieve it. In the team player category the person and health care professional work together, responsibilities and limitations are clear and shared (McGrath 2001). Using this model to reflect on my interaction with Pete, I think we have moved from hero worship towards resignation, but my intent is to move toward team player. To increase his perception of his own competence I need to continue to listen to him, educate and evaluate his understanding of the proposed treatments.

To be or not to be ITB

Over three consecutive days Pete has increasing doses of ITB (25 micrograms (mcg), 50mcg and 75mcg). With each dose there is a very slight reduction in his spasticity but no effect on his spasms and the goal is not achieved (Figure 3.2.1).

Scale[36]	On admission	ITB 25mcg	ITB 50mcg	ITB 75mcg	IP trial
Ashworth Scale: (Ashworth 1964) (The average score is presented here)	3	3	3	2	0
Spasm frequency scale (Penn et al 1989)	4	4	4	4	0
Overall comfort rating	10	6	5	5	0
Goal achievement	-	No	No	No	Yes

Figure 3.2.1: A selection of Pete's objective and subjective measures

Pete however notes a marked improvement in his comfort and feels that he would like to proceed with a pump implantation. I am very reluctant for Pete to have a pump; in addition to the goal not being achieved I am influenced by two previous similar experiences where we did proceed with ITB. Both individuals became disillusioned with the outcome within six months. For one person this led to severe depression and for another we removed the pump as its presence was causing him increasing distress. My other concern is the potential impact on Pete, Pat and the carers of having to participate in the management of the pump. I do not think Pete has grasped from my education what it means to go through with a pump implant and the maintenance afterwards.

Whose treatment choice is it?

My challenge is to work with Pete so as he can appreciate the potential impact of the pump on his life. We revisit the effects of his spasticity and spasms on the quality of his life. Pete now focuses on his main problem as being discomfort in his chair rather than being unsafe. He repeatedly states, 'My comfort is important...'

[36] For descriptions see protocol 2

He attributes his change of perspective to experiencing comfort during the trials for the first time in years. Do I 'hear' that comment? Am I concentrating more on his carers needs than his? He feels the original goal is still relevant, but the change in his comfort is enough to warrant the work involved with a pump. He is aware that it will not impact on his positioning or wheelchair safety and will not reduce the incidence of him having to lie down.

Pete frequently comments, 'Time may not be on my side but I have time on my hands.'
Although a person with MS may have a normal life expectancy this is probably unlikely with Pete due to his advancing severe disability and relatively young age. Each time he makes the statement it jars me and I consider that he appreciates his life expectancy is perhaps shorter than that of others. The comment propels me to maximise his engagement in the process, or to fill the 'time on his hands', hoping that in the long term the chosen treatment will optimise his situation for the duration of his remaining life.

Revisiting the treatments

I want to try a different way of educating Pete. Propping an A3 pad so as he can see it, I draw the options on a piece of paper and try to weigh up the pros and cons of each treatment with him. We repeatedly discuss the outcomes of the trials; the minimal affect on his spasticity, yet the long-term maintenance of pump refills, pump replacements with no real indication that the overall treatment will have a lasting effect on his comfort.

I try to visualise with Pete how in his every day life the pump could be managed. Who could take responsibility for acting if the pump alarms sounded or if he experienced side effects? Pete felt he would require help to do this and he identified Pat. We spoke to her and she was reluctant to take on this responsibility especially as the trial effect had been minimal. Pete felt he had too many different carers to be able to rely on them.

I continue to frame the potential outcomes into the reality of how Pete describes his lifestyle. I want him to focus on how the treatment would affect his life in his own home environment in the long-term, not just here in the hospital setting.

I continue to build up our visual diagram of pros and cons, moving on to include IP. I highlight it involves less commitment than a pump, on average 2- 4 injections over a year, with immediate and no titration period. I list the potential side effects, mainly, disruption of bladder, bowel, sexual function and lower limb sensation. I point out that as Pete has a supra pubic catheter and a regular effective bowel management strategy, IP was unlikely to change these already refined management strategies. I'm aware of my potential power in influencing Pete's choice and that I am being paternalistic. Woodward (1998) suggests that within current discourse paternalism is viewed as less desirable than respecting autonomy. However she challenges this view, not all patients want to be autonomous or have the ability to be self-determining. She advocates if a nurse believes an individual is making a

choice that will be detrimental to their health, the nurse needs to confront it. She warns that failure to do so could leave the individual feeling abandoned, deprived of expert knowledge and skill to help them decide. I persist on striving to provide information in the right format for Pete to comprehend and choose between the treatments.

Brought back down to earth

I think we are communicating well. I rattle off and repeat the previously rehearsed effects of IP and Pete seems to be grasping the difference between the treatments. Then he grounds me in reality, 'Lou I know I am not currently in a relationship, but I am ever hopeful. I do not want the phenol as it may affect my ability to have erections.'

Silently I scream, 'Of course! It's so obvious that the potential devastating effect of reduced sexual function is concerning Pete.'

I am shocked I have avoided discussing how he feels about the potential of IP affecting his sexual function; instead I have just made sure I included it in my list of side effects to convey to him. Why have I not thought about the effects on his sexuality? Was it the level of his disability? It would certainly be difficult for him to maintain any sexual position without spasms occurring, but this was only the physical aspect of sexuality. I have been given clues that sex was important to him, his carers shared that he was often sexually suggestive and that they found it hard to deal with. Have I resisted entering into such a conversation in case I too had to deal with sexually suggestive comments? Is he sexually suggestive or just trying to share an intimate need that he has - a need that is not being heard? In interviews exploring the meaning of sexuality (Gagliardi 2003) five woman and three men with multiple sclerosis, all expressed sexuality as an important issue and they viewed themselves as fully sexual beings. Do I think of Pete as an 'asexual being' a category often attributed to disabled people (French 1994)? Perhaps I just want to avoid talking about sex.

Acting on the issue

I realise I do not know the actual effects of IP on sexual function; the limited literature available on IP (Kelly and Gautier–Smith 1959, Nathan 1959, Williams et al 1995) pays scant reference to it.[37]

I discuss what I know, that we try to minimise side effects by specifically targeting the injection, but if they do occur, they may be transient or require a change in management, such as increasing the strength of enemas used to manage constipation. I then arrange for the consultant who injects the phenol to discuss these issues in more detail, and ask him to consider injecting a slightly lower dose to minimise the likelihood of side effects, despite this potentially providing less effective spasticity management.

After seeing the consultant, Pete decides to have the trial of IP, as this would allow him to compare the outcomes with those of ITB. The IP trial eradicates his spasticity and spasms the goal is achieved and his comfort improves (Figure 3.2.1). However his lower limb sensation is disrupted, with this

[37] In a subsequent publication (Jarrett et al 2002) I document the effect of IP on the sexual function of people who have used our service.

outcome it's likely he would experience an effect on his sexual function. On balance Pete decides the overall benefit is greater with IP and he decides to proceed with a low dose. Following the phenol injections Pete reports improved safety in his wheelchair and no adverse effect on his sexual function.

Three months later: Journal entry

Mark has been admitted for IP his wife Sally is his main carer. I am cautious in my approach but confident that I have to broach the potential effect on his sexual function. They share that their sexual relationship is an important aspect of their life together and they value the information on the potential side effects to assist them in deciding whether to proceed with IP. I feel awkward but they do not seem embarrassed to discuss this issue and their response confirms to me the importance of addressing this issue.

I recognise that to appreciate a person's whole pattern I need to consider addressing sexual issues.

The pump clinic

August 2001
Team present: Tom, the neurology registrar and myself

It's going to be a long clinic today, eight people are on the list and all of their pumps need refilling. I wish I had brought lunch with me, so I could snatch it between appointments. Working in a teaching hospital it's not unusual to have health care professionals visiting and observing. Fiona, a senior neuroscience clinician, is joining us today.

Cliff and Julie

Cliff and Julie are the third couple we see, I first met them five years ago on the neurorehabilitation unit. I have seen them every three months in the pump clinic since starting this job two years ago. During this time Cliff has also had a five-day in-patient stay for a pump replacement after the battery depleted.

Julie expertly manoeuvres Cliff and his elongated wheelchair, into the small, cluttered clinic room.
'Sorry we are late the train we normally catch was cancelled.'
The once suitable chair now overshadows Cliff's tall, bony body. He looks thinner and uncomfortable.
I offer, 'I can always arrange transport by ambulance for you... if it would be easier?'
Cliff laughs, coughs, and we reposition him so as he can clear his airway.[38]
Julie looking at Cliff interprets, 'I think Cliff is trying to say that the train is both more comfortable and reliable than hospital transport.'
Cliff nods; I smile and think how independent they both are. Not many people would use public transport with such a large customised wheelchair. I feel irritated that I cannot offer this couple an easier way to travel to the clinic.
Julie interrupts my thoughts and leads the discussion, 'You can probably tell from Cliff's cough, his swallow is worse. It takes so long for him to eat anything; he choked really badly on his favourite curry last week even though I had prepared it like the speech therapist had said.'
Cliff smiles at Julie. She gently teases, 'No point in just smiling. *We* have to get nutrients into you. You are becoming skin and bones.'
She turns to look at me her facial expression changes. I read the signal she is worried, 'Lou, his skin... on his bum, its red.'
Usually such a comment would have sparked a joke from Cliff, today he just laughs, again he starts to cough, Julie and I reposition him so as he can clear his airway. I smile at Cliff but with a serious tone I confront him, 'Cliff you know *we* cannot ignore red skin. If your skin breaks down *we* have a wound, a pressure sore. If these occur on your bum they can be notoriously difficult to heal, as it's difficult to

[38] Laughing for someone with poor respiratory support for speech can lead to coughing and shortness of breath.

reduce pressure to promote healing. Red or broken skin will also exacerbate your spasms that in turn can lead to further friction on your skin. It's a vicious circle *we*'d best avoid.'

I am mindful of supporting Julie; I know she does a fantastic job at caring for Cliff. I sense she's feeling guilty about the potential pressure sore. I continue,

'Sometimes, despite exemplary care, the awkward limb positions that spasticity can cause together with skin friction from spasms makes preventing red skin and pressure sores very difficult.'

We talk about his spasticity; it remains severe. His spasms are frequent and now occur more than once an hour,[39] possibly resulting from the red sacral area. We agree to increase the ITB dose. I feel *we* are on the edge of a precipice; I want to keep *us* here and prevent *us* from spiralling downwards. I know Cliff plays down situations and Julie rarely shows concern. Today is different she is worried and I wonder if Cliff is listening to her? I probe, 'Julie is concerned Cliff, that you are not getting adequate nutrition and this is impacting on your skin... chances are she's right.'

He laughs, nods agreement and smiles at Julie I continue, 'Cliff *we* cannot ignore it. Can *we* ask the district nurse, wheelchair therapist, dietician, speech and language therapist to come back in and see you?'

I reel off the titles quickly, finishing with a sharp intake of breath. I know he prefers to resist all intervention from hospital or community staff. I cross my fingers and hold them up so as he can see and tentatively await his reply.

We all wait.

Cliff finally grins... I sense he wants to make a joke, he chooses to smile and wink which, is perhaps safer than risking a laugh and shortness of breath. He speaks for the first time today, '**Ok** ... **I** need to **eat**... but it takes so **long**... I get **tired**.'

I note the increase in effort for Cliff to speak, only certain words (in bold) are audible the others I guess.

Cliff has previously rejected the use of a percutaneous endoscopic gastrostomy (PEG) feeding tube. I revisit the topic and tentatively stress if he receives nutrition via a PEG he could continue to eat orally without worrying whether he is eating adequate amounts. He nods. I continue to detail issues about a PEG he seems more open to the idea. Julie's facial muscles relax, her shoulders drop as I breathe a sigh of relief and uncross my fingers. We all smile at each other.

We continue to discuss his spasticity management and refill his pump.

Dissonance

After they leave I suggest to Tom and Fiona that something is different today. I note Cliff's body is changing, he is thinner, has more spasms, a red sacrum, reduced swallow and respiratory support for speech, but there is something else and I can't put my finger on it.

[39] Moving from 2 to 3 on the Penn Spasm Frequency Scale (Protocol 2).

Maud and Rolf

Hungry and tired Tom and I summon up energy for the last appointment. Luckily it's Maud and Rolf; we usually have a cheerful and efficient exchange with them. I look for them in the waiting room; I catch the eye of Rolf and wave as I approach them. Rolf shows no emotion; Maud's head hangs low she doesn't respond to my greeting. Something is the matter, but the waiting area is busy, I want to get them into the privacy of the clinic room. Silently they follow me, unusually for Maud she doesn't self propel she allows Rolf to push her.

As I enter the clinic room I furrow my brow at Tom silently cuing him that all is not well. As soon as the door closes, Rolf reveals 'She's depressed.'

I feel my spirit sag. This appointment isn't going to be straightforward, but I know we have to explore the issue. Tom quickly picks up the cues, speaking softly and directly to Maud he asks her, 'How are you feeling?'

Without looking up she manages to vehemently reveal, 'I hate my MS, I hate my chair, I hate my pump, I hate my life. Suicide, ending my life has to be better than this.'

Her words hang in the air.

Tom probes her feelings to establish her suicidal intent. Maud throws up her head and retorts, 'But how can I, with this useless body, how can I physically do it, I am not able to take my own life!'

The impact of her words, her restricted choice permeates the whole room; the atmosphere is heavy and tense. I am mindful of how her disability limits her actions, yet I am relieved that she can't commit suicide. Tom continues to explore Maud's feelings, she details how frustrating it is not to be able to leave her house independently, how she fears not being able to ever go on holiday again and how she no longer feels useful at home as a mother or wife. Rolf shows no emotion. I'm thankful this is the last appointment so as we are not pressured by time.

Maud cries. I kneel down and touch her hand. She grasps my hand. Anxious to reassure, Tom and I acknowledge what she is saying. I repeat what she has previously told me about her life: how she contributes to the household and the raising of her children. She smiles through a veil of tears, and confirms she still carries out these roles. I am relieved that I know these aspects of Maud's life pattern. It enables me to be intimate. She readily agrees for a referral to a local psychiatric service. The atmosphere in the room lightens and I feel that perhaps with expert help she will move through her despair.

We continue to discuss her spasticity management and refill the pump.

Feedback

As we start to tidy up I acknowledge Tom's skill, 'You did really well with Maud; I was struggling to summon the energy to engage with her. I am so glad she agreed to seek further help.'

Tom retorts with a phrase we commonly use in the team, 'Oh it's just another day in the pump clinic... Who said it was only about refilling pumps!'

Fiona interrupts our laughter as she coolly interjects, 'It's a tough clinic. Do you ever wonder what *we* are doing for these people? Are they really being helped or are *we* just prolonging the length of time they have to cope? They are so disabled.'

I'm startled, is she implying that providing a service to severely disabled people is a waste of money? I reply, 'I have to look at it another way, what would happen to these people if *we* were not providing this service? They are likely to be in pain, not be at home, some may even not be able to be seated so would have to spend all their time in bed.'

I sense more warmth as she responds, 'I have no problems with the treatment and its outcomes; it is just quite hard to see people coping like that. I have no doubt it's very therapeutic to come to the clinic to see you, have a laugh and a joke, but their lives are quite hard.'
I feel my defensive language dissolve as I consider the level of complex disability she has witnessed in the eight people we have seen today and how she is struggling to comprehend their lives.

A few days later in my journal...

Fiona's comment makes me realise it can be challenging to just observe the clinic rather than participate in it. I need to be mindful to prepare visitors and be aware of how they are coping throughout a visit.

August Supervision

CJ highlights my use of 'we' and 'us' (highlighted in italics through the text). I suggest this reflects my belief that managing spasticity and complex disability requires a joint commitment and responsibility from all involved. Although not evident in these experiences we consider that I need to be mindful in practice that I do not use a collective approach to mask issues I am individually responsible for and could resolve.

CJ challenges me to consider if Cliff is 'resigned' to his suffering and whether his usual cheerful persona masks his feelings, similar to Simon. Yet in this interaction the mask is slipping and I use playful, parental statements in an effort to 'cheer him up' or to repair the mask and avoid dealing with his emotions?

I hadn't considered this perspective before and wonder whether Maud's usual cheerfulness also masked her feelings. Perhaps I have missed cues in previous clinics that if acted on could have stopped her reaching the level of despair she was in today. I need to continue to consider how I use humour in my interactions and whether I use it to avoid dealing with the emotions of others.

Intimacy

I felt intimate with Maud, but what enabled that to occur? Williams (2001) used semi-structured interviews and diary analysis with ten nurses to explore the meaning of intimacy. She found an

important issue linked to intimacy for vulnerable, dependent patients is the physical presence of a nurse, which include activities such as giving time, being with the person and demonstrating an appreciation of their experience. Tom and I spent time to appreciate how Maud was feeling and I shared with her how she had previously described her role and value as a mother and a wife.

Putting my finger on it

I ponder on Cliff and Julie's appointment; what had stood out, what was different? It wasn't just the physical aspects, their interaction with Tom and I was different. Julie is Cliff's main carer, yet despite his high level of disability they choose to have very little support from other agencies. They always portray an image of coping, the management of Cliff's MS and associated symptoms are merged into their daily lives and do not appear to dominate.

There is a history of MS in both families and they always ask if there is any new research or treatments that could help Cliff's MS. However Julie didn't ask about new treatments at this appointment, instead she sought confirmation that she was doing everything possible for Cliff, that there was nothing else anyone could do. I didn't pause to consider my response. I knew Julie was an exceptional carer. I felt it important to reiterate that she was doing an excellent job and that many people would not manage at home and have the quality of life that they had together. At the time I knew something was different but I couldn't verbalise it, now I can:

This was the first time I had seen them totally focused on maximising Cliff's current situation.

They did not seek any new research knowledge.

Looking for a cure was no longer a priority.

Reflective text 4: Team interactions 2 **Supervision session 8, 9 & 10**

Surfacing conflict within the harmonious team

September 2001 – Supervision session

I share with CJ the positive feedback Norman had given me this morning in the assessment clinic, 'I have really valued this appointment in particular how you involved me in the decision-making. Normally I am just told by health care professionals what's going to happen.'
Hearing this I felt privileged to be part of the spasticity team. CJ encouraged me to reflect on what happens in the clinic, what are the team dynamics to make someone feel empowered like this? On my journey home wearing 'rose-tinted' spectacles I wrote in my journal:

> *'Each member of the assessment team is clear of their individual roles; they are not defensive if role boundaries blur or overlap. Team members respect each other.'*

Preparing for my October supervision: Seeking the truth about my feelings towards the spasticity assessment clinic

Reconsidering my journal entry I realise it is representative of my vision, how I strive to work as part of a team. It resembles the dynamics of the pump clinic but not the assessment clinic. In my September supervision I was working under the illusion of the harmonious team, denying conflict exists. The harmonious team is described as:

> '...concerned with maintaining a facade of togetherness or teamwork. It does not talk about difficult feelings between its members and seeks to protect its members from outside threat. Conflict is brushed under the carpet or is inadequately resolved.' (Johns,1992, p91-92)

I question myself further, how do I really feel about the assessment clinic?
More truthfully I write,

'I dread it every month'.

Within my role it is inevitable that I will work closely with physiotherapists, as movement, positioning, stretching and exercise are key components in the management of spasticity (Lockley and Buchanan 2006). Although junior physiotherapists welcomed my new role, senior physiotherapists were less certain, some even voiced that the post should have been developed as an extended role for a physiotherapist not a nurse.

So how do I position myself to manage such overt conflict?

October supervision session

Being kept in my place

I explore with CJ how the clinic has developed. The neurologist and Wendy have worked together in the clinic for four years. A routine has developed that the neurologist commences the assessment by

asking the person to describe their spasticity and spasms. Points are clarified first by the neurologist, then Wendy and I am invariably last to speak. CJ identified this as being kept in my place – third not in second place next to the neurologist. This triggered a memory of an occasion when I did speak after the neurologist; whilst it seemed he didn't notice it was met with a great deal of hostility from Wendy that lasted for several weeks. She heavily disguised her comments so that others were not aware of her behaviour. Dickson (1982) describes such behaviour as indirectly aggressive. This behaviour is un-collaborative and manipulative. For me it is also insidious, I was not aware of it until discussing the situation with CJ in supervision. He feels I am 'sucked into Wendy's web'. In an effort to stop her negative comments and behaviour affecting my practice, he suggests viewing her as an object and distancing myself from her so as I can place any subsequent negative comments and behaviours into the 'newly developed space' between us.

October assessment clinic

Present: Neurologist, Wendy and myself.

Becoming assertive

The first person we assessed today was Vivian; she was suitable for ITB. Whilst I was carrying out her one-to-one education session, the neurologist and Wendy started to assess the second patient Cyril. His ambulance was waiting to take him home so they quickly assessed him and decided he would benefit from IP. They did not give him the information sheet and let him leave before I had a chance to meet him to provide any further education. Cyril lives in a nursing home in Hertfordshire, it is going to be difficult to visit him to discuss the treatment in person. I glean from their assessment documentation that his speech was slow and low in volume so telephone communication was also likely to be sub-optimal.

I am angry that I have not been included in the assessment. Feeling confident from my reflections and the insights I gained from my reflective text on Pete,[40] I calmly and assertively explain to the neurologist and Wendy the importance of my initial contact. I state that the appointment and one-to-one education is a vital time for me to start to get to know the person and their lifestyle. I can gauge their feelings about the treatment and how I may need to pace the education and in what format. I ask if in the future one of them could call me so as I can organise my time to make contact with the person before they leave. The neurologist apologises and acknowledges it would be problematic for my future interactions if I did not have this opportunity, he would in the future let me know. Wendy was silent.

November supervision: Knowledge and Power

The doctors and Wendy use abbreviated terms for the muscles and doses they are considering injecting with botulinum toxin (BT – Fact sheet 6). I have not learnt this terminology as I feel it will duplicate existing expertise, but this limits my involvement and keeps me in fourth place if we include

[40] Pages 112-119

the neurophysiologist. Reflecting now I realise how powerful this knowledge is and how at times it has been used to undermine my position in the clinic, perhaps to ensure my position in the pecking order. By not challenging this behaviour I have allowed situations to develop where I feel my clinical skills are inadequate.

November assessment clinic

As I arrive at the clinic, a physiotherapist from another Trust who I have previously worked with is waiting to attend with two of her patients. She greets me by saying, 'What on earth do they need a nurse at the BT clinic for?'

I feel relieved I have reflected on my role and can articulate why my skills are required. I explain the clinic does not just offer BT and although my skills are readily utilised with individuals requiring ITB and IP, there are times when I can offer advice and input to people requiring BT in particular about skin care. She nods but seems unconvinced. As I walk into the clinic room I deflect her negative comments into a space and concentrate on maximising the clinic experience for the people attending. The neurophysiologist is new; I sense he is nervous. I try to ease his discomfort by describing how the clinic runs. I offer to assist him with drawing up the injections, as I know this can be time consuming and can delay the clinic. He is grateful and shares his concern about getting the new EMG machine to work correctly. The clinic runs effectively, with the neurologist and Wendy assessing and the neurophysiologist and I carrying out the treatment. Both of these elements I feel are of equal importance to the success of the clinic.

Continuing to be assertive

At a subsequent departmental research seminar I present my degree dissertation (Jarrett 2000, Appendix 1). Previous experience of Wendy's aggressive questioning techniques at seminars led me to prepare answers to potential questions she may ask. As predicted she was very challenging, but I felt empowered and able to answer, even challenge some of her comments. I felt we had a healthy debate and the situation was certainly a win-win. Afterwards several people comment that they could not believe how belittling and scathing she had been. They share that they would not feel confident to present in front of her. I reply that I had taken time to prepare and some of her comments could be viewed positively and acted on whilst others I could choose to ignore.

Journal Reflection

These experiences illustrate uncertainty surrounding my role and patterns of power within the team and between professional disciplines. Roberts (1983, 2000) suggests that nurses are an oppressed group and states.

> 'Characteristics of nurses i.e. warmth, nurturance and sensitivity have been viewed as negative when compared with those of the dominant culture, i.e. intelligence, decisiveness, and lack of emotion.' (Roberts, 1983, p27)

I identify with these nursing characteristics but recognise they are concealed or non-existent in my practice in the clinic. I use the work of Friere (1996 [1970]) and Roberts (1983, 2000) to reflect on why this may be.

Friere (1996 [1970]) describes an educational philosophy he developed whilst working with illiterate people in Brazil, his aim was to enable them to participate in the development of their society. He describes a model where a hierarchical relationship of power exists between landowners (oppressors) and peasants (oppressed). The landowners have power over the peasants to complete work (Figure 3.4.0).

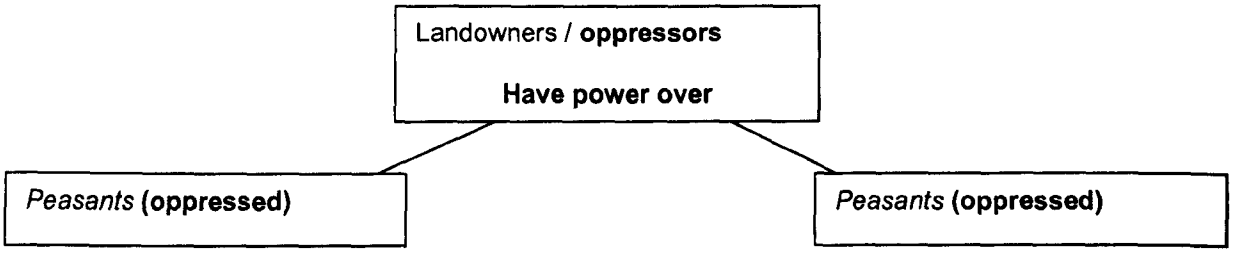


Figure 3.4.0: A diagrammatic representation of Friere's (1996 [1970]) hierarchical model.

Friere (1996 [1970]) describes how the oppressed may feel angry, but as they are so submersed in the situation they do not understand why. They are unable to recognise and label their oppression. This passive aggressive behaviour leads to a negative, unproductive working environment and the oppressed experience low morale and self esteem (Roberts 1983). This reverberates with my dread of the clinic. I feel oppressed.

Friere (1996 [1970]) describes the most desirable option for the oppressed is to become one of the 'bosses' (oppressors). An intermediate stage can occur if the landowner (oppressor) chooses a peasant (oppressed) to be 'overseer' to ensure the work is completed.

This helps me to appreciate why I do not enjoy the clinic. I feel undervalued so do not discuss my role or make explicit my contribution to the assessment process. Whereas Wendy is articulate with her assessment outcomes and rationales for treatment choice. I feel this enables her to assume the 'overseer' position (Figure 3.4.1).

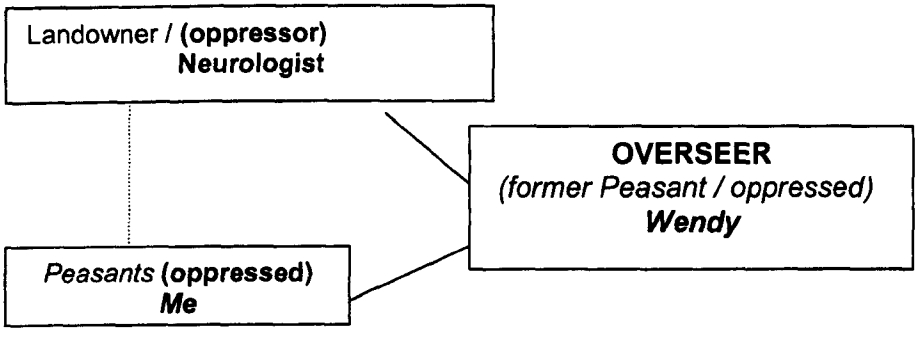


Figure 3.4.1: Illustration of Friere's (1996 [1970]) model of oppression in relation to my position in clinic

Roberts (1993) and Friere (1996 [1970]) suggest that if the oppressed feel unable to vent their anger on their master they will start attacking each other or themselves. I have suppressed my anger about

the clinic and how Wendy has acted towards me, but this has only led to me doubting my own abilities rather than challenging her behaviour. However when I started to assert my role having missed Cyril's assessment, I did challenge her position.

Friere (1996 [1970]) states the overseer often becomes more aggressive than the landowner in order to keep the peasants in their place. Wendy was definitely more aggressive and critical of my work than the Neurologist. Dickson (1982) describes the 'aggressive type' person as always seeking to put others down, in public or private, to enhance their own perceived higher status. They often alienate people around them, making individuals defensive and in fear of speaking out in case of further dispute. This resonates with the fearful responses from my colleagues after witnessing Wendy's style of questioning at the seminar.

Through dialogue with CJ and using the work of Friere (1996 [1970]) and Roberts (1983, 2000) as reflective frameworks, my position within the clinic has become clearer. To be available to people with spasticity and their families I need to negotiate, clarify and assert my role within the multi-professional team.

I need to overcome my internalised (socialised) sense of oppression so as I can be fully available and demand respect from the team.

Insight

Guided reflection has enabled me to clarify and assert my role and confront my reluctance to embrace conflict. In doing so, I am more confident and have shifted the practice environment so I am more able to fulfil my role and act with integrity.

Reflection is empowering.

Kieffer (1984) interviewed 15 people who had emerged as leaders through citizen-led initiatives within their communities. He asked them to describe their personal transition. He explores the paradox that people can emerge as empowered despite being in an environment of apathy and hopelessness.

He describes empowerment as attaining participatory competence within a community and involves moving through four phases of involvement (Figure 3.4.2).

Phase	Development
Era of entry (Birth of struggle against conflict)	Birth of emergence of participatory competence. Integrity is violated provoking and mobilising a sense of frustration and powerlessness towards an empowering response.
Era of advancement (Continuing struggle)	Maturation of empowerment through extension of involvement and deepening understanding through intensive self-reflection with the help of an external enabler.
Era of incorporation (Continuing struggle)	Reconstructs sense of self as author and actor in environment. Learning to confront and contend with barriers to self-determination leads to a sense of mastery and competence in the individual's sense of being.
Era of Commitment (Continuing struggle)	Adulthood of participatory competence – integrates new abilities and insight into reality in meaningful ways.

Figure 3.4.2: Attainment of participatory competence through four phases of involvement (Kieffer 1984).

When my space to practice was minimised by the actions of other team members, I felt my integrity as a nurse was violated. Discussing these issues with CJ and dialoguing with other literature, I was able to visualise my position in my practice environment and consider how to change, thus preparing myself for future action. I recognise this as moving from the 'era of entry' toward the 'era of advancement'.

Reflective text 5: **Supervision session 10 & 11**

Flowing with pressure

December 2001 journal entry

'I feel overwhelmed with what I am trying to currently achieve. I am juggling several roles and I'm afraid of 'dropping a ball', something important being forgotten.'

December supervision

In supervision I explore my struggle to manage different aspects of my role: my clinical work, my research, the nursing input to the cannabis trial, lecturing commitments and office dynamics.

Clinical work: Three people who have initially responded well to ITB are now showing signs of deterioration. I need to safely facilitate investigations that we do infrequently: Magnetic Resonance Imaging (MRI) of patients with implanted pumps and radiopaque dye studies to ensure an implanted pump system is patent. I will need to be active at supporting the individuals and their carers, X-ray staff, surgeons, junior doctors and ward staff in ensuring the safety of the individual. To reduce risk, prior to arranging the investigations, I need to simulate the process of each procedure, identify any potential problems and work out a plan to minimise them. I then need to communicate the planned process to all involved.

One couple, Vera and Jack are particularly challenging to work with. They are very unhappy about the outcome of Vera's ITB treatment. They often apportion blame at members of the spasticity team, including myself. They do not accept her increasing level of disability is a result of her MS. I feel they want the ITB treatment to do more than is possible.

Having learnt from my reflection on my interactions with Pete I appreciate the importance of educating individuals about ITB, in particular what it can do as well as what it cannot do. Vera was one of the first people I supported through the ITB process. Looking back I feel the detail of education I gave Vera and Jack was minimal and related to my low level of expertise at that time and I feel, as a team, we never really addressed their long-term expectations.

Jack can be aggressive to junior staff but quite charming to medical and senior staff. I know I will need to support the ward team and address Jack's behaviour if it becomes problematic. I must be careful not to allow his negative behaviour to impact on my interactions with Vera.

Research: Carrying out audit and research are the first things sidelined in my expanding workload. I feel as if I am in a constant battle, always fighting to find time to complete projects. Two projects need writing up for publication as the results are pertinent and could change and directly affect the care of individuals. One relates to the safety of people receiving replacement intrathecal pumps and the second reviews the outcomes of using IP. The latter study includes statistics; I have never been taught how to do them. I am teaching myself or learning from others. I am not finding it easy.

Cannabis in Multiple Sclerosis (CAMS) trial: The department is participating in a nationwide multicentre trial to assess the effectiveness of cannabinoids on spasticity. I am providing support to the nurse co-ordinator. Although this is a great opportunity to expand my research skills it is my first exposure to the running of a clinical trial. It requires flexibility and creativity to ensure the trial data is collected effectively and people with spasticity are cared for appropriately during the two years of the trial.

The first co-ordinator unexpectedly left and the recruitment process for a replacement has failed. I am currently overseeing the work, so as this does not become part of my existing workload I need to negotiate with my managers and the research team to promptly restart the recruitment process. I also need to give feedback to internal people who were unsuccessful at interview.

Lecturing: I have made too many commitments and have insufficient time to prepare. Although I enjoy lecturing once I am doing it, its anxiety provoking when I do not have enough preparation time. I want to do well and need to widen my reading to increase my knowledge base.

Office dynamics: I share an office with six senior therapists and one other nurse specialist. Our manager's post has been vacant for some months and several senior therapists have recently left. The amount of change and uncertainty about whether vacant posts will be filled is making people in the office 'on edge'. This impacts on how I cope. In particular one person repeatedly states that I must be very stressed with my current workload. I keep replying I do not feel stressed; if I am not communicative it is because I am busy. I feel she is stressed and wants reassurance that her peers are too. However I find her approach de-motivating and not conducive to the senior team giving each other peer support during this period of uncertainty.

However I can share with CJ some positive issues:

1. The Trust has confirmed that they will now make the spasticity management nurse specialist post permanent. I will not need to seek funding from charities, drug or product companies to continue developing this post.
2. I have been asked to present at a national conference.
3. I have managed to continue supervising two other nurses as part of the wider action research project.
4. The spasticity service is entering an exciting period of change. An additional doctor and a new specialist physiotherapist (Wendy has left) are joining the team.

CJ suggests I need to 'flow with the pressure'. I like how this description acknowledges pressure is there but that it need not hinder my progress. I draw the following diagram to illustrate this.

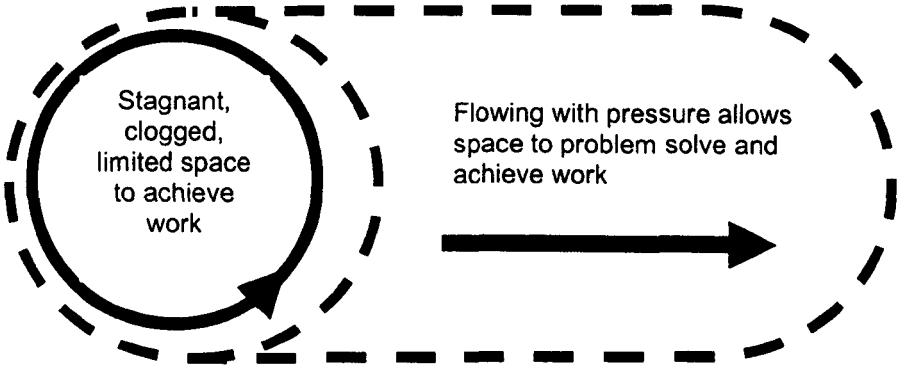


Figure 3.5.0: Flowing with pressure

Cope (2001) suggests the need to examine choices made at work as one part of a bigger decision that of, 'knowing where you are going'. He states having a clear goal to strive for in one's career can minimise the pain of indecision, overcome insecurity and restrict confusion when being pulled in different directions. I have always resisted planning ahead in my career. Instead I aim to consolidate my skills in new roles before considering my next career move.

CJ describes that each job has elements that need to be completed; these can be described as structural, based on the components in a job description. Then as with most jobs, there is extra work that can be described as discretional. I need to review my boundaries and make choices about what I can and cannot do within my current level of work. Further I need to build in the ability to be flexible, so as I can respond to emergencies as they arise.

Cope (2001) suggests using a 'decision corridor,' to plot where you are going and what you will and won't do over time. I sketch this (Figure 3.5.1) and although only short term, my 'decision corridor' gives me a modicum of control over juggling competing demands. Collaborating and communicating my 'decision corridor' to others will create a shared success (Cope 2001).

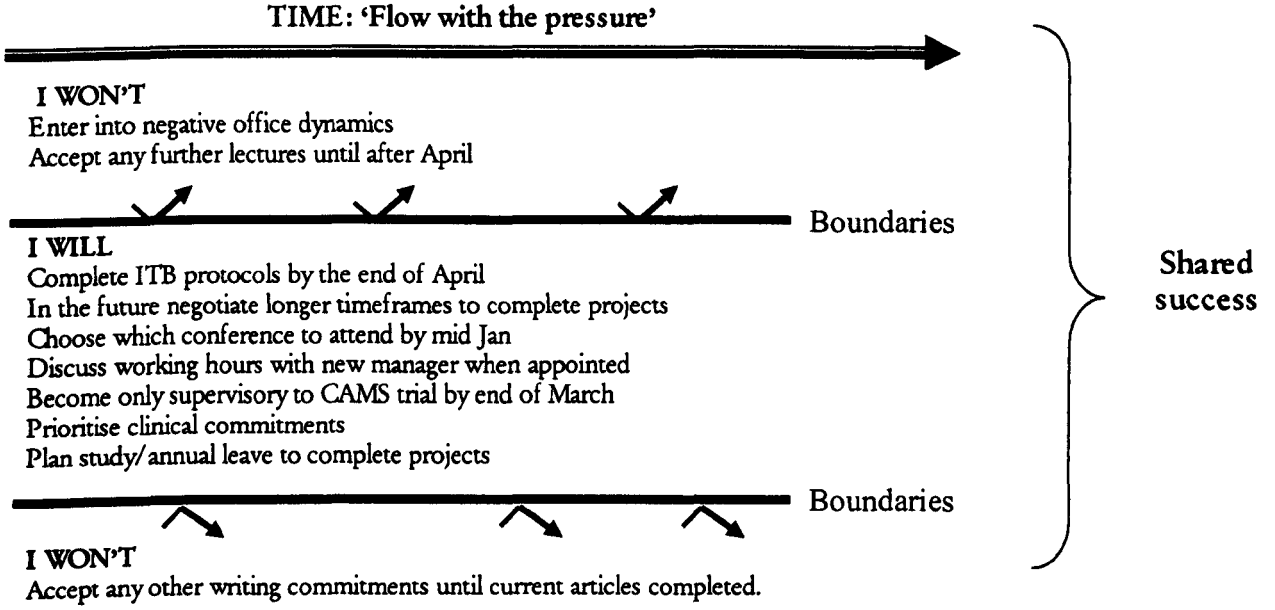


Figure 3.5.1: My Decision Corridor (Based on Cope 2001)

Creating a suitable environment

To 'flow with pressure' I need to be more mindful of it and resilient at saying 'No'. Journaling, supervision and plotting my 'decision corridor' has enabled me to visualise the scope of my nursing role. I can see what needs to be 'juggled', allowing me to prioritise and recover a sense of control. I appreciate my control is precarious, fragile and I will need to continue to adjust to new pressures to maintain a sense of movement towards my growth and transformation.

The value of guidance

Because I felt so pressured this morning I was tempted to cancel this supervision session. In reality it enabled me to identify how to use my time more effectively, thus managing my workload before stress becomes unmanageable. This is similar to a finding in the action research study; once supervisees become committed to supervision they realise it helps them manage their time more effectively in practice (Figure 3.5.2).

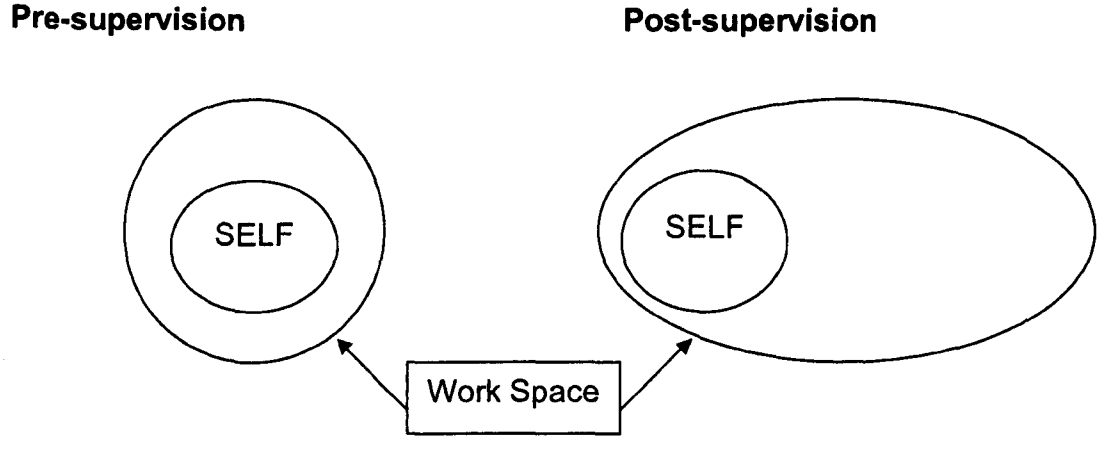


Figure 3.5.2: Supervision - Expanding space

Reflective text 6: **Supervision session 13**

Revisiting the assessment clinic

February 2002
Present: The neurologist, neurophysiotherapist and myself.

Carol

I no longer dread these clinics. I am confident with my skills and positive about the new specialist physiotherapist joining the team. I am motivated to explore how collaboratively we can improve the service.

Just as the neurologist enters the room, there is a loud, high pitch wail from the waiting room. It cuts through the air, dominating the space, muffling all other sounds; it stops us all in our tracks. I look at the others and say, 'That sounds like Carol. Its three months since we last saw her and she is coming for review.'

I rush into the waiting room. The noise intensifies. Sure enough I see Carol's carer and community physiotherapist trying to pacify her, stroking her arms and saying soothing words. The atmosphere is tense, people in the waiting room look away or stare, their faces horrified. I wonder if they have ever witnessed such distress. I want to remove Carol from their gaze. I take her straight into the clinic room.

Carol seems more distraught than previously, her carer reports that occasionally she gets like this. I get a wet, cool flannel and wipe away the beads of sweat, which are starting to drip into her eyes. She screams louder. I feel at a loss, unable to ease her suffering.

Carol is 32 and two years ago she experienced an anoxic brain injury during an asthma attack. She is fully dependent for all her care needs and is unable to speak. She lives in a nursing home where she receives intensive care, 24 hours a day. She has severe upper limb and truncal spasticity, both elbows and wrists are fully flexed and held tight against her body, she has contractures of her shoulders, elbows and wrists. Her legs are contracted in extension.

On her last visit the carer reported that due to the position of Carol's upper body it was difficult to wash and dress her, and she appeared in pain each time they touched her. I also noticed redness and the potential for pressure sore development where her contracted thumbs and fingers were continually digging into her chest wall. We had injected botulinum toxin (BT), although we were uncertain of whether it would be beneficial due to the extensive contractures; but due to the potential skin breakdown we were keen to try something.

The carer shares, 'The injections did make a difference, Carol is easier to position and appears less agitated when being washed and dressed. Her arms can now be positioned slightly away from her body.'

This seemingly small change has made a marked difference to her skin; the red areas have receded. However the community physiotherapist states, 'We are concerned because the stiffness is returning and we think she needs more injections?'

As the physiotherapist and I start to move Carol's arms, she starts to spit as she forces air and a higher pitched scream out through her clenched teeth. It's difficult to assess but it appears her arms have a greater range of movement, they are easier to flex and extend. Although we cannot be sure we feel her movement is now restricted by contractures not spasticity. BT injections will not help. As we start to discuss these issues with her physiotherapist and carer, the neurologist firmly states he is not prepared to administer injections to someone in such a distressed state, especially when we are unsure of their potential worth.

Carol's physiotherapist looks perplexed, panicky and the carer is dejected. I feel a wave of empathy and wonder just how difficult is it to care for Carol on a daily basis? How much hope had they put into these injections? Had we previously misled them? Despite this, I can also appreciate the need of the neurologist to assert his authority. Although he has the support of the physiotherapist and I, Carol is unable to consent and the responsibility as to whether to inject ultimately falls to him.

Poignantly Carol's shrill screams persist necessitating the need for us to raise our voices to hear each other. I can't help but wonder if Carol's screams are her way of communicating that she doesn't want further injections. Even though the atmosphere is tense I feel compelled to voice my perspective, 'She may recognise where she is, associate it with distress and not want to have the treatment again.' Her physiotherapist and carer withdraw. I want to reach out to them, to let them know we are listening and can appreciate the challenge of her care, but today BT is not the appropriate treatment. I suggest to the neurologist that we try some oral drugs, as her spasticity is quite global, he agrees. The carer looks grateful but unconvinced, the physiotherapist avoids eye contact. We arrange to review her again.

Unexpectedly the silence after they leave is deafening.

Molly

We review the minimal information in the referral letter from Molly's elderly care physician; she lives in a nursing home, has had several strokes and the doctor wants advice on how to manage her spasticity.

A nurse from the nursing home wheels Molly into the room; it is clear from Molly's persona that she is minimally aware of her surroundings. We speak to her but she doesn't reply or show any signs of engagement. I am relieved she is with someone who knows her.

I ask the nurse questions. She doesn't answer and looks scared. She thrusts the nursing home medical notes at me. The notes tell us the drugs she is prescribed, but little else. I can see the nurse is getting anxious, I smile and say, 'Thank you for the notes they are helpful but I wonder you know Molly better than us, can you share with us her daily routine and whether her legs feel stiff or move on their own when you are washing, dressing or transferring her?'

The nurse blurts out, 'I'm an agency nurse I don't know her. I was only hired to do the escort.'

The neurologist sighs as he concludes, 'Unfortunately with such limited information we are not going to be able to use this time with Molly effectively and advise on her management. We will need to seek further information.'

Later I speak to Molly's key nurse at the home she responds in a distant and off hand way. She states, 'We don't have any problems looking after Molly. It's the family that have pushed for this referral. I advised them to attend the appointment but they couldn't make it.'

Journal reflection

I feel drained. I have been emotionally moved by Carol and Molly's situations. To me they represent two extremes of complex disability, Carol trying desperately to engage in her environment whilst Molly was completely impassive to it. I ponder how these two women would describe good care?

I know its okay to be emotionally moved, that is the way it is and I must flow with it. Yet I sense somehow I shouldn't be moved perhaps a reflection that I still partially hide behind my 'professional façade' (Jourard 1971). Acknowledging its okay to struggle is liberating. I realise that as much as I want to, I cannot fix Molly or Carol's situation and distress. I shift my energy from feeling frustrated to exploring how the clinic organisation could be improved for people like Carol and Molly.

Reorganisation

I arrange for the neurologist, physiotherapist and I to meet and brainstorm the organisation of the clinic. We decide to work towards two main related aims: to maximise information about the individual pre-clinic to enable thorough assessments at the appointment and to enable effective post-clinic feedback to their relevant community team members.

To achieve these aims we plan to; contact the person and their community team's pre clinic by telephone and amend the standard letters we send out on receiving a referral letter. To the referrer we will ask for any additional information from other teams involved and in the appointment letter to the person with spasticity we will ask them to consider the main problem their spasticity causes them and to bring contact details of professionals involved in their care to the appointment.

We agree to start work on a care pathway to detail a person's journey through our service. Following the meeting I construct an algorithm for the management of the referral letters and set up a database for the joint collection of information.

Post March clinic

The next clinic runs more smoothly and is more satisfying. The conversations with community staff are very positive, they appreciate their opinions being sought prior to the clinic and it gives them time to plan their workload if it is thought the person may need to be seen post any treatments.

Reorganising the clinic has a positive impact on the work of the team; it has drawn us together in collaboration, rising above any professional preciousness that has previously limited effective teamwork.[41]

[41] At the MS Trust conference in November 2003 the team win first prize with our poster reporting on the restructuring of the clinic (Appendix 6).

1st Analytical Pause

The Being Available Template

Dwelling in layers 5 and 6, I reflect on my description of using the Being Available Template (Johns 2002) described on page 85.

> 'I visualise the being available template as a cylinder, spinning on an axis. The axis represents my ever-present but changing practice environment. The spinning movement represents the dynamic nature of integrating the template into my practice.'

I have used the template and its six inter-related factors; having a vision, knowing the person, knowing self, having skills, concern and appreciating the environment, to frame and appreciate different aspects of my practice. This has enabled me to make sense of my practice and to draw out significance and insights. Whilst my insights relate to the different factors, I have found they are *irreducible to single factors; each insight uniquely contributes to the whole of my practice.*

Contemplating these issues I reflect further on the first 3 texts and identify the following insights:

- Working with people with spasticity involves appreciating and flowing with their life pattern (Cowling 2000).
- Spasticity impacts not just on the person's life pattern but that of those around them – managing spasticity is a family affair.
- *To work with a person I must also understand my own pattern of engagement in order to tune* in and flow with their life pattern.
- I recognise that living in a nursing home can enhance a person's evolving life pattern.
- I sense how I position myself within the paternalistic- autonomy tension.
- I use catharsis tentatively.
- I feel uncomfortable discussing sexuality.
- I sense the significance of guarded alliance (Thorne and Robertson 1988,1989) and how it *plays itself out within relationship.*
- I have become more aware of compassion within my practice and its impact on being available.
- My work is emotionally and physically draining I need to be aware of the impact of this on self and colleagues.
- My practice can be influenced by tradition, power and oppression.

The being available template has influenced me to view my practice as a dynamic, network of connected interactions rather than a static, sequential series of events.

In brief, I have a growing appreciation of the impact of spasticity on the person and their family. I am developing insights on the impact I can have on the person, their family and vice versa, plus other influences on me such as team dynamics and oppressive behaviours from others. The being available template has helped me to conceptualise my practice as a 'space', an evolving space which I can mediate and shape in order to be available and become a more effective practitioner.

The impact of living with spasticity

I describe the impact of Simon's increase in spasticity as, 'His whole body looks tense.' (p107)

Pete describes the spasticity in his legs as, 'They've been stiff for three years, spasm all the time and are uncomfortable.' (p112)

Common terms people use when describing to the team how their bodies feel include being, 'tightly held' or 'screwed up in a ball'.

I have observed that through effective spasticity management, a person's body can become looser and calmer with reduced unpredictable movements. It is as if the person's body unfolds, moving from occupying a small, contracted space, to opening up and relaxing into a larger space. Often this transition is marked by the person describing that they feel safe and less vulnerable. For instance when I first met Pete, his limbs were enfolded and only one buttock and shoulder were in contact with his chair. His spasms further compromised his safety. Following the phenol injections his back, buttocks and thighs were in contact with the chair and it was less effortful for him to maintain his posture as he no longer gripped the armrests of his wheelchair fearful of unpredictable spasms propelling him from his chair onto the floor. He was able to occupy more space in his wheelchair. Cliff had an increase in spasms and reported feeling tired. In addition with increased physical activity from his spasms and reduced calorific intake he was losing weight. People have shared with the team and I that by reducing the frequency and unpredictable movement of spasms plus any associated discomfort can promote a more restful sleep. It is suggested that effective sleep can improve a person's cognitive functioning (Lerdal et al 2007, Haimov et al 2008). Porter (1997) reports that following the use of ITB and a reduction in spasms people can experience weight gain despite no change in their diet, suggesting that the physical movement of spasms demands a certain level of calorific intake. My insight is that reduced cognitive functioning influenced either through lack of effective sleep or inadequate nutrition can limit a person's ability to engage with others, limiting their life space.

Maud was experiencing emotional pain. Douglas et al (2008) explored the presence of living with chronic pain in 32 people with multiple sclerosis and deduces that pain is pervasive and intrudes into their daily lives, impacting physically, emotionally and socially, causing them to restrict or be unable to participate in activities. Our intent for Maud to seek further help was to give her space to address her own emotions, the feelings of those close to her and for her to participate again in activities.

Reflecting on my work with Simon, Pete, Cliff, Julie, Rolf and Maud[42], I recognise that to appreciate the impact spasticity maybe having on a person's life pattern, I need to work with intent to evolve my appreciation. This requires actively listening to individual's descriptions, dialoguing with other sources of knowing and continually challenging my own understanding of how spasticity and spasms impact on each person.

Appreciating a person's life pattern is vital to be able to support them in the management of their spasticity and if required to effectively incorporate technology into their lives.
As I work with different people I layer my experiences and individual interpretations to collate a general, wider appreciation of living with spasticity and the impact of my involvement and the treatments we use. This contributes to my developing knowledge and can be particularly influential

[42] Reflective texts, 1; 2 and 3

when responding to people with severe spasticity and spasms who have reduced communication, such as in the situation with Carol and Molly[43].

A common thread to these interpretations is that effectively managing spasticity can 'create space' for a person. I consider whether 'creating space' is an important aspect to my practice. In an effort to deepen my appreciation of my practice 'space', I think about influences on my understanding of 'space' and revisit the work of Margaret Newman and Barbara Hepworth.

Space

From the Cambridge dictionary (http://dictionary.cambridge.org/define accessed 16/2/09), 'space' as a noun is defined as an empty area which is available to be used or that which is around everything that exists and which is continuous in all directions. As a verb it describes arranging things or people so that there is some distance or time between them. In addition the Oxford dictionary describes space as, the freedom and scope to live and develop as one wishes (http://www.askoxford.com/concise_oed - accessed 16/2/09). This latter statement relates in particular to how I view managing a person's spasticity can increase their life space.

Space and Time

Newman (1999) states that the concepts of space, time and movement are inextricably linked, she discusses that space can be considered from different perspectives: personal; shared; physical; geographical; regulating distance and life. Time can be viewed as subjective, objective, private, coordinated or shared. Relating this to people with spasticity, their space can be restricted due to physical aspects, their body can be stiff, uncomfortable with unpredictable movements; how they mobilise with or without equipment can reduce or increase the space they inhabit both from a distance and geographical perspective. Consequently a person's perception of time duration, how they can use time in their lives and what time they have for themselves and others can be altered. To put it more starkly, Newman (1999) suggests a mobile person is likely to have a wider life space and struggle to find time to participate in activities, whereas a person with restricted mobility experiences reduced life space and may perceive they have time to fill. As Pete repeatedly stated, 'Time may not be on my side but I have time on my hands'.[44]

I now appreciate that through successful spasticity management a person's life space can increase and this may alter both their perception and potential use of time.

The influence of Dame Barbara Hepworth

For some years I have appreciated a beauty in the bold, stark sculptures of Barbara Hepworth and contemplated in awe at the level of skill required to produce them, but have not, prior to this thesis, made any connection with them to my nursing practice.

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[43] Reflective text 6

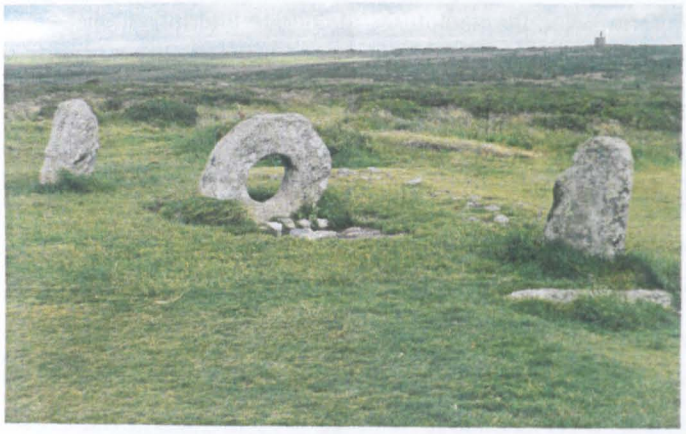
[44] Reflective text 2, p117

When I view her sculptures I am drawn to how she uses heavy materials (e.g. stone and metal) yet simple curved outlines to represent the human form. I find the sculptures striking in their physical presence but not always so easy to interpret, similar to how I view meeting a person with spasticity. A person with spasticity can be constantly moving, changing in and out of different positions, often with the threat of compromising their own safety or that of others. Whilst I recognise this is an important part of 'who' this person is, in the past such postures, their physical presence, has dominated my interactions. My awareness now is not to just focus on a person's physicality but to take the time and effort to know the person, their life pattern and how we can work to smooth their life journey, or metaphorically to appreciate the 'simple curved outlines' as well as the 'physical presence' represented in Hepworth sculptures.

Barbara Hepworth and Megaliths

Barbara Hepworth lived in St Ives, Cornwall from the 1930's until her death in 1975. Art historians (Curtis and Wilkinson 1994, Gale and Stephens 2001), suggest that her sculptures are linked to nature and her experience within particular landscapes. Prehistoric monuments are also influential, such as Stonehenge and Cornish standing stones, in particular 'Mên-an-Tol' a prehistoric megalith situated near Morvah in the Penwith district just outside of St Ives, which I visited in June 2007 (Figure AP1.0).

In folklore the central, circular pierced stone of Mên-an-Tol is regarded as having properties of healing and fertility. Being passed or crawling through the hole is suggested to heal tuberculosis, rickets, neck and back problems (McNeil Cooke 1996, Pederick 1989, Alexander 2002). Many of Hepworth's sculptures are pierced (Curtis 1998, Figure 2.14, p118). She was fascinated by what could be revealed inside a sculpture as well as its relationship with the space around and within it (Pheby and Lilley 2005). Her appreciation of the 'whole' prompts me to consider not just what I can visually see when looking at a person with spasticity but to consider the 'inside' or what cannot be seen such as how the person is feeling and how they fit into their environment, or the 'space around' them. Discovering a link between healing and the sculptures of Hepworth strengthens my commitment to continue to investigate her influences on my practice.



'The horizon is dominated by the silhouettes of abandoned tin mines, whose chimneys seem to relate, as do the prehistoric standing stones, to the vertical forms of Hepworth's sculpture, and ultimately to her obsession with the standing figure in landscape.' (Curtis and Wilkinson, 1994, p64).



Figure AP1.0: 'Mên-an-Tol' photographed 20/6/07

Shaping my practice space

Inspired by the layout of the Hepworth Sculpture; Three Forms 1935 (Figure AP1.1, Gale and Stephens, 2001, p53), I visually represent my interpretation of the impact of spasticity on a person and how this influences our practice space (Figure AP1.2).

I use the sharp angular edges of a square to represent a person not able to manage their spasticity, and a rectangle to depict how spasticity can impact on their lifestyle. The smooth curved oval depicts my intent to widen their living space. The piercing represents getting to know the different perspectives of a person and their family, their public and private personas, plus how they relate to each other and their environment.

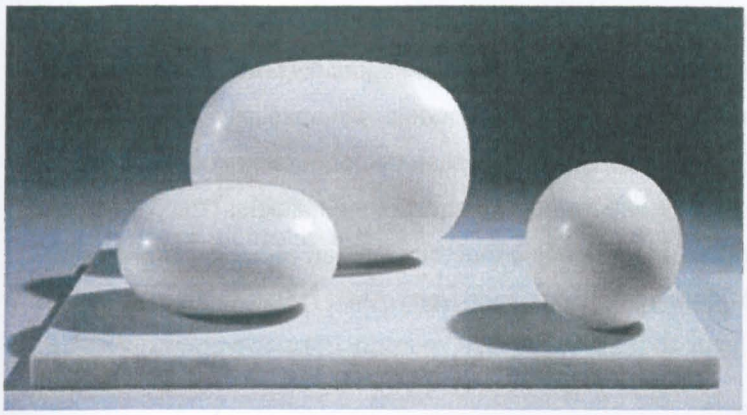


Figure AP1.1: Three Forms. Hepworth 1935. © Tate Collection on Line http://www.tate.org.uk (accessed 9/2/09)

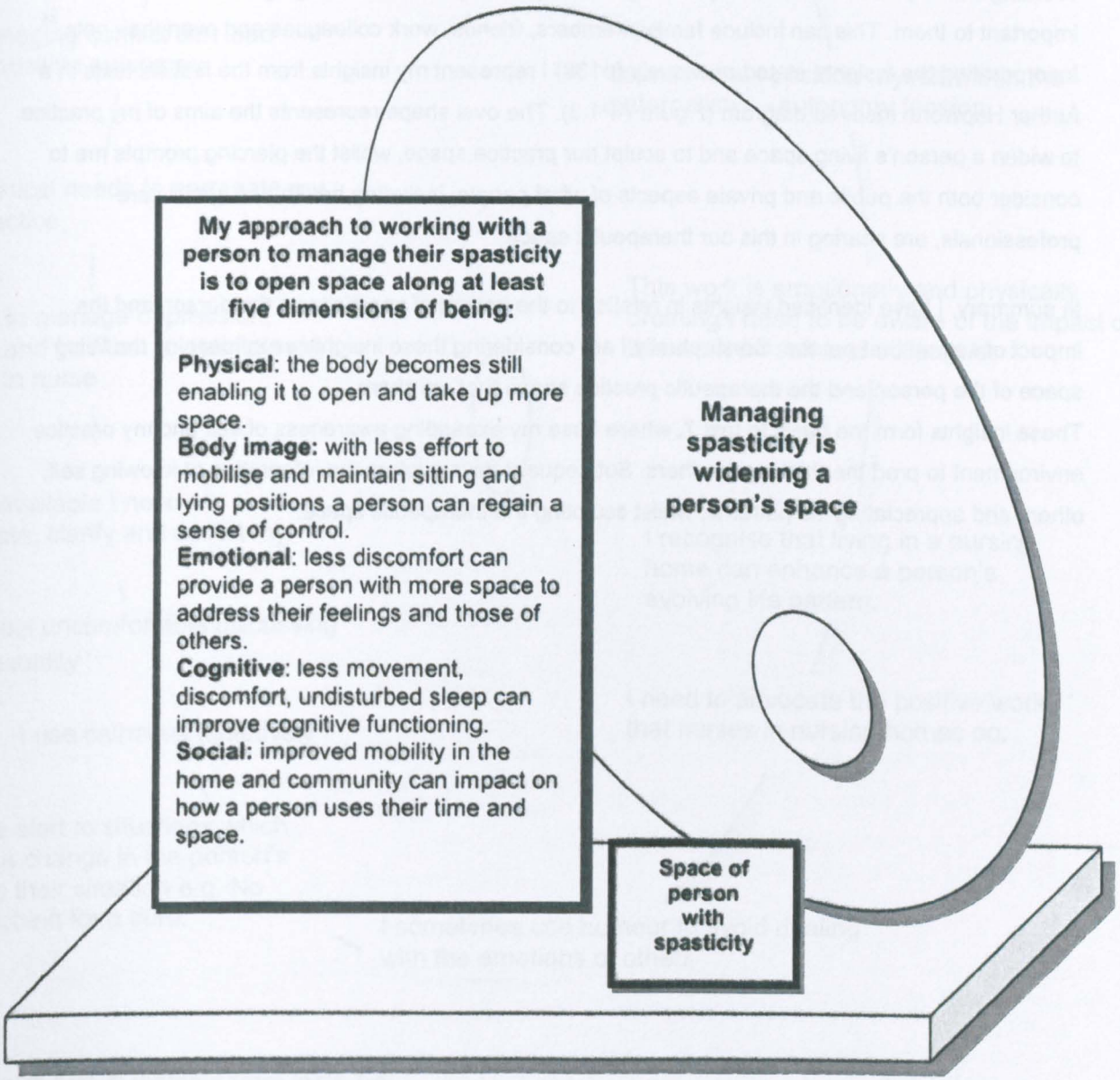


Figure AP1.2: The different dimensions of space for a person managing their spasticity.

Sculpting the therapeutic space

How can I effectively extend a person's living space? Space is my metaphor for creating a practice environment where relationships can flourish. To be available to people with spasticity I need to mould and sculpt this space. In Martha Rogers' (1970) conceptual model for nursing she describes human beings as dynamic energy fields that are integrated with environmental fields. These fields are identified through pattern appreciation and an understanding that they are part of a wider universe of open systems which are continuously integrating and influencing each other. I view my nursing space as ever present, an open system where I can engage with others, mutually influencing how our interactions progress.

Working with a person to effectively manage their spasticity requires engaging with individuals important to them. This can include family members, friends, work colleagues and even their pets.[45] Incorporating the insights stated previously (p138) I represent my insights from the first six texts in a further Hepworth inspired diagram (Figure AP1.3). The oval shape represents the aims of my practice to widen a person's living space and to sculpt our practice space, whilst the piercing prompts me to consider both the public and private aspects of what people, including health and social care professionals, are sharing in this our therapeutic space.

In summary, I have identified insights in relation to the impact of spasticity on the person and the impact of self on that person. Conceptually I am considering these insights as influencing the living space of the person and the therapeutic practice space that we share.
These insights form the basis to text 7, where I use my expanding awareness of self and my practice environment to prod the thinking of others. Subsequent texts explore the integration of knowing self, others and appreciating life patterns, whilst sculpting the therapeutic space.

[45] Telephoning one person often involves acknowledging their talkative parrot as he repeats 'Hello Lou' in the background of our conversations!

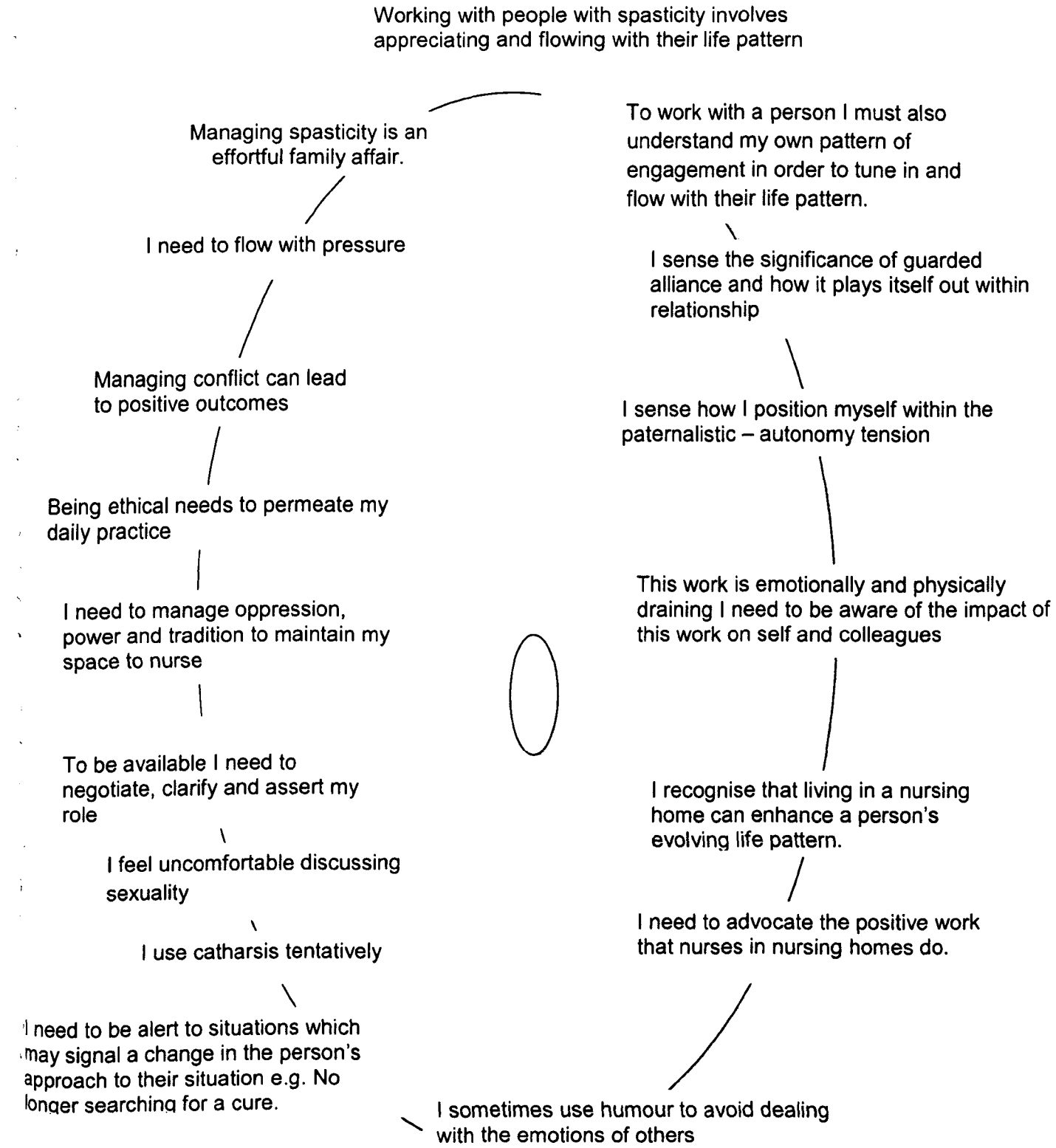


Figure AP1.3: Insights from texts 1-6

Reflective text 7: *Sessions 14 &15*

Others have negative attitudes too.

April 2002
Journal entry

What a difference a day makes

A year has passed since I revealed my negative attitude towards nursing homes in Simon's story. As I flick through my transcript of a workshop I facilitated yesterday;[46] my feelings are mixed. I feel drained and relieved it is over and privileged to have led the group, yet also a sense that the work is unfinished.

I re-read the transcript. It is compelling. I feel the essence should be shared more widely. I contemplate if I can construct it into an article.
Before the workshop I was anxious about exposing my negative attitude and appearing as an uncaring nurse to my peers. I smile as I remember chiding myself prior to the session for having ever suggested the workshop to the MS Trust education committee, yet now only 24 hours later I am considering publishing the outcome.

Insights on leading the session

Preparation and the courage to be flexible with the workshop structure contributed to its success.
In an effort to minimise my nerves I made sure I had adequately prepared for and planned the session.[47] Key to its success was allowing the timings to slip and to give the participants the space to voice their opinions and to share their experiences. Participants responded positively to Simon's story. This dispelled my anxiety about whether it was a valuable topic to discuss and that perhaps only I had a negative attitude. The introductions took over 60 minutes to complete and I now realise that using an imperfect 'story' to trigger the participants own reflections liberated them and led the group to consider and reach consensus on a problematic field of practice. The following insights were discussed.

Insights from the session

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[46] 'Exploring nurse's attitudes to the transition of people with multiple sclerosis (PWMS) from home to long-term care', at the MS Trust nurse specialist national conference

[47] Workshop plan:

Introduction to topic: briefly sharing Simon's story	5mins
Participant introduction and sharing of any relevant experiences.	15mins
Revisit the details of my story through the use of ethical mapping.	45mins
Group work exploring the use of ethical mapping	45 mins
Feedback from group work	45 mins
New care home Regulations 2001	30 mins
Writing a summary of the session for the MSTrust newsletter	30 mins

Negative attitudes exist amongst nurses towards the care provided by long-term care homes.
Each of the twelve participants had key experiences related to talking to people with MS and their families about moving and living in a home. A few had positive experiences; one nurse shared how relieved a man felt once he moved into long-term care,
'He was exasperated with his inflexible care package it never met his needs and didn't provide regular carers, or as he described; 'I was so fed up. It didn't feel as if I was living in my own home, every day I would have different fingers in my cutlery drawer!"
Commonly though the experiences were laden with emotion and steeped with negativity. Participants readily shared how difficult these situations had been for them personally.

The decision-making process to move into a home was viewed as emotional and difficult for all involved. The issues resonated with Simon's story. For instance the need to, involve a person in choosing a nursing home, acknowledge their need to grieve for a past life, plus adjust to a new one, provide ongoing support to carers and relatives to manage their guilt and to help them reconstruct their roles. Many of the nurses felt a commitment to help both the person but also their family and described feeling in the middle if there was not a family consensus on the decision to move a relative into long-term care.

The group shared the difficulty of raising the topic of potentially moving into a home. One community nurse shared, 'With one couple I knew from visit one I needed to bring up the topic of long-term care, but I couldn't. Then on the third visit I managed to and the husband looked so relieved.'
I asked her why she had waited. She said she didn't feel it was part of her role. The group explored with her, how at each visit she was carefully monitoring and constantly reviewing the situation, picking up subtle information from the couple so as she could assess when the best time was to raise the topic. The nurse admitted she hadn't previously recognised her skill in doing this. The participants concluded that nurses do have the skill to time such a conversation and to carry it out sensitively. However they acknowledged such conversations are challenging and effort is required not to be over whelmed with emotions such as sadness, guilt, negativity and a sense of failure.

The experiences of group members had prompted them to imagine needing to move permanently into a home themselves; these thoughts had provoked strong negative emotions of despair and fear. The group felt such attitudes limited their practice and agreed without confronting such destructive attitudes the negative stereotype of care homes would prevail.

Nurses in other sectors oppress nurses who work in nursing homes.
Barriers exist between nurses working in different care sectors; this was poignantly illustrated by one of the participants. She works permanently in a long-term care home and does regular agency on one of the acute wards at the local NHS hospital. She knows the ward staff well and feels respected being on their preferred list to cover shifts. One day when she answered the phone at the nursing home, one of the ward nurses that she knew and worked with, started to hand over a patient, but in a very

basic, condescending way, as the nurse described, '...as if I was thick! I made myself known to her and she instantly changed her tone and started to talk to me in a 'nurse to nurse' manner.'

The nurse shared with the group how angry and devalued this had made her feel. This resembles findings from the work of Friere (1996 [1970]),[48] where oppressed groups exhibit self-hatred and dislike for each other. Other participants in the group confirmed they too had experience of nurses treating other nurses in demeaning ways. Roberts (2000) advises to rise above oppression nurses need to unite and,

> '... develop an individual and collective positive self-esteem through a renewed appreciation for their own history and attributes' (Roberts 2000, p72).

The group shared how our discussion illustrated the need for nurses to appreciate the differing knowledge and expertise of nurses across all sectors. Respecting and embracing each other's skills rather than judging them as superior or inferior to each other.

This was poignantly illustrated further, when we discussed the new national standards for long-term care establishments (DoH 2001a). Highlighting the external pressures facing nursing home staff, enabled one acute sector nurse to link this to her experience of the CHAI (Commission for healthcare audit and inspection, DoH 2003) visits to hospitals. The group recognised the similarity in the stressors facing the two sectors and how futile and destructive it was for nurses not to respect and support each other.

I felt the energy being generated within the group was uniting and I hope would lead them to challenge internal oppression in the future.

Inadequacy of long-term care environments

A particularly emotive issue was discussing the inadequacy of long-term care homes for younger adults, as one person described, 'Younger people in long-term care become forgotten citizens in our society.'

Certainly in the literature research is geared towards older people and their families (Nolan et al 1996, Nolan and Dellasega 1999, 2000, Lundh et al 2000, Ryan and Scullion 2000). Individuals described funding as an ongoing tension and a limiting factor to finding appropriate placements as one nurse claimed, 'It's as if there is an ongoing debate between social care and health services on who should fund what. So much so there is no time to care.'

Two people agreed to discuss these issues with the UK MS nurses association, with the intent to influence the Department of Health to consider the following issues when devising the National Service Framework for long-term conditions:

- To urgently review funding of health and social service provision, to enable clear pathways for people with multiple sclerosis to choose their preferred option for care.

[48] Reflective text 4, p127-129

- To provide suitable long-term care for younger people with multiple sclerosis. Stressing that sometimes long-term residential care can provide a better quality of life for an individual than an extensive care package. However an individual needs to have choice and flexibility.

Facilitating the article publication

The group expressed how powerful they had found the session and it had made them think about their practice. The energy generated in the group I believe motivated me to pursue the article publication.

Eventually an article was published in the Nursing Standard (Jarrett 2003); the editor would not allow the entire group to be authors. I discussed with the editor how each person had contributed to the workshop and had the opportunity to comment on the manuscript. I stressed how I felt it was important that their input was individually recognised. They were finally listed as contributors at the beginning of the article. I was driven to pursue this by the group participant's excitement about being involved in publishing an article. For many it was the first time and one shared, 'I never thought I would have anything valuable enough to say in print.'

The comment reverberated with how I have felt oppressed in the past and my work not valued. I felt energised to pursue the 'voices' of the group to be heard and recognised, as Roberts (2000) states,

'Nursing work is too valuable to go quietly unexpressed' (Roberts, 2000 p77).

When I received payment from the Nursing Standard for the article I negotiated with the MS Trust to add to the amount to enable each contributor a small financial reward in recognition of and to 'value' their input.

Personal insights

This workshop and its outcomes were way beyond what I anticipated. It has helped me to recognise the empowering value of group learning and my own value in facilitating others.

I feel this experience represents an accumulation of insights from the previous texts and considering Kieffer's model[49] has enabled me to move to the third phase, the era of incorporation.

> '...participants confront and learn to contend with the permanence and painfulness of structural or institutional barriers to self-determination. (Kieffer, 1984, p22)

Through teaching I have tested out my emerging insights, engaging in the 6th dialogical movement. I have widened my practice space, by directly using my experience and texts to confront and motivate my colleagues. Sharing my insights enabled others to consider their position and to participate in dialogue about their own practice. My research opened a 'space' for them to consider their practice and to develop their own knowledge. Collectively we have recognised how we can influence the environments we work in, we altered our '...fundamental sense of relation to the socio-political world.' (Kieffer, 1984, p23).

Through this I have reconstructed my sense of self by recognising how I can influence and lead others.

[49] Figure 3.4.2, p129

Living with complex disability: Unexpected threats to the stability of daily life.

Sid

Sid has lower limb paraparesis and has used ITB for over 5 years; he equates how well he feels with how far he can walk. We have continued to refine his dose in an effort to improve his walking; the success of this has fluctuated. He is now on a relatively small daily dose.

Sid is also cared for by a cardiologist for cardiac insufficiency and a haematologist for a blood disorder. In preparation for his pump replacement, at our request, they have carried out various tests and concluded that despite being over 70 years old he is fit for a general anaesthetic.

August 2002: Pump clinic

Present: Tom the neurology registrar and myself

Sid walks into the room. He looks tanned, relaxed and his gait is the most efficient we have observed for some time. Tom and I enthuse about how well he is looking and walking. As we chat I place the telemeter over the pump to read its microchip. It bleeps to indicate no signal, only I hear it, but as I move the telemeter to try and obtain a better signal it continues to bleep. Soon it attracts the attention of Sid, his wife Beryl and Tom. Sid and Beryl look disbelieving as I share that the pump battery has depleted and it is likely that Sid has not been receiving baclofen for the last few days.
Tom equates the absence of drug to Sid's improved walking. Sid is adamant that his current wellness is not related to the pump ceasing. Gently I state, 'Perhaps the baclofen was making you weak, without it you are able to utilise your stiffness to walk better.'
He looks unconvinced. Tom suggests we should wait to see how he progresses before replacing the pump. Sid firmly states. 'I want my pump replaced.'
Tom replies, 'But you may not need it, we don't want to expose you to the risks of surgery unless we need too.'
Sid hangs his head. Beryl is normally very interactive about his treatment however she remains silent. I ask her what she thinks she replies, 'You're the professionals, I don't know.'
I wonder if she agrees with us but doesn't want to be disloyal to Sid.

We agree to regularly monitor him.

Subsequent journal reflection

Have we made the operation seem more important and significant by asking his other doctors their opinion on his fitness for anaesthesia? Have we transferred an air of urgency and significance to the doctors, which then reinforced to Sid and Beryl the importance of the pump? We have never discussed that he may no longer require a pump, they had no warning or preparation that this maybe an outcome.

Sid and Beryl construct their lives around hospital appointments and take great pride in discussing details of consultations and treatments. Kralik (2001) discusses how illness can shape an individual's identity and how it may be difficult to relinquish as they move through the illness experience. We are asking Sid to reconstruct his life by minimising his illness management, but he resists this fundamental change to his identity. To no longer need the pump could affect Sid's lifestyle and sense of identity.

Lindsey (1996) interviewed eight people with a chronic illness on their perceptions of feeling healthy and identified six themes; honouring the self, seeking and connecting with others, creating opportunities, celebrating life, transcending the self and acquiring a state of grace. Reviewing Sid's response in light of these themes, I think ITB helps him to achieve a sense of health.
Having a pump contributes to Sid being a favoured subject for doctor's exams and he spends significant amounts of his spare time carrying out this role across London. In addition ITB necessitates regular contact with us, both of which have created opportunities and expanded his 'social' network. This in turn enables Sid to honour himself; it validates his disease and contributes to defining his identity.

Perhaps Sid emotionally and socially needs a pump; but it would never be implanted for such reasons. The current NHS, dominated as it is by the medical model would only see it pertinent for the team to replace Sid's pump if it was required to treat physical symptoms.

Penny

August spasticity assessment clinic

Penny has had MS for 20 years. Over that time she reports having lots of symptoms and treatments, culminating in her current complex drug regime that includes regular opiates. She shares, 'It's difficult to know what is helping, or whether side effects of the drugs are adding to my problems.'
She was referred to the spasticity team with increasing leg stiffness over the preceding six months. We decide to admit her for investigations and a trial of ITB.

Penny and her husband Fred agree to the plan, but state, 'We are nervous about an admission, our relationships with health care teams have previously broken down due to poor communication.'
I recognise they are communicating from a level of guarded alliance (Thorne and Robertson 1988) and a position of resignation where no health care professional is trusted (Thorne and Robertson 1989).[50] I go over the plan for the admission and how we will endeavour to keep them informed at every stage. I give them my contact details and arrange to call them in a couple of days.

In-patient admission

When the physiotherapist and I assess and measure Penny's spasticity and spasms, it is apparent she uses the spasticity in her legs to transfer. Reducing her spasticity with ITB could increase her

[50] Figure 3.2.0, p115

dependence by limiting her ability to transfer. The neurologist agrees not to proceed with a trial and shares that he is not convinced her symptoms are as a result of MS, he suggests further investigations.

Penny is very scared of each test. I coach her through each one repeatedly stating that they are needed to find the cause of her symptoms. I listen to her concerns and negotiate the best way to complete the tests. From my previous experiences with Simon[51] and Pete[52] I sense the tension between being paternalistic and respecting her autonomy.

Penny states performing a lumbar puncture without an anaesthetic would be impossible due to her intense back pain. I negotiate with her to use a topical aesthetic to her lumbar area prior to the injection with the assurance we will stop immediately if it is unbearable. Even getting her into position and the sensation of the anaesthetic cream was too much; we stopped and agreed to do it under x-ray guidance with sedation. Fred angrily states, 'I have previously used threatening behaviour to get the correct care for Penny in hospital, I will do so again if you continue not to listen to her.'
He clearly feels the need to threaten me. I acknowledge his anger but gently challenge him, 'Fred, as a team have we ever been unclear about the plans or not asked for your agreement before proceeding?'
He replies, 'No, we like working with you all, but I just hate seeing Penny in pain.'

I acknowledge that this situation is equally difficult for both of them. I encourage him to attend the weekly ward round so as he can address some of his questions to the neurologist directly.
Each of the test results comes back clear putting the diagnosis of MS in question. Penny and Fred are very distressed. Penny sobs, 'This news is invalidating my life. All those times over the last 20 years when I haven't felt 100% I have blamed my MS, now you tell me I haven't got it.'

It feels uncomfortable putting this couple in limbo taking away their diagnosis whilst not being able to give them back an alternative. I try to hurry the investigations, chase up results and patiently wait for the opinions of other experts in balance and movement disorders.

The following week on the ward round Fred is annoyed he shouts at the neurologist, 'I feel as if you and your team are keeping information from us. What is going on? '
The neurologist's reply is equally stern, 'I want you to know that in my practice I do not keep information from anyone, people need to know information so as they can deal with it.'
He went on, but more gently, 'I think what you may be sensing is uncertainty, as a team we feel uncertain about your wife's diagnosis, it is not that we are keeping things from you but at the moment we are unclear about what is going on.'

[51] Reflective text 1, p107-111
[52] Reflective text 2, p112-119

Fred warmed to this description and apologised for shouting his frustration. I picked up the word 'uncertainty' to use in our subsequent discussions; both of them agreed it accurately describes how they feel and how they had perceived the lack of information.
Some of the junior nurses on the ward share with me, 'We don't understand why Penny is so upset; surely she should be glad she doesn't have MS?'
I discuss the uncertainty for Penny and Fred of not having a diagnosis; hence justification for her symptoms and their concern of being isolated from health and support networks that exist for her because she was thought to have MS.

The neurologist persists with the pursuit of an alternative diagnosis; the tests continue to come back clear. One of the junior doctors implies her symptoms probably have a non-organic cause. I share that I feel uncomfortable with his view and state, 'What I see is a very disabled lady with stiff legs, dysarthria and severe pain that requires a cocktail of drugs including morphine.'
To myself however, I acknowledge my struggle to ignore the test results whilst providing ongoing support.

August supervision

CJ challenges me to consider whether I find it easier to treat physical rather than emotional or mental illness? Confronting this I realise a new aspect of myself, I struggle to let go of my own need for certainty. Mishel (1990) states in today's society,
'Uncertainty is feared and accuracy is valued.' (Mishel, 1990, p257)

As a team we relentlessly pursue the diagnosis. By introducing uncertainty to Fred and Penny we undermine how they have been living their lives, but also expose ourselves to feeling vulnerable and out of control. Kralik (2001) discusses that receiving a diagnostic label can be momentous and should not be underestimated, despite the initial feeling of chaos, knowing a cause can make the person feel validated. Without a diagnosis Penny stated she felt invalidated. It put both Penny and Fred in chaos. It is as if carers absorb the suffering of their partner as if their own. Likewise I absorb some of their distress as I had done with Carol and Molly.[53]

I need to resist the trap of glibly reassuring individuals that everything will be all right, such as when I coached Penny through the tests. Cope (2001) describes having thick or thin trust in relationships. Thick trust once established is hard to disrupt whereas thin trust is fragile. He describes five aspects to consider when establishing trust; Truthfulness and honesty; Responsiveness and willingness to share information; Reliability; The willingness to protect, support and encourage others; To have competence and technical knowledge.

My intent is to work towards establishing relationships of thick trust, my success with Penny and Fred is mixed. Whilst I strive to be honest, by pursuing the lumbar puncture without a general anaesthetic, I

[53] Reflective Text 6, p135-137

jeopardise the development of our trust by appearing not to listen and support her. I sit with them sharing information, discussing how they are feeling and clarifying their understanding of the plans. I spend time with them becoming their main link to other team members, but despite this I feel our trust is thin and fragile.

CJ feels I am trying to tune into the concerns of Fred and Penny on their wavelength and flow with them. I give them space to talk and get to know me; because of this I answer the bulk of their questions and experience their emotions, this can include their anger. Being cathartic, exposing their emotions makes me feel emotional, vulnerable and I find it hard to resist absorbing their distress. As my tolerance is stretched I take on their projected anxiety. My coping strategies are challenged. These feelings were eased when I asked Fred to attend the ward rounds, as the team became more aware of their anxiety and started to share in its management. Although I sense even with the disclosure we were not withholding information, as a team we haven't as yet moved far from 'thin' towards 'thick' trust. Individually and as a team we need to continue to build our trust with Penny and Fred.

Mishel (1990) suggests that acknowledging uncertainty can remove a barrier to trust. The neurologist managed to strengthen his communication and trust with Fred and Penny when he labelled the tension they felt as 'uncertainty'. By repeating the neurologist's observation in my subsequent conversations with Fred and Penny I was able to maintain a level of 'guarded alliance' rather than reducing us to a state of 'disenchantment' (Thorne and Robertson 1988) and ineffective communication. Likewise using the idea of uncertainty with the nurses helped them to view Fred and Penny's perspective differently. I now feel able to recognise uncertainty and to dwell more comfortably with it.

Update: Penny has an enzyme deficiency, which can cause a specific dystonia. This could account for some of her symptoms and can be treated by taking dopamine. Importantly her MS nurse has agreed to maintain local support as they continue to make the transition to a new diagnosis.

Reflective text 9: Janice and Ann **Supervision session 17, 18, 19 & 20**

Fearing hospital admission

September 2002

Janice

I have known Janice and her husband Bill for four years, recently her MS has progressed and ITB is no longer effectively reducing her spasticity and spasms. She describes being in constant agony with a deep gnawing pain in her joints, which is intensified every time she is touched or moved. Janice weighs under eight stone but is difficult to position; pressure sores have developed on her sacrum and heels. She gets frustrated with the physical effort of trying to express her needs and no longer shares her quick wit. I miss it in our interactions.

Her whole situation is impacting on her mood making her short tempered, irritable and I sense an increasing tension between her and Bill.

The team have previously discussed the option of IP (Fact sheet 2); Janice has now decided to see if it could be effective.

Pre-admission

I discuss with Bill and Janice what her needs might be whilst in hospital. Bill lists the type of pressure relieving mattress she uses and other management techniques that have been refined with the community team. They feel it is vital she maintains her bowel management regime; she requires alternate day enemas to remain continent. This has been successful for eight months and incontinence is now rare. Bill stresses how he can cope with all of Janice's needs except managing faecal leakage. I assure him I will pass his concerns onto the ward team and we will endeavour to maintain this routine. He agrees to bring in her community care-plan.

September supervision

CJ challenges: How can I be sure? Was I going to be there to monitor her care? How was I going to 'assure him'? Did I mean reassure, could I really do this or was it a glib statement to say something in the short term to make them more confident about the admission? My aim is to reduce the anxiety of people being admitted. However, am I effectively doing this to maintain a trusting relationship? Or am I giving false hope by making promises I cannot keep, potentially raising my own anxiety if their needs are not met?

Reassurance has been defined as an attempt to communicate with people who are anxious, worried or distressed with the intention of inducing them to predict that they are safe or safer than they presently believe or fear (Teasdale 1995). Although when used it can deny individuals the opportunity to express emotions (Balint 1964 cited in Teasdale 1995) or stop the professional from saying the wrong thing (Kirkham 1987 cited in Teasdale 1995) and is usually a matter of the therapist reassuring himself rather than the patient (Sullivan 1954 cited in Teasdale 1995). I was trying to demonstrate to

Janice and Bill that how they managed was important. But who was it important for, me, the ward staff the hospital managers? Probably myself, I was trying to ease my own anxiety that, although I respect their skills and knowledge, this maybe at odds with how they will be viewed in the acute hospital setting.

I was using reassurance as Teasdale (1995) describes but I was not aware that I was doing this to stem my own anxiety. I believed I was using it to make Janice and Bill feel safer and to further the conversation not to stifle it. Rather than stopping myself from saying the wrong thing, I was saying something to demonstrate I was listening; trying to plan and problem solve ways of managing the issues raised. However, I was not explicit about how I could support them through the admission.
I share with CJ one of my journal entries,

> *'They both seem anxious about coming into hospital, but it's usual for people to be apprehensive about an admission. I will try to ease the process by sharing details of her care with the ward nurses.'*

CJ asks whose admission is it and why do I say that people are usually apprehensive?' I realise that by respecting Bill's knowledge of Janice's care, I do view it as 'their' admission. CJ's questioning raises an awareness of my practice that previously I took for granted. In future experiences I will be mindful to explore this and consider whether there is an inherent pattern in how I approach individuals coming into hospital.

Admission

The mattress available on admission is not of a high enough standard to relieve Janice's pressure. It takes 36 hours for a suitable mattress to be fitted. Sharing my irritation of this delay with the ward sister, she states that to order a high-grade pressure-relieving mattress they require a risk assessment (the individuals 'Waterlow score' (Waterlow 1985). Ironically I record this score in outpatients but have never shared it. Doing so will speed up the process of supplying appropriate mattresses in the future.
Bill expresses concern that Janice is being kept in bed for long periods. He states her cognitive impairment is less evident and her moral improves if she sits up for approximately 3 hours a day. A plan to achieve this is agreed between the ward and spasticity team, however it is proving difficult to achieve. Janice's suprapubic catheter blocks, the doctor changes it, but the problem persists. The nurses are reluctant to seek Bill's opinion. When I do, he informs us, 'Oh yes, it normally happens especially if she is lying in bed. It drains better when she sits up.'
Regardless of this information the nurses continue to nurse Janice in bed and need reminding to maintain her bowel regime. I am frustrated that there is resistance to communicate with Bill, and maintain her normal routine.

October supervision

CJ thinks I am again taking a parental role. Rather than negotiating with the family what I hoped the nurses would do, why had I not including the nurses in the discussion so as they could verify what they could do?

I wonder if resources are so restricted that nurses can only practice in a limited way, not enabling them to respond to the specific individual needs of people. They can only react to situations, so are not proactive at trying to replicate successful home care strategies in hospital? Maybe my understanding of complex disability is at odds with what the ward nurses believe?

Journal reflection

I explore my understanding of the meaning of chronic illness.

- Disease is a condition of the body that causes symptoms that may or may not require treatment.
- Illness is when the disease process hits a crisis and requires medical, nursing and or therapy intervention to sustain life.
- Chronic illness is a life long disease process that can change over time and may need a series of adaptations or treatments to cope and manage new or existing symptoms.
- Wellness is a successful management of symptoms to enable the individual to fulfil a chosen lifestyle or ease their approach to death and dying.

From this, my definition of illness is very narrow and I believe individuals with chronic illness can be in hospital for input to improve the management of their symptoms but I would not class them as ill. However, for nurses based on acute wards, I think their dominant belief is people are only admitted to hospital because they have reached an acute illness crisis, which requires a full review of their care. I view Janice as 'well' but with symptoms to manage, whereas I think the nurses view her as acutely ill. True, the intrathecal treatments have risks, necessitating an in-patient stay but other effective management techniques that have taken targeted effort and time to perfect such as her bowel management need not be abandoned.

What is my role? I need to explore how I can be more interactive with the ward team to ease a person's transition in, through and out of hospital.

October pump clinic

Present: Tom, the neurology registrar and myself

Ann

Ann has used ITB for 5 years, she chats to Tom as I perform telemetry; I find her pump battery is depleting. I share with Ann and her husband Ray that we need to plan a hospital admission for a pump replacement. Ann ceases to talk; a fearful look spreads across her face, she exudes anxiety that in the silence feels palpable.

It triggers memories of Janice.

I immediately try to understand her fear and ask her to describe what is wrong. She replies, 'Do I need to stay, can't it be done as an outpatient?'

I ask, 'What's the problem with being admitted?' She grimaces, collects herself and states,

'It's 5 years since my last admission; I will be unable to use a call bell.'

I reassure, 'We could look at where to position you on the ward, perhaps near to the nurses' desk, and I can explore the use of a call button that you can switch on by turning your head.'

Still her look of fear persists. She is an overweight lady with unpredictable spasms she will require skilful moving and handling to promote safety of all involved. At home her husband lifts her. I wonder if she is worried about being hoisted. She responds, 'Oh no, I know that they will need to hoist me'.

She went on: 'I am afraid of the nights the most. Normally I have to get up once a night to go to the toilet.'

I respond, 'That will be Ok the nurse will not mind helping you to the toilet.'

She looks unconvinced. I pick up this cue, 'You still look concerned?'

She replies, 'Well yes, because often in the night I need to be moved...you know every two to three hours.'

'That's fine; the nurses will be keen to assist you.'

She then shares how she has never had pressure sores. I state, 'We'll try to prevent that at all costs.'

Still she looks anxious, 'It's something else isn't it?'

She replies, 'It's getting out in the night to use the toilet, I am so afraid they will say I will have to have a catheter. It's the one thing that I have held onto in all of this, my bladder control and the last thing Ray and I want is a catheter.'

At last I reveal her core concern I emphasise, 'Having a catheter is your choice. You will not be forced to have one.'

I feel uncomfortable using 'force' such a strong sounding word, but it cuts into the tense atmosphere and Ann visibly starts to relax.

I ask what has prompted this deep concern. Ann recounts how in a previous admission an indwelling catheter had been suggested.

So this is a learnt fear from previous experiences rather than an imagined one. From the ward nurses perspective I can see how a difficult toilet transfer may trigger the nurse to consider the effort and safety for Ray, leading to a review of management options and a catheter being suggested.

I suggest I act as a link between her and the nurses, and if she feels unable to deal with issues we can discuss and problem solve them together. We agree to speak in a week to finalise the plans. She seems relatively calm as she leaves.

A few days later

It's Friday and five o'clock when the bed-manager telephones,

'Is it appropriate to call Ann and ask her to come in at short notice over the weekend?'

Although her pump needs replacing and can stop at any time I don't think she is psychologically prepared to come in. However, today in the NHS with restricted resources available beds are scarce; turning a bed down is uncommon. Despite my explanations this was met with slight disbelief from the bed-manager who thinks she is doing me a favour. She threatens, 'Missing this opportunity could delay her admission...'

With no objective evidence I risk stating, 'I understand but I believe if we rush Ann's admission we will extend her duration of stay.'

Thankfully the risk paid off, predicting an extended length of stay changed the manager's attitude, and I negotiate an admission date for six days later.

November supervision

CJ challenges why did I think I didn't have any 'objective evidence'; was I looking for empirical evidence? Was my knowledge of knowing the person not good enough? Indeed, it had given me the confidence too refuse the bed but also to negotiate an action plan for six days later, which was not normal practice. I realise knowing Ann empowered me to prioritise her anxiety management above the risk of her mechanical treatment failing, whilst knowing that if things did start to physically go wrong we had a relatively short time before being able to admit her. I was able to see the person not just the technology.

Outcome

The following week I telephone Ann. She has no further issues. We confirm how best to manage her admission.

All goes to plan, her needs were met overnight, a urinary catheter was not suggested, her pump was replaced and she was discharged within four days. I ask her if we could have improved the process. She thought long and hard, 'There really was nothing more you or the hospital could have done everything went so smoothly, the rest had to come from me.'

I ask her to explain, 'I had to prepare myself that things would be different to home. I made adaptations, I know nobody else can position me as comfortably, quickly and easily as Ray, I changed my sleep position so as someone didn't have to try.'

I fed Ann's comments back to the team including the bed-manager they agreed it had been very successful. Ann illustrated to me that effective health care has to occur in partnership with all those involved. Each person has a unique role and is interdependent on each other to achieve the overall aim of working together towards shared success.

December supervision

Precarious harmony

Bury (1982) from his research interviewing people on their experience of living with rheumatoid arthritis, describes chronic illness as a disruption to the structures of everyday life where individuals are required to rethink their own biography and concept of self and how they use the resources available to them. Musing in my journal, I consider how people represented to date in my texts actually live day to day with their complex disabilities. I write,

> *'It feels as if people with complex disabilities live teetering on a precipice of coping or not with their daily needs. Yet through a detailed routine, which varies very little they establish a harmonious lifestyle that works for the individual and their family. Although what is particularly striking is that even the smallest variation in routine can lead to an imbalance, a breakdown in their lifestyle equilibrium, which can take months to restore.'*

Such small variations in routine can occur in hospital and can lead to unwanted legacies long after discharge home, such as Janice being kept in bed potentially causing ongoing bladder and bowel

management difficulties. As CJ and I discuss the above journal entry we label this issue as people living in a 'precarious harmony'.

CJ asks me to reconsider text 5[54] and whether the precarious control I have over my work is a parallel process to the 'precarious harmony' I feel people living with chronic illnesses experience? I can see similarities; firstly applying a framework such as the decision corridor helps me to define what I need to do, similarly people with complex needs devise a structure to their daily lives to ensure their needs are met. The skill is to apply these frameworks loosely so as issues that can make situations 'precarious' can be managed. For instance I need to 'flow with pressure' and support people with spasticity to minimise lasting effects on their 'precarious harmony'; being mindful that such states of flux maybe opportunities for growth for us individually and as we work together.
In trying to support people with complex needs in the hospital setting I am living the tension of moving between advocacy and paternalism,[55] it is hard to enable people with disabilities to be in control within acute care. Kralik (2002) analysed the narratives of 81 midlife women living with a chronic illness, she describes different transitions in their lives as they strive to incorporate illness. A quest for ordinariness was interpreted from the women's stories. Ordinariness was described as:

> 'Reconstructing life with illness' this entailed trying to find a place for illness to fit into their lives. They achieved this by taking calculated risks, surrendering security, making choices and forcing the boundaries that illness had imposed on their lives' (Kralik, 2002, 151).

Reading this helped me to reflect on the way Ann and Ray strove for 'ordinariness' in their lives; in particular how they carried out transfers and wanted to maintain their method of managing her bladder. This quest for ordinariness was also evident with Janice, for instance when Bill requested that she sat out for 3-4 hours each day and that we followed her bowel regime.
Maintaining ordinariness resonates with my description of precarious harmony, a person establishes a framework to live their life. However, a person's precarious harmony can be easily disrupted such as attending a hospital.
Whilst I realise a hospital admission may be significant for most people, this is particularly so if you have complex needs and often the impact is as big for the carer who may take the lead in trying to negotiate care.

Reflecting further on Janice and Ann's care, I muse – do nurses only pay lip service to individualised care or is it just asking too much within the resources available? I am aware nurses are increasingly coming from differing countries and cultures, with widely different nursing experiences and training. At times it is hard for them to grasp the nuances of the UK acute model of care. I then challenge that norm and ask them to look at care in a different way. I wonder if I can do more to effectively manage the unique needs of individuals with chronic illness coming into hospital?
After exploring several options I decide to arrange a teaching session.

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[54] Pages 131-134
[55] Reflective texts: 1, p107-111; 2, p112-119

January 2003

Today with a neurology ward sister I jointly facilitated a teaching session to explore tensions between acute and chronic illness models of care. Nurses attended from across neurosciences. They were able to articulate differences between the models and appreciate difficulties for people with chronic illness coming into an acute environment and the importance of listening to their families and carers about their care needs.

One nurse insightfully shared the pressures facing people with chronic illness. She used an example from her practice, which clearly demonstrated skill at negotiation. A patient wanted to use the commode but didn't want to be hoisted. It was not safe to move or transfer him any other way. The nurse explained this to him and gave him the options of hoisting or using a bedpan. When he couldn't decide she didn't pressurise him, giving him time to consider the options; he chose the bedpan. This gave him choice and an element of control. Although it could be argued he was pressurised by needing to go to the toilet, she felt from that moment of negotiation, they worked well together during his admission. I used this example to illustrate differences in power between health care professions and patients, and how if we work to balance power it can impact positively on current and subsequent interactions. The nurses related to their colleague's story. Perhaps if I had used one of my experiences it may have appeared remote from their practice and so the messages may not have been as effectively understood.

The nurses discussed feeling time pressured when a person with complex needs is due to be admitted. To manage this, common practice within the group is to negotiate with the bed-manager a delay in the admission, ideally to the next shift. This appears to a subtle version of what Johnson and Webb (1995) describe as social judgement. Nurses label patients and this effects how they are perceived by colleagues, in the situation described above the judgements begin before the patient is on the ward. From the outset the individual will need to battle against a negative stereotype, something that is claimed difficult to do (Johnson and Webb 1995).
I ask if the session will alter their practice. Some reply and others nod agreement that, it had made them think and would impact on how they next approached an admission of a person with a chronic illness but a nagging doubt haunted me – would they? I need to continue to reflect on these issues to see if other strategies maybe useful.
Listening, I am mindful of clarifying and shifting my own perspectives or chipping away at my embodied responses. Kieffer (1984) discusses that to become empowered requires,

> '... a continuing internal 'constructive dialogue' or the maintenance of the creative force of internal contradiction' (Kieffer, 1984, p.25).

Through supervision I am able to continue to explore my embodied contradictions continuing my quest toward desirable practice and my vision. Guided reflection has helped me appreciate the tensions that surround bringing people with complex needs into hospital not just for them and their family, but also the staff involved.

Rag Doll

February 2003:

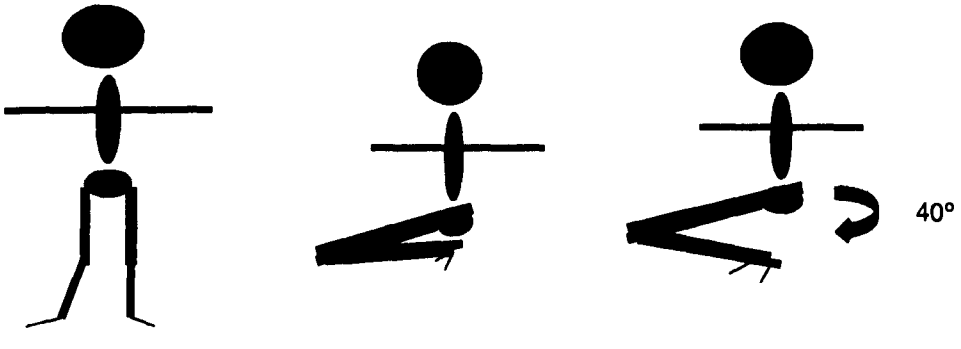
Journal entry

Jay has waited six months to be admitted for IP. Delays occur because there is only one doctor in the hospital who is prepared and has the skill to do this destructive treatment (Fact sheet 4). I appreciate that doctors are reluctant to learn this skill as it destroys nerves and is non-reversible. Nevertheless I wonder if this treatment is also viewed as unimportant and given low priority, because it's labour and time intensive to perform and consent is difficult or is unable to be obtained. Individuals are often passive recipients, restricted by their disabilities to speak out. My role is to educate but also to negotiate and support them through the hospital system, if necessary 'getting their voices heard' and their treatments given, acknowledging and respecting their autonomy in tune with my holistic vision.[56] I feel that with Jay, as with Simon, Pete and Penny, I traverse the advocacy – paternalism continuum.[57]

Admission day

As I walk to the ward my excitement is tinged with trepidation, would Jay's multiple sclerosis and spasticity have deteriorated since the clinic six months ago? We have shared several phone calls; I know she is desperate to have the treatment so as when her two young sons visit her in the nursing home they can once again sit safely on her lap.

She looks more contracted. In a lying position her lower limbs are flexed, adducted and rotated to the right. Her knees are bent as far as possible up towards her body with her heels touching her bottom. From this position I can passively straighten her legs approximately forty degrees, however strong frequent flexor spasms take her heels right back to the starting position, resting by her bottom (Figure 3.10.0).



Diagrammatic representation of a person lying in supine

Jay's supine position

Extent of passive movement

Figure 3.10.0: Jay's position

[56] Figure 1.7, p 44

[57] Reflective texts: 1 and 2 specifically pages: 110, 160.

Possibly as a result of her spasticity and spasms, but certainly aggravating her situation, she has two large grade 3 pressure sores, one on each buttock and a third on the inner aspect of her right ankle where her skin is often in contact or friction. The pressure sores are deep, infected and difficult to dress. She looks very thin and dehydrated; her urine output is low and concentrated. She admits to having drunk and eaten little over the previous 24 hours.

This severity of disability can provoke anxiety in a team. I know in the past I would have questioned whether a person such as Jay is receiving adequate care and would have attempted to address all her needs in one admission. I now realise this is quite an arrogant attitude and an unrealistic aim as a hospital stay is but a snapshot in the life of someone with a chronic illness.

Jay's admission will be no longer than five days and because she fatigues easily, I am keen that we prioritise her available energy to discuss IP. The ward nurses and dietician disagree and feel we should prioritise her poor nutritional state and potential need for a PEG. I discuss with the spasticity and ward teams the need to remain focused on what we can change in the time available and to provide advice on other issues. We agree to seek advice from a tissue viability specialist nurse and to raise the idea with Jay and her community team of improving her nutritional status, but our focus is to use our expertise to more effectively manage her spasticity. Prioritising care in this way is never easy but later our decision is ratified when the dietician discovers from the community team that they have been negotiating the need for a PEG with Jay for quite some time.

Discussing IP

I ask Jay what she hopes IP will do for her. She replies, 'To make my legs straight, enable me to stand and if I am really lucky take a few steps.'
I am confused and wonder how she has developed these ideas. We have previously discussed that the aims are to improve her wheelchair comfort, posture and to ease lower half washing and dressing for both her and her carers. I gingerly query, 'Do you really think IP will help you to stand and straighten your legs?
'Yes.'
Perplexed I ponder if she really knows what IP will do? Is my honesty being tested as Pete had done? I confront her,
'Jay the treatment will not help you stand, transfer or walk.'
She averts her gaze and doesn't reply I leave the silence.
'Jay how do you feel?'
'Disappointed.'
'Do you remember what we talked about when we first met?'
'Yes but I still thought I would be able to have straight legs and stand.'

I reiterate what the injection will not do. I am conscious of saying my words starkly I need to be clear and precise. I want her to understand and have no scope for interpreting false hope. Yet my words feel harsh, cold and I am aware of extinguishing a great deal of hope.

Does my body language show these thoughts? For she looks at me with a huge beautiful smile and mischievously says, 'Bit of a NO person aren't you?'
I smile, 'I guess so, I just want to be sure you are aware what will happen with this injection, shall we move on to discuss what it can do?'

As I walk away I compare our conversation to my work with Pete, I know the importance of being honest and clear about treatment aims. I know I had to confront her with realistic expectations, for only then can we work and flow in tune with each other.

Next day: Family involvement

Jay is divorced and her parents are her next of kin. Jay's father is a taxi driver and snatch's hospital visits between fares. Today he greets Jay 'Hi love, make sure you get this injection so as we can get you back on your feet again.'
Jay rolls her eyes and says 'Lou, tell him, will you, about the treatment.'
I reiterate the aims, he replies, 'But we thought she would stand and perhaps then with hard work take a few steps.'

He looks bewildered as I gently disintegrate his illusion.

Journal reflection

I ponder how information regarding IP had infiltrated Jay's care team and family. A senior nurse from the nursing home had accompanied Jay to the spasticity clinic, but Jay has since moved to another nursing home. After the clinic at Jay's request I had discussed IP and our treatment aims with her mum over the telephone, she had asked pertinent questions and seemed to understand my explanations.

Nevertheless I realise that information about the treatment and outcome of IP would have been passed through various care workers and family members. As treatment with IP is uncommon its aims and limitations would not necessarily be easy to communicate. It is possible the potential outcome of IP for Jay has become distorted leading to unrealistic hopes. Perhaps what occurred, resembles what happens to a message in the game 'Chinese Whispers', the starting statement bears no resemblance to the end statement after it has been verbally communicated through a series of people?
I could have improved the situation by contacting the new nursing home, to ensure they were aware of the aims of the pending treatment.

Trial

The trial is successful and Jay decides to proceed. The registrar comments that Jay has marked cognitive impairment that limits her understanding. I share how with repetition and time she is able to participate in making decisions. Jarred by his comment I want to see if Jay can verbalise what the

plan is, but I want to do this sensitively and not by direct questioning. I ask her if she is happy with what we are planning to do – she smiles and details the aims.

Treatment day

Last night Jay's aunty visited, she was angry and aggressive towards the nurses, shouting she didn't understand why the injection was no longer going to straighten her nieces' legs. The ward nurses had not found it easy to communicate with her. I explain there is a misunderstanding between the team and the family as to the possible goals. I ask Jay what she would like me to do; did she want me to speak to her family? She rolls her eyes upwards, starts to laugh and shake her head.
'Lou don't worry don't do anything! They do know my legs will not straighten, I have told them enough times. They shout because they feel bad about my situation.'

She went onto describe how her family communicate with each other through her, 'I am their linchpin. I managed to get a loan for my sister from my dad and they don't even speak! Sometimes it's difficult to escape all the family politics, often I close my eyes and pretend to be asleep.'
I reflect back to her how people including health care professionals can assume she is not engaged in what is going on around her. She smiles and states,
'I know... but sometimes I just need them to stop... and to go away. I need to escape.'
I am moved by Jay's ingenuity to escape situations that she can no longer walk or wheel away from. Newman also noticed this in her work and suggests,

> 'Few of us stop to consider the control that movement affords us, to approach and withdraw as we please.' (Newman, 1999, p60).

To remain in control, Jay acts asleep, but at a cost of appearing distracted perhaps even cognitively impaired. I consider how easy it is to label people as cognitively impaired. I am jolted from my thoughts as Jay's nurse that morning shouts across the ward 'Lou I need a word with you before you go.'
I am surprised at her manner, as I turn back to Jay she has a huge smile on her face and confidently says, 'I know what that's about – I won't wash!'
I smile back, 'Ah and the nurses are challenged by that because it's out of their routine?'
Seemingly determined to demonstrate her comprehension she replies, 'Yes exactly but as I said to them if my legs are going to be easier to handle after the injection I would rather wait until I have had it done.'
I laugh, 'Seems logical!'
I sense she feels uneasy, I gently probe, 'Jay is there something else?'
'Not really.'
She falls silent I keep my silence. Eventually and obviously irritated she says, 'But when they walk towards you with a bowl of water and say they are going to wash you, without even asking if they can. I feel this enormous 'NO' welling up inside me and I become very strong and determined. How dare they think they can just do that to me, I am not stupid!'

'I know you are not stupid.' I reflect her statement back in an effort to show her I'm listening and that I see her as a person, not an object or thing without feelings and needs.
She continues, 'There is no way she is going to treat me like a rag doll!'

The use of the term rag doll is powerful, but in my eyes appears contradictory to her situation, a rag doll gives the image of being floppy and easy to toss about. Whereas other than being small Jay is very stiff and difficult to move or turn over.
I ask Jay if she would like me to speak to the nurse. 'No I can handle her – I can say NO louder and louder if I need to.'
I reply, 'You appear very strong at handling what must be quite a difficult situation.'
'I'm used to it living in a home.'
She continues thoughtfully, 'Although it is different there you have to live with them as well, not just be with them for a short time, it's a bit harder to shout.'

My paternalism for this vulnerable woman is offset by her confidence in fighting her own corner, but my frustration at the ward staff lingers. I need to let go of taking responsibility for Jay. Her voice is louder than mine.

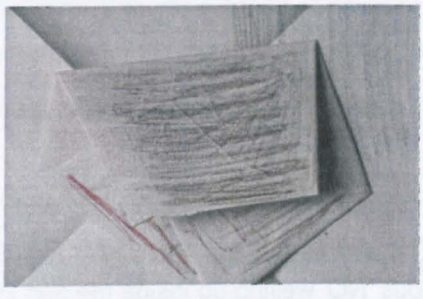
Workshop: 'Mindful inquiry – A Research Methodology' facilitated by CJ.

The group were asked to individually represent an incident in art form. I felt uneasy, not sure what to do and confused at how this may impact on my practice. As I noticed others engaging in the process seemingly unperturbed, I grabbed some pencils and paper and retreated to a corner of the room. CJ directed us to think of a recent incident; Jay's story inspired my following work.

I begin by drawing a series of dark circle enclosing each other; this represents the clinic or hospital as a rigid, inflexible and controlling structure.



Separately I irregularly fold a piece of paper; the edges form strong dark lines. I colour the centre brown and black.
This represents the stiff limbs of a person with spasticity, inflexible, angular and often folded over each other.



This folded piece of paper placed on the circle is enclosed by it, representing the restrictions on a person coming into hospital.

Around the dark circle I drew lines of orange, yellow and red radiating out. This represents the person's personality and individuality, which emerges as I work to negotiate care and treatment options with them.

Gradually I open the folded piece of paper to reveal softer torn edges and the same warm yellows, oranges and reds in the centre.

Once fully opened it transcends out beyond the circle completely covering it. Representing how people with spasticity, however disabled, can influence way beyond the hospital and clinic.

The torn edges represent looking beyond the stiff, bent body to see the person. The warm colours portray the person's strength, determination and beauty as opposed to the strong dark colours of the clinic or hospital.

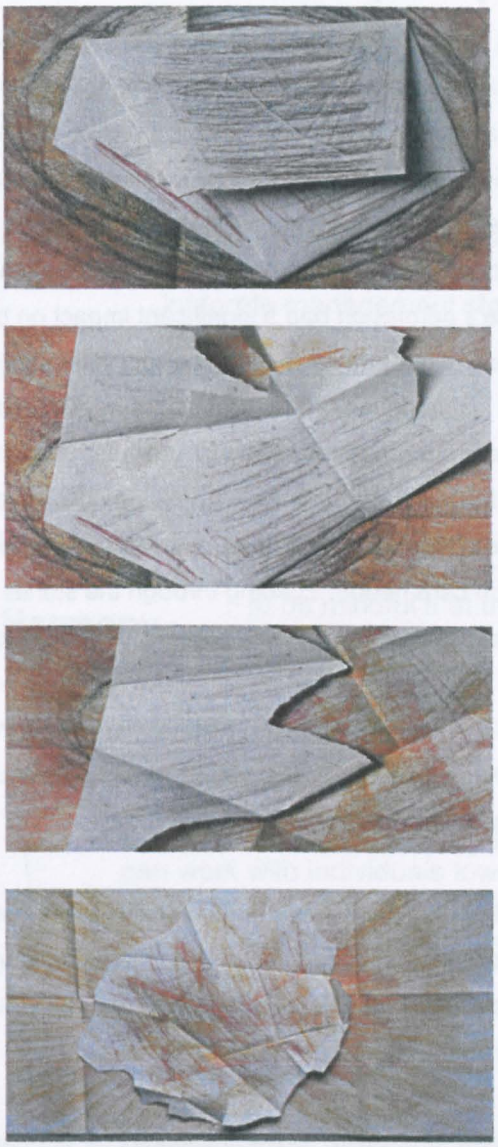


Figure 3.10.1 Unfolding art

I like the fact the picture requires action you cannot just look at it and grasp the meaning. It needs to unfold in front of your eyes, much as getting to know someone requires time, effort and determination to appreciate who they are and how they have chosen to live their life. The final open image represents the benefit of seeing the person, appreciating their pattern rather than just their disability.

Despite my initial reticence, I found participating in this workshop stimulating and enjoyable. I was surprised at how keen I was to share my work with the rest of the group. Expressing my thoughts in this way was liberating, I was not constrained or inhibited like I can feel when having to express myself in writing.

2nd Analytical pause

My insights from the previous four texts are summarised in figure AP2.0. In the main they show my deepening awareness of the impact of living with spasticity and its associated complex disability for the person and their family, and how I can strive to smooth the flow of their journeys through hospital. The most significant insight is that people with complex disabilities fear coming into hospital and their carers can absorb the person's suffering as their own. A hospital visit or admission can be as significant for the carer as the person with spasticity, or in some situations be more traumatic for the carer. Janice's admission had a significant impact on both her and her husband Bill. Conway (1996) reported from a literature review that people with physical disabilities worry about being admitted to hospital not just because of their illness but how their disability is going to be managed such as access to bathroom facilities, who will carry out their care needs and will they be proficient in doing so. Adding further support to this, Buzio and colleagues (2002) found that 31 adults with cerebral palsy reported their needs were not met whilst in hospital and they felt the nurses lacked basic knowledge on care needs. Echoing through the stories of Penny, Janice and Ann are their fears that relate to coming into or being in hospital and lack of expert support to meet their care needs.

Conway (1996) recommends the importance of encouraging the person's autonomy and allowing them to participate as much as possible in decision making. These threads were picked up in the teaching session I did with the ward sister.[58]

Conway (1996) also highlights that 'medicalising' symptoms can add to the trauma of being in hospital. This was highlighted in Janice's situation where the nurses wanted to nurse her in bed rather than sit her out and with Ann where she feared she would be forced to have a urinary catheter to limit the transfers she required.

As part of a new strategy to develop services for people with disabilities in Oxfordshire, Davis and Marsden (2001) carried out an action research study to evaluate a new specialist nursing role, to support people with disabilities in an acute hospital setting. They found that people with disabilities received an inferior service to people without disabilities. Reasons for this included lack of disability awareness amongst all grades of staff, lack of resources and unsuitable environments for people with disabilities to function in. They concluded that the needs of disabled people were not met in hospital and that people feared admission. Carers reported not being listened to and that they felt their experience was not valued, until a care need presented itself that the nurse did not want to do such as continence management. Following implementation of the new specialist nursing role, people were reassured and their anxieties were reduced, equipment was provided in a more timely way and staff awareness was improved through training and support from the specialist nurse.

[58] Reflective text 9, p161

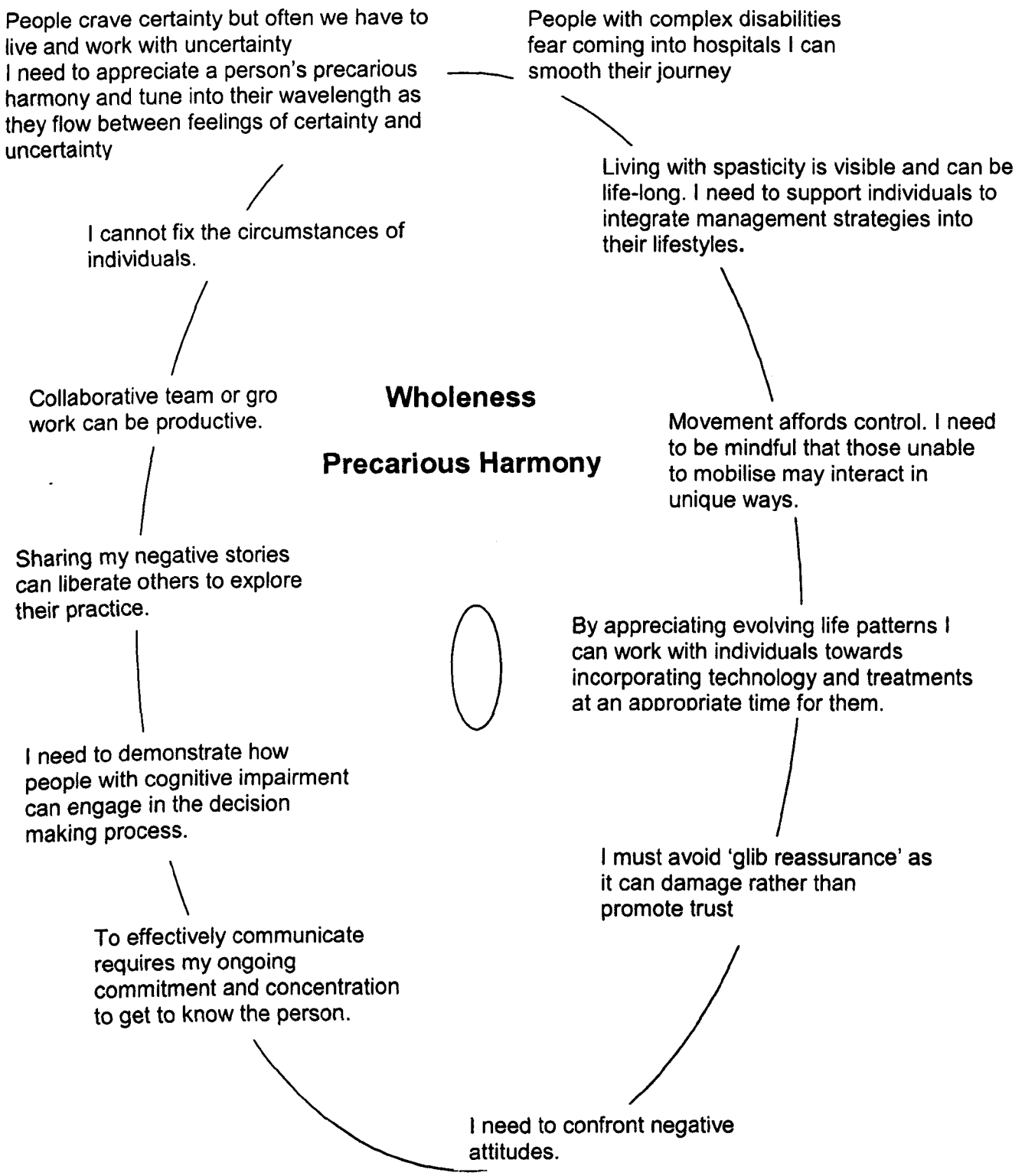


Figure AP2.0: Insights from texts 1-10

I can see similarities in the outcomes of this specialist role and the important issues evolving in my role. I view one significant aspect of my own role is to minimise the anxieties of people being admitted to hospital, to smooth their hospital journeys, much as I tried to do with Penny[59] and Janice and finally achieved with Ann.[60]

Other key issues include the need to raise awareness of the needs of people with disabilities and the value of their carer's experience and skills through teaching,[61] leadership[62] and role modelling. [57, 58] By considering my insights and reflecting on the turmoil that coming into hospital can create for a person with spasticity, their families and carers, I feel my description of individual lives being in harmony, but precarious, easily tipped by seemingly small events is strengthening. I feel tuning into the nature of this 'precarious harmony' is becoming a vital aspect of my practice.

Towards a deeper insight of living with spasticity

Precarious and Harmony

Precarious can be defined as not securely held or not in position, dependent on chance and uncertainty.

Harmony can be related to music or defined as the quality of forming a pleasing and consistent whole or an agreement or concord. (http://www.askoxford.com/concise_oed - accessed 9/2/09)

In a concept analysis Easley (2007) describes harmony as an integral part of effective communication and positive relations. Its defining attributes are peace, balance and rhythm. To occur it requires time, a receptive environment and objects to intertwine or come together (Easley 2007).

Precarious harmony

I use 'precarious harmony' to describe a matrix of highly refined strategies, unique to each person with a complex disability and their family, which allows them to effectively function as a family unit. The family unit 'intertwine' in a 'receptive environment', their home, and develop a 'rhythm' to their lives.

Such a matrix is fragile, not secure and is often jeopardised by the smallest of variation, for instance when a person is admitted to or even just visits a hospital.

Easley (2007) states that;

'Harmony is a term we usually associate with music. I take the position that harmony is an unspoken intricate detail that is directly unobservable and most often lost within the interpretation of many clinical situations that have a direct impact on patient care.' (p 552)

This resonates with my idea that a person's precarious harmony largely goes unnoticed even when nursing interventions have jeopardised it. For instance the precarious harmony of Janice was put at

[59] Reflective text 8 p150-154
[60] Reflective text 9 p157-161
[61] Reflective text 7 p146-149
[62] Reflective text 7 p146-149 and 9 p155-161

risk when the nurses insisted on nursing her in bed because her catheter kept blocking even though Bill her husband shared that this often occurs when she is in lying and that to promote urinary drainage it is best to sit her in her wheelchair. His concern was not just rooted in the short term care of Janice but how it may impact on care after she went home.

Ann didn't want a catheter as she was concerned it could affect how she and her husband integrated her bladder management into their rhythm of their lives.

From these insights I suggest that knowing a person, their family and appreciating the environment they inhabit requires appreciating their precarious harmony. Precarious harmony defines the work of their living space and is part of their overall life pattern. This is vital information when supporting and guiding people to consider the best ways to manage their spasticity.

Lowe (2002) when describing aspects of Native American culture on nursing states,

'Harmony is a state of inner peace and contentment that results from being in balance in all areas of living. To the Native American, the eagle is viewed as a role model of harmony. As the eagle spreads its wings and soars across the sky, it is perceived to be in harmony with the creation /universe. The eagle does not fight against natural elements such as strong winds; rather, it soars with the natural flow of life and events.' (Lowe, 2002, p.6)

Linking this analogy to appreciate a person's precarious harmony, I believe it is important for nurses and other health care professionals to tune into a person's precarious harmony (to flow with the eagle's flight path), not trying to impose their own beliefs or values, or suggesting interventions or imposing organisational rules, traditions or beliefs without considering the impact (divert it off course), but to flow with the person as they engage in their life journey and make choices (soar with the natural flow of life and events).

Appreciating precarious harmony and sculpting the practice space

My intent is to understand the wholeness of the person and their family (as far as this is possible) and to appreciate their precarious harmony. This seems vital to effective spasticity nursing. Looking at photographs I took when visiting Barbara Hepworth's garden in St Ives some years ago I remember that when I approach, touch and observe Hepworth's pierced sculptures, I do so from different angles giving me a sense of the whole, but also a feeling of engagement as I share the sculptural space. I sense that Hepworth captures the wholeness of something and yet depicts the fragility of the wholeness within it.

Integrating family

Viewing 'The family of man' (Figure AP2.1), a Hepworth sculptural composition, challenges me to not only focus on the individual's space but also how family members integrate into the space.



'Family is a universal survey of humanity, but also a personal history. The sculptures become symbolically more sophisticated in composition as they mature, from Young Girl and Youth at the bottom of the hill, to Bride and Groom, Parent I, Parent II, Ancestor I, Ancestor II and the Ultimate Form.'
(Pheby and Lilley, 2005, Hillside Zone, p1):

Photographed April 2006: Yorkshire Sculpture Park

Figure AP2.1: The family of Man.

Sculpting the therapeutic practice space

When sculpting the practice space, I position myself to appreciate how different aspects of the person's lifestyle mesh together. I seek to understand their life pattern, and how this influences their precarious harmony and could impact on the smooth transition to use particular interventions.
I tune into the person's and their family's precarious harmony. I look beyond the surface of what I see or what they publicly share, in relation to managing their spasticity I need to ascertain their inner thoughts and wishes. This requires shared honesty, trust and intimacy.

My previous texts demonstrate the challenge of appreciating a person's precarious harmony and shaping our therapeutic space. With Jay[63] I felt we did work together to shape our practice space, but with Sid and Penny[64], differing views and the presence of uncertainty influenced their precarious harmony and were barriers to developing our relationship. Once 'uncertainty' was recognised, in particular with Penny, it enabled a more collaborative shaping of space.

Similarly professional interactions influence the therapeutic space. For a person to successfully integrate ways to manage their spasticity requires professional liaison across care sectors, between different health and social care team members. As I dialogue with others, we share the intent to engage in caring, the shape of our space is determined and evolves; we shape our space. We are metaphorically in the midst of jointly carving a sculptural form, influencing and creating the therapeutic space.
The following texts look at my interaction with other health care professionals, nurses in particular, and how this impacts on a person's precarious harmony and our practice space.

[63] Reflective text10, p161-166
[64] Reflective text 8, p150-154

'You can miss so much when you just concentrate on the physical aspects.'

July 2003

Tina: Measuring Spasticity

Tina has recently recovered from an MS relapse, her fourth since being diagnosed five years ago; she has been admitted to consider the possibility of an ITB trial. I have arranged to meet Tina and her husband Leon to assess and measure Tina's severe lower limb spasticity. As I walk to the ward with Kay a physiotherapist, the new medical registrar joins us; he is keen to learn how we measure spasticity.

We ask Tina to describe a typical day and how her spasticity and spasms make an impact.
'Oh my legs are heavy all of the time; I can't do any activity without thinking about how to move them. Then the spasms, they just happen, no warning, my legs just shoot out. It's so uncomfortable and well, very embarrassing.'

Kay and I stand either side of Tina lying on her bed, alternately we start to passively move her legs, and on extreme stretch we elicit severe extensor spasms. Kay and I agree her legs feel stiff, but it's mild,[65] predominantly we can feel weakness.
I ask Tina if she can isolate a main problem, she immediately answers,
'Oh it's the pain, but my difficulty with walking is a close second.'
I discuss that ITB could ease her pain and reduce her spasticity and spasms however without the stiffness and with her existing weakness it was possible her walking could deteriorate.
Throughout our interaction, Leon has stood at the end of the bed with a furrowed brow and his arms crossed, intently observing our actions but saying little. Suddenly he bursts into the conversation, 'But really the mobility is the issue I mean it has deteriorated markedly in the last two years. She looks so different. I mean she used to be able to walk up the hill to our holiday home now she can hardly get out of the house.'
I sense he is struggling to accept Tina's increasing weakness, mobility problems and her changing image. As we finish the measures, their angst seeps around us like a dense morning mist. I suspect they are hunting for one single treatment to solve all the problems multiple sclerosis is throwing at them. The tense atmosphere increases as the futility of their search dawns on them.

Unease

As we leave the ward I share with the team that something during the assessment has made me feel uneasy but I can't quite put my finger on it. They ask me to explain,

[65] Ashworth grade 1 – protocol 2

'I am not sure this is the right time to be offering an ITB trial. It will force them to look at Tina's level of ability and to consider the future. We could destabilise their home life and coping mechanisms if we do this before they are ready to face reality. I think they both have, perhaps Leon more than Tina, some psychological adjustments to make.'

I explain how throughout the assessment they only interacted briefly with each other and with us. Leon's body language was very defensive, perhaps scared. I felt they only wanted to hear that ITB would improve Tina's walking. When we did not collude with their wish, they disengaged from us. Perhaps this assessment has already made them confront her disability; that her walking may never improve and they are starting to wrestle with how this will impact on their current and future lives. As a couple they seem distant not united, Leon never moved from the foot of the bed, not even when Tina looked tearful. I get a sense they are struggling to manage their own feelings and do not have the space yet to support each other. I will try and explore these issues with them so as we can provide advice and support in the most effective way.

Kay looks at me incredulously and asks, 'Did you deduce all that from just this assessment?'

I nod, 'Well and from clinic.'

Laughing Kay concludes, 'Gosh, you can miss so much when you just concentrate on the physical aspects.'

I laugh and retort 'I guess so. Perhaps it's nursing.'

The doctor interjects, 'It shows the value of the team approach. I was more interested in learning how you moved her limbs without initiating a spasm.'

August supervision

CJ and I discuss that by paying attention to why I felt uneasy illuminates the complexity of holistic practice; the hidden aspects, reading between the lines, looking for the emotional pulse. As I work with individuals I remain alert for clues to how they maybe managing and coping and what the illness experience means to them. Without knowing this information the team cannot help people successfully select treatments to manage their symptoms. I need to consider how I document the process of gaining this knowledge so as it is accessible to all team members.

Considering again the idea of guarded alliance (Thorne and Robertson 1989),[66] where the degree of trust a person has in a professional interplays with their own perceived competence and can result in one of four styles of interaction; hero worship, team player, consumerism and resignation (Figure 3.11.0). I feel Tina and Leon, like Pete came with high expectations of ITB and our team; they were in the hero worship quadrant. When I discussed what ITB could and could not achieve Tina and Leon expanded their understanding of ITB therapy, but when I particularly stated that ITB would not help Tina walk, this potential outcome did not match their aims, it threatened their precarious harmony.[67] Simultaneously they disengaged from us as a team symbolising a reduction of their trust in us; they

[66] Pages 110, 115, 138, 151, 154, 174-175, 186, 192, 245, 248.
[67] Pages 159-160

moved into the consumerism quadrant, still wanting to shop around in the hope they will yield a remedy (Figure 3.11.0).

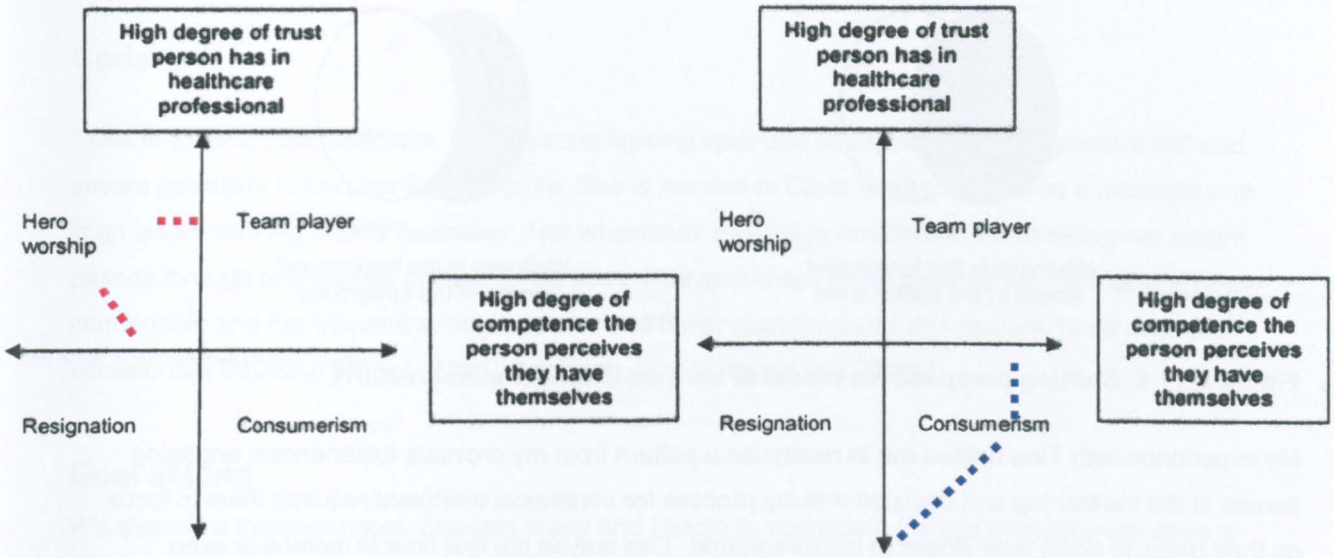


Figure 3.11.0: Model of guarded alliance (Adapted from McGrath, 2001 p77 and Thorne and Robertson 1989) showing change in interactive state.

CJ asks me to consider the doctors response of only wanting to learn how to move a limb, and directs me to the work of Virginia Woolf and I quote,

> 'No delightful as the pastime of measuring may be, it is the most futile of all occupations, and to submit to the decrees of the measurers the most servile of attitudes.' (Woolf,1993 [1929] p.96).

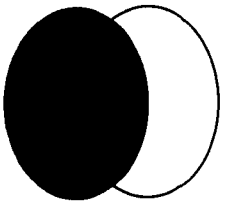
Whilst I teach the doctor how we carry out the measures, provide him with tools or a,

> 'Measuring-rod up his sleeve' (Woolf,1993 [1929] p.96).

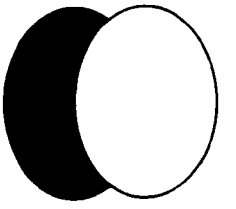
I wonder if we are slaves to measurement, particularly if we only concentrate on certain aspects and do not consider the impact on the different parts of a person's life pattern. I regularly use outcome measures, they are valued by the team in guiding us to select and recommend treatments, but I now realise how a person's limbs are positioned or move is only part of understanding the impact that spasticity and spasms can have not just on the person but also their family members. Paterson (2001) describes that people with chronic illness can live with either illness in the foreground and wellness in the background or vice versa (Figure 3.11.1).

Some people successfully merge their disability into their daily lives, it does not dominate, they live with wellness in the foreground, whereas for other people their symptoms and underlying impairments can be a focus of how they choose to lead their lives and they live with illness (disability) in the foreground (Paterson 2001). The nature of measurement means we try and quantify what we see, we make a value judgement both subjectively and objectively. This can trigger individual's to focus on

how their body is changing, this can be a threat to how they have envisaged or constructed themselves within the context of their illness (Charmaz, 1983: Kralik, 2002).



Wellness in the foreground
Illness in the background



Wellness in the background
Illness in the foreground

Figure 3.11.1: Shifting perspectives model of chronic illness (Paterson 2001).

My experience with Tina helped me to recognise a pattern from my previous experiences; engaging people in the measuring and decision-making process for intrathecal treatment requires them to focus on their body, to bring their illness to the foreground. This maybe the first time in months or even years that they have objectively viewed themselves. It is not always a positive experience as they may have chosen to ignore how their deteriorating condition was really impacting on their bodies and daily life, or in other words living with illness in the background. Conversely Tina was living with illness in the foreground, seeking treatments to minimise her symptoms. She was keen to be involved in the measurement process, but became dejected when she realised that ITB would not help.

As well as a physical judgement of someone's spasticity and spasms, the process of measurement can provide the opportunity to appreciate how an individual and their families approach living with a disability and whether it is a suitable time to be introducing an invasive treatment. With Tina and Leon, I felt the experience of an ITB trial at this stage, when they were not ready to accept a reduction in her pain at the expense of her walking, could have prevented them from considering it in the future. I was keen to preserve its potential as in the long term it may be a suitable treatment to manage her symptoms. From past experience such as I share in Pete's story,[68] I know the timing of introducing ITB is crucial to its ongoing success and acceptance as a long-term management strategy.
I need to continue to reflect on the process of measurement, what it is like for a person to be measured and my role in the process; holding these issues as tentative insights that require further consideration in my future experiences.

[68] Reflective text 2, p112-119

Steering a racehorse

August 2003

Carla

Carla is 31 years old, vivacious, with a strong fighting spirit and does not let her progressive MS and severe spasticity restrict her fully living life. She is married to Dave, works full time as a manager and is an award winning charity fundraiser. Her wheelchair posture is windswept; when sitting her weight passes through one buttock and her lower body, hips and knees spiral towards the right. She is rarely comfortable and her frequent strong extensor and flexor spasms cause this position to be unstable, occasionally thrusting her out of her wheelchair. She is having an ITB trial.

Goal setting

We discuss a treatment goal. She lists many and I begin to appreciate Carla's management drive to isolate and solve problems. I share with her my previous experience of working with individuals who had long goal lists, particularly how they became disillusioned with the work involved in maintaining ITB therapy when it didn't meet their expectations. I ask her to focus on one goal, which would make a difference to her daily life. We narrow her goal, to be able to put on her shoes and socks independently. Achieving this will relieve her reliance on Dave, giving him extra time to prepare for work.

Using imagery

As we discuss the potential impact of ITB on Carla's lifestyle, she dismisses each side effect as unproblematic. Concerned her straightforward approach is lack of understanding I share, 'When I work with you I feel you are a thoroughbred race horse running free, galloping over all these hurdles only really seeing them as passing hindrances, if you see them at all. I feel like a jockey pulling on the reins, keeping you on track to face the hurdles.'

Carla laughs and replies, 'It feels exactly like that. It's good; you keep me grounded and realistic. It helps me share with my family and be blunt with them what the treatment will and won't do. I have told them all that it will not help me walk so they better get used to the wheelchair!'

It is the first time I have used imagery so explicitly in my interactions and it seems to be drawing Carla and I together as partners in this journey to manage her spasticity. I am inspired by the words of Cowling to continue in this quest for appreciating her pattern. Cowling (2000) states,

> 'It is the capacity of engaging in change and patterning that provides the opportunity for mutual discovery of possible avenues of action. The actions chosen emerge from the knowledge of wholeness that comes from exploration of ones pattern. The exploration and discovery mode of the process is created through a partnership. In this partnership the nurse provides a contextual process of appreciating pattern, which is open to modification depending on the desires of the participant. The participant is viewed as an expert on his or her own life and the source of his or

her own power and knowledge. Each encounter in the appreciating process is primarily in the form of a dialogue with content focused on life experiences, perceptions and expressions. However the use of music, imagery or movement also might serve the dialogue and the emergence of useful pattern information to understand the person's wholeness.' (Cowling, 2000, p25).

I enjoy communicating with Carla; we both listen intently and challenge each other to clarify issues. It feels as Cowling describes that we are 'mutually discovering'. I strive to understand her pattern, her wholeness and she works to appreciate the potential of ITB to affect her daily life.
As Carla and I spend more time together her comments often refer to our race horse and jockey imagery:
'Oh here she goes again holding onto the reins – pulling me back.'
'Oh yes keep me on course, keep me focused on reality.'
These exchanges keep us connected or as Cowling suggests above, '...serve the dialogue...' from which I continue to deepen my appreciation of her pattern.

Wednesday - The trial

As the 50 mcg baclofen trial dose peaks, I closely observe Carla for any signs of side effects; simultaneously I am aware that Dave is restlessly pacing the ward. I sense he has reservations about the treatment, I ask him to share his thoughts, 'I'm worried that if she gets weaker in her middle it will restrict her ability to independently do car transfers which would impinge on her getting to work.'
I reply, 'Where is your car parked?'
He looks bemused but answers, 'It's immediately outside the hospital.'
Carla currently has no side effects from the trial and her observations are stable. I decide to take a risk, 'Carla lets go and see what affect ITB has on your car transfer.'
She transfers with added ease into the car. She is ecstatic and Dave relaxes.

I quickly usher them back to the ward, passing the consultant on route, he raises his eyebrows in a quizzical fashion. We smile and wave as we continue on. I hazard a guess that my heart rate is currently the fastest, but I am relieved that she has not experienced any signs of excessive weakness, drowsiness or respiratory depression. It was a risk but importantly it gave this couple the opportunity to assess the effect of ITB on a key aspect of their lifestyle and provided me with further knowledge of their pattern.

August supervision

CJ challenges me to consider the outcome if the car transfer had not been so positive. I believe knowing negative information would have been as important to Carla and Dave in enabling them to assess the potential impact on their lifestyle and whether ITB was worth incorporating into it.
I recognise that in listening to Dave and Carla, to flow with them and appreciate their pattern I have been both intuitive and creative, characteristic's that have been identified By Benner (1984, et al 1996) as features of expert practice.

Monday

Mindful of my experience of ignoring Pete's sexuality, I am keen to discuss ITB and pregnancy with Carla and Dave. I share with them the limited information available, that there are just two reports of babies being carried to term with an ITB pump insitu (Dellhaas and Verhagen1992, Munoz et al 2000). Carla and Dave share that their current sexual practices are limited, becoming pregnant would be difficult without more effective management of Carla's spasticity. Carla states, 'I'm going to put motherhood to the back of my mind for now and focus on managing my spasticity.'

Friday

The pump was successfully implanted on Wednesday. From today I am on nine days leave a mixture of study and holiday. I feel I have prepared as much as I can for Carla's discharge next Wednesday. Carla is aware of her role in managing the pump, how to recognise an emergency, what to do, who to contact and the date of her follow up appointment. She is excited about attending her sisters' wedding the following weekend. I have sent her GP an information pack and spoken to her district nurse in detail about ITB therapy and management of the surgical wounds. I have taught all the relevant doctors including those on-call, how to use the telemeter. Finally the senior physiotherapist is prepared to complete the measures and the discharge report.

Returning from leave

I am shocked. Carla is still in hospital. She has a pressure sore behind her knee, has been lethargic and was prevented from attending her sisters' wedding. I am angry about the avoidable pressure sore and feel sad she missed the wedding. The team joke, 'See Lou you are not indispensable!'
I retort, 'We provide a poor service then! I believe it's unsafe to run services that only rely on certain personnel. I want to learn from Carla's experience and strengthen the care plans and ITB guidelines.'

Poor care

Anti-emboli stockings wrinkling behind Carla's knee, pressing on what was a previously vulnerable area had led to her skin breakdown. I have repeatedly discussed with the ward nurses that people with spasms do not need to wear stockings after the day of surgery, as there legs involuntarily move, but still they continue to use them. Further they did not follow the protocol with Carla, of removing the stockings daily and checking her skin. I am very frustrated.
I raise these issues with the nurses on duty; they say little and seem resigned to taking the blame. They are not interested in considering how to prevent it happening again. I try to share how the pressure sore might impact on her life and how in the past it has taken people with spasticity over a year to heal such wounds. This just makes them withdraw further from communicating with me. The tissue viability nurse reviews the wound and is more explicit than I have been about the poor standard of care and documentation. A recent study confirms our concerns, Spilsbury et al (2007) interviewed 23 hospital in-patients and concluded that 91% stated their pressure sores affected their lives emotionally, mentally, physically and socially, but nurses failed to recognise the pain, discomfort and distress that they caused.

Missed opportunity

On the day of the wedding Carla's blood pressure was low and the on-call doctor felt she shouldn't go. However in her notes we had documented our previous concern about a low post – operation blood pressure. At that time we increased her fluid intake and it made little difference, our doctors concluded and recorded in the notes that Carla was someone who functions on a lower than average blood pressure. The consultant neurologist was furious that he had not been consulted about the decision.

What I find interesting is Carla who I describe as strong, with a fighting spirit did not demand to go? Why was she so disempowered?

I ask, 'Did you try and say to the doctor that you really wanted to go?'

She replies, 'Not really, I guess I just resigned myself to the fact I wouldn't be going.'

I apologise and share that in my wildest dreams I wouldn't have predicted this outcome. She replies, 'I know, I really wish you had been here on that day...in fact the whole week.'

She continues, 'I had planned to wear to the wedding a new pair of slip-on sandals encrusted with crystals. You know the sort of shoes I haven't worn for years because of my spasms. My family had arranged to have an official photograph taken for you to use... you know when you lecture about goals and the pump.' She is tearful. I hug her, which stems my tears.

I rarely hug patients but Carla is very tactile and this brief moment of human contact, shows I care, I'm listening, and grateful for the thoughtfulness of her family. Previously I would have avoided such intimate physical contact through fear of seeming unprofessional, but in this situation and with Carla it felt appropriate.

Menzies – Lyth (1988 [1959]) in her seminal study on how institutions manage anxiety suggested that nurses avoid intimacy because they have been socialised against becoming 'too involved' with patients, as a way to minimise the potential of nurses becoming distressed. She noted how working environments encouraged distance between nurses and patients through strategies such as task allocation and labelling people by their illness rather than using their names. In a more recent study by Henderson (2001) which focused on nurses' approaches to the care of abused women, she states,

> 'The more self-reflexive the nurse, the more likely they were to value emotional connection with their patients... The majority of nurses, see emotional engagement as a requirement of excellence in nursing practice' (Henderson 2001, p133).

I identify with these studies; as my skills in reflection have deepened and become part of what I do as a nurse and as I get to know individuals, sharing in their life journeys I feel more comfortable with being intimate.

I am mindful working in this way is emotionally draining (James 1989) and I need to care for self. Exploring my feelings and experiences during supervision allows me to recognise personal signs of stress and be supported to explore how to manage and minimise it from occurring again in the future. Dealing with stress in this way helps me to be intimate and remain available to others.

To bring Carla and I out of this moment I use imagery and humour, 'The past week really did have too many big fences for you to cope with. It seems worse than the Grand National!'
She laughs, 'Yes, where was my jockey when I needed her?'

Perhaps Carla masks her vulnerability and wants to appear to cope as a disability champion, maybe I have misread her, feeling her more capable to assert her needs, whereas in this situation she was unable to 'honour self' (Lindsey 1996). Maybe I have not fully appreciated her level of precarious harmony? Charmaz (1983) interviewed 57 people with a chronic illness and identified an overarching theme in their lives was loss of self. This was described through living a restricted life, social isolation, becoming a burden and discrediting definitions of self. Carla missed and so was isolated from a significant family event by not attending her sister's wedding. Not wanting to make a fuss or become a burden she felt unable to express her needs to the doctor or nurse. I feel through this issue she experienced a loss of self (Charmaz 1983).

September supervision

CJ helps me frame my work with Carla from the perspective of agentic and victim and how she fluctuates between the two. With the spasticity team she has an equal role in the decision-making; however with the ward team she is less able to assert her needs.

I share with CJ my fury about the pressure sore. CJ questions why I had not taught Carla to be more proactive about ensuring her stockings were removed on a daily basis. This is a good point and could easily have been achieved, making a huge difference.

I comment that the ward sister has now reviewed the anti-emboli stocking protocol and has started to stock knee length stockings. We have agreed people having intrathecal treatments will not routinely use anti-emboli stockings; if they are necessary the spasticity team will request them. I plan to include a relevant statement in the revised care-plans.

I was concerned that the junior nurses may withdraw from Carla, through fear of making further mistakes, therefore not being as available to her, making her more dependent on others such as myself. It is a fine balance for patients to highlight poor care and still have their needs met adequately. Similarly for specialist nurses it is a fine balance to highlight poor care, change practice and remain able to work effectively with colleagues.

CJ queries whether nurse specialists, including myself, are disempowering to ward nurses? I strive to share my knowledge and work with ward nurses which is suggested as a way to promote junior colleague development (Humphries 1999). Although this has been unsuccessful with Carla and Janice[69] with Ann the team worked collaboratively.[70]

[69] Reflective text 9, p155-157
[70] Reflective text 9, p157-161

I state to CJ that perhaps what I fail to do is to hide my frustration when I believe poor care is evident, which risks nurses not engaging with me. He challenges me to consider that at times I may need to express my frustration so as others appreciate the seriousness of a situation and the lasting effects of poor practice on a person's precarious harmony, such as the length of time it will take to heal Carla's pressure sore.
As part of my vision I will continue to strive for excellent levels of care being mindful of how I communicate with others.

Pump Clinic September

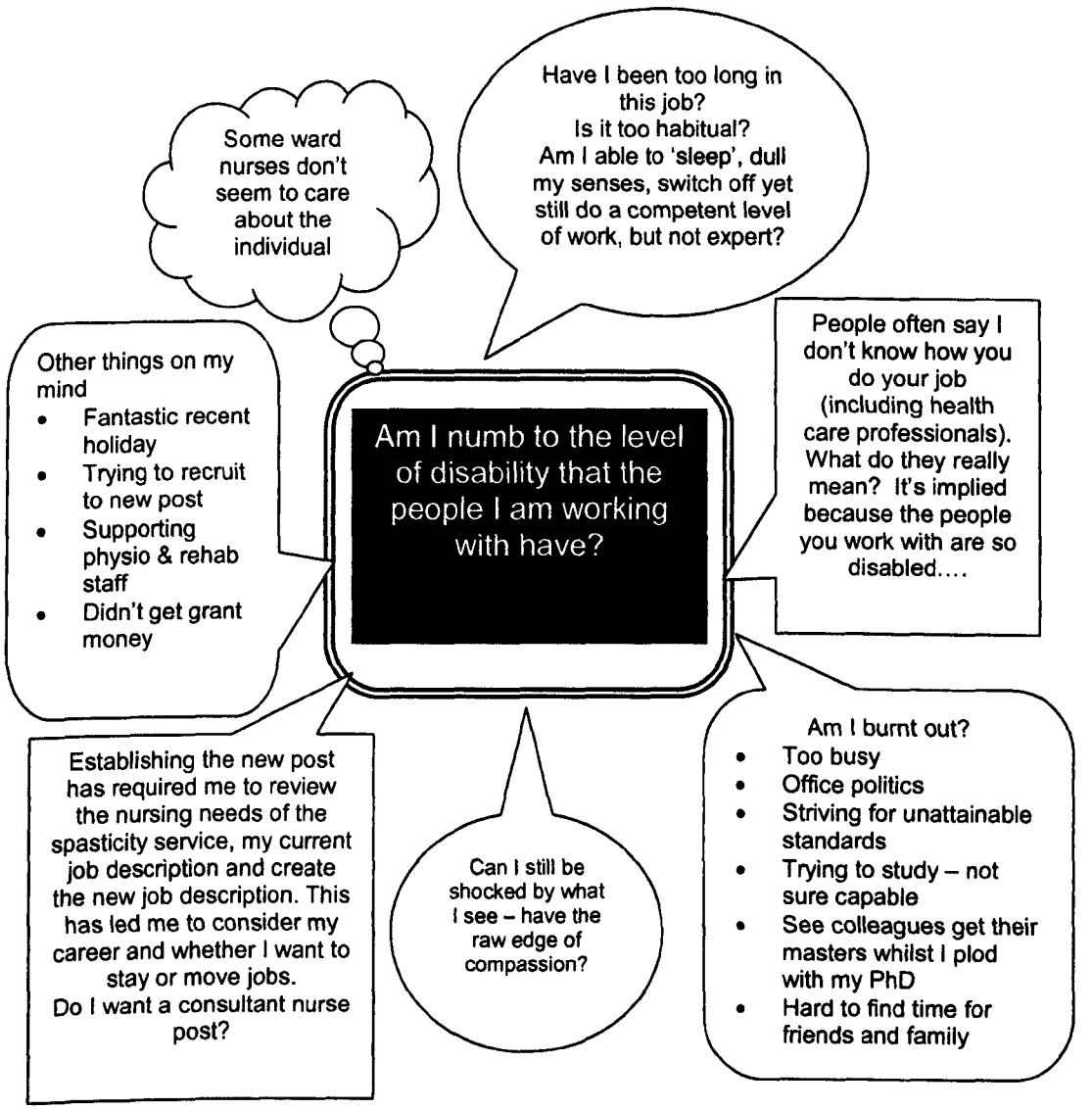
There are several visitors in clinic today. Carla's spasticity and spasms have improved, but her legs still spasm if she moves or is touched. She asks for a large dose increase, Tom agrees, but I am more cautious, 'I think we should continue to increment the dose slowly and see you more regularly. I don't want to compromise your transfers by making you too weak.'
Carla laughs and starts to mime the action of a jockey riding a horse and pulling on the reins stating, 'Here she goes pulling on the reins, steady now Carla not too fast!'
Tom and I laugh. The visitors look bemused. Carla continues, 'Its Ok Lou I know we have to go slowly I'll come to clinic again next month.'

Tom was aware of the imagery but it didn't feel necessary to relay the details to the visitors. It would have somehow broken the code of trust that Carla had developed with the team and myself; besides some jokes are hard to convey succinctly so remain private.

Am I numb?

October 2003: Supervision

Recently I have been wondering whether I am numb to the level of disability I encounter. CJ suggests I map an influences grid to explore what has triggered these thoughts.



Influences map: Am I numb?

Constructing the grid highlights my current work pressures and allows me to organise my thoughts and feelings. It contributes to the exploration of my practice in the following two incidents and to appreciate whether: 'I am numb?'

October spasticity clinic:

Present; Neurologist, physiotherapist and myself

An ambulance crew expertly manoeuvres Mabel, who is sitting up on a stretcher into the clinic room. Her daughter Pam holds her hand. Mabel looks well and is dressed in a pretty blouse that matches

the neatly arranged blankets covering her legs. She appears alert and unperturbed by her journey from a distant nursing home where she lives. She looks at us when we say hello but doesn't speak. She continues to stare as we listen to Pam tell her mum's story starting from her diagnosis of MS, fifteen years ago.
Mabel doesn't engage but her intent stare probes me and I wonder just how active is her mind? What can she understand?

As Pam finishes we ask if we can examine Mabel's legs. Pam nods. Mabel remains passive. As we remove her blankets the doctor, physiotherapist and I together exclaim in loud, surprised tones, 'Oh!' Immediately I feel embarrassed, have we acted inappropriately by showing our shock at how Mabel's legs are positioned? I check Mabel and Pam's faces for any sign of offence. There is no emotion on their faces. I wonder if our shocked response is usual and they no longer respond to protect themselves or so as not to embarrass us further. We quickly compose ourselves and continue with the assessment.

Mabel's hips are internally rotated by 90 degrees so the kneecaps would face each other, although one leg rests on the other. The knees and ankles are both flexed. Unsurprisingly she is in a great deal of pain at rest and if touched or moved. She has minimal rotation of her trunk so with no view of her legs her sitting posture looks good (Figure 3.13.0). Her skin is in excellent condition and she has no red or broken areas, but it is increasingly difficult for her carers to wash her lower half and she can only wear skirts and pop socks.

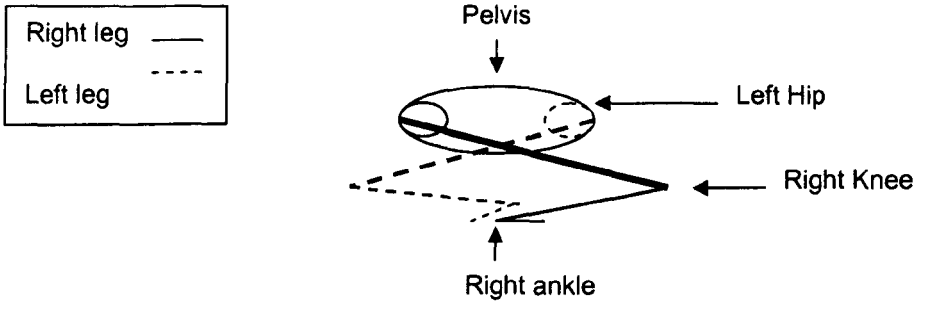


Figure 3.13.0: Diagrammatical representation of the position of Mabel's legs

Later journal reflection

This moment only lasted seconds but I felt its impact. Linking it to my influences map it demonstrates I am still moved by the people I meet and their predicament. I am conscious of the impact of my actions and how individuals and their family maybe feeling. Perhaps this is the raw edge of compassion? Roach describes compassion as:

> 'A way of living born out of an awareness of one's relationship to all living creatures; engendering a response of participation in the experience of another; a sensitivity to the pain and brokenness

of the other; a quality of presence which allows one to share with and make room for the other.' (Roach, 1992, p58).

Pam's narration did not obviously stir my senses however facing the reality of Mabel's leg position prods my compassion; I am propelled into action to consider more consciously my practice and how I am interacting. I want to get to know Mabel and see if we can help reduce her pain.

Any visual cues to the extent of Mabel's spasticity were absent. The neatly arranged blankets provided a sense of order and effectively disguised the position of her legs lying opposed but relatively flat on the stretcher. The 'disguise' worked well, or did it? Perhaps going through a public area such as the waiting room she would not have attracted attention and negative stares but when the team were deprived of visual cues we audibly reinforced the perception that her leg position was abnormal. Reinforcing that appreciating a person's pattern is influenced by visual cues.

Mabel's uncommon presentation makes me realise that a common feature of having spasticity is it's difficult to look neat, tidy and blend into the background. Clothes and blankets are difficult to wear or organise due to the position limbs are held in and the regularity with which their position changes with unpredictable spasms. For people with spasticity and spasms it is difficult, mostly impossible to disguise their disability. Random sudden movements can draw attention from others and can be a barrier to a person with spasticity being seen as a person. The gaze of others becomes focused on the moving limbs, the impairment, and the person becomes obscured from their line of vision. Focusing on a person's impairment is felt by the disability movement to contribute to negative societal attitudes and the alienation of people with disabilities from mainstream society (French 1994, Swain et al 1994). This incident has made me more aware of the difficulties people with spasticity face trying to function in the wider society or indeed their immediate local surroundings, just because of the way they look.

Ben's IP admission

Ben's MS trajectory has been relentless since diagnosis six years ago. For two years he has been unable to sit in a wheelchair because of his flexed leg position, contractures and persistent sacral pressure sores. During this time he has lived in a nursing home but his parent's share with us he is determined to live in his own flat again. Ben's speech is difficult to understand, he tends to spell words or use a pointer board. As we measure his spasticity and spasms, his father Sam, helps us to interpret what Ben is saying, and simultaneously teaches us ways to maximise our comprehension of his speech.

Olive, an agency nurse is caring for Ben. She asks if she can watch the assessment, Ben agrees and I'm encouraged by her interest. However I soon realise her motive is to complete the nursing admission documentation. She corners Sam and asks in an incredulous voice, 'Was he born like this?'

Sam replies, 'Pardon.'

I cannot work out whether Sam hasn't heard or cannot believe what he has heard? I intervene firmly, 'Olive, I'll share Ben's history with you later. Ben and his parents have already recounted it to us.' She leaves and I involve Sam and Ben in the measuring.
After we finish, I find Olive and explain why I had intervened. I show her his medical notes particularly our detailed clinic letter, which details his history, nursing and physiotherapy needs. I suggest she can probably complete most of the documentation from this, using her time with Ben to clarify if anything has changed rather than starting from the beginning. It's difficult to communicate with her. I pay attention to my tone of voice and my body language. I work hard to support her need to gain knowledge but she remains convinced that the most efficient way is to question his parents and states, 'I don't have time to read all this.'

I take a different tact; trying to be collaborative I offer to complete the form with her. I weave into the conversation the impact Ben's level of disability is having on him and his family and by getting them to repeat his history can cause them emotional pain. I detail how he is able to communicate his needs and how as nurses we can positively influence his involvement in decisions. I talk of his past job. I want her to see him as a person, not just as a twisted body that is difficult to communicate with and understand.

As we finish the form Olive smiles. I wonder if I have helped her to see Ben the person, or is she just pleased the job is done and I will soon leave the ward so as she can complete her shift without further challenges to her practice. I am reminded of Carla's nurses, routinely using anti-emboli stockings, I sense nurses remain driven to complete tasks rather than seek out a person's individuality.
I don't explain to Olive that by not finding out his history, she was at risk of portraying to Ben and his family that the team communicate poorly and how this could jeopardise the trust we have been establishing with this family, moving us to a state of disenchantment (Thorne and Robinson 1988) . Maybe she didn't feel like a team member, or didn't see it as important as she was only working in this team for one shift. I feel relieved I created an environment to discuss these issues with Olive and that I strived to be collaborative in my approach, it at least helped me deal with my frustration.

'Wake up calls!'

CJ describes these experiences as 'wake up calls', bringing issues to the fore of my consciousness. He asks: 'Are their any golden rules you would teach Olive or future agency nurses?'
I readily respond with a list:

Golden rules

- Communicate directly with the person but judiciously use other resources open to you to gain information. Use the information so as your nursing interactions can be unique and meaningful allowing you to clarify what you have learnt, deepening your understanding of the nursing needs of that person.
- Don't assume anything or jump to conclusions.

- Look beyond the disability and see the person's past, current and future life world.
- Appreciate their life experience and lifestyle as they tell you about it. Listen, observe and clarify.
- Always consider how your nursing intervention will impact on an individual's life whilst in your care and how it may have a lasting impact on them even when they are no longer in your care.
- Be aware of yourself and the image you are portraying. What emotions are you creating in the other person or their family? Question yourself is this the right time to show a particular emotion (for example happiness or sadness) through your words, tone of voice, touch, eyes and avoidance or over care? Through this careful consideration try to nurse the individual with an awareness of the knowledge you have developed your nursing vision and how you perceive the individual wants to be nursed.
- Always be open to new cues and information about how the individual wants to be interacted with and cared for. If appropriate share these observations with colleagues.

CJ asks, 'So are you numb to the level of disability that the people you work with experience?' Smiling I reply, 'Seems not. I am still striving toward my vision to work with the person with spasticity, their family and carers, jointly sharing our knowledge, expertise and experience to maximise the impact of spasticity on the person's lifestyle.'

We discuss how my core values become masked by other issues such as creating new posts, reviewing my job, anxiety about ability to study and office politics. It is these issues that cause stress and affect my ability to focus on my clinical work. I am numbed by external factors and the environment I practice in, they restrict my ability to perceive my practice, be creative and develop. Guided reflection provides a vehicle for me to remove these masks and see my practice. This encourages me to create a practice environment where I can be more available to people with spasticity and colleagues.

As I start to pack up I exclaim, 'Oh my goodness, I forgot, I received a personal letter from Ben's parents today thanking me for the kind consideration I had shown to Ben and themselves and how it had made a positive impact on their hospital experience. Thank goodness for guided reflection else that positive feedback would have been lost in the milieu of the day.'

'It was a pleasure to meet you.'

December 2003

Mabel

Ed, a junior physiotherapist wants to learn about IP and asks to work with Mabel and I. We meet on the ward to measure Mabel's spasticity and spasms. Cathy, her nurse asks, 'She hopes to walk again, is that likely?'

I shake my head and share what I know about Mabel from clinic; Ed looks concerned as I continue, 'I've found its common for people to hope to walk even when they haven't stood or walked for years. Part of our role is to address her expectations.'

Ed doesn't relax.

We introduce ourselves to Mabel and I ask, 'Why do you think you have been admitted?'

'I don't know.'

I slowly explain the reason and emphasise that the phenol injections will help her pain and we hope her wheelchair sitting position. She stares at me intently.

We wait.

The silence and maintaining eye contact is arduous. I persevere as I hope through my body language I'm conveying that I want to engage with her. Finally she responds, 'I want to walk?'

'How long is it since you have walked?'

She looks away and doesn't answer. I repeat the question. Irritated she spits out, 'Months, years I don't know.'

Gently I clarify, 'The phenol injections will not enable you to walk. The injections stop the nerves working to your muscles so you will not be able to walk; but they will ease your pain.'

Mabel starts to cry and without looking at any of us, she states firmly, 'What is the point of being here if I will not walk. I may as well die.'

Ed and Cathy look panicked and seem to metaphorically step away from the bed and melt into the side-room walls. Feeling alone with Mabel I ask, 'Why do you want to die?'

'What's the point of living?'

'From what I have seen of your family they care about you and want you around.' She shrugs her shoulders.

I am mindful from working with Pete and Jay[71] these conversations can be painful, and I need to share information in a clear and honest way. I wonder if I could have been less blunt about the injection, a little gentler whilst guarding against being vague and opening any avenue for false hope. Mabel doesn't seem to be testing my honesty like Pete and Jay; she is more emotional as if she really thinks she might have walked again.

[71] Reflective texts: 2, p112-119; 10, p 162-167.

Mabel seems low in mood; I wish I had spoken to the nursing home staff about her coping mechanisms. I wonder why she thought she might walk again, has anyone colluded with her? I solicit, 'Who said the injections would help you to walk?'
'Everyone.'

After the assessment I stay with Mabel and apologise if I have been too blunt about what the injection will and won't do. I share with her that I prefer to be honest and that I cannot practice under an umbrella of half truths, or lies.
She doesn't seem to be listening and still will not make eye contact. I conclude by saying, 'I'll come back tomorrow.'
She replies. 'No point if the injections will not help me walk.'
I reply, 'I would like to come back, do you object to that?' She shrugs her shoulders.
As I walk away I reflect that people do not normally reject my input, but it feels an appropriate reaction from Mabel, considering the conversation we have just had. I wonder how severe her cognitive impairment is and whether she will remember our conversation tomorrow? I will tread carefully.

Next day

Nervously I walk into Mabel's room but she throws me a beaming grin and maintains eye contact. It's difficult to know if she recognises me. I tentatively query, 'Do you remember our conversation yesterday?'
She nods. I enquire, 'Can I stay?' She keeps smiling, I continue, 'Would you like us to do anything?'
She responds, 'Get rid of the pain in my legs. Something has to be done.'
I review the injection procedure and the aim to improve her comfort and I gingerly repeat, 'The injections will not help you walk again.'
Fractiously she replies, 'I know that, I just want to get rid of the pain.'
I respond, 'But yesterday you were very low about not being able to walk again?'
She shrugs and I ask, 'Do you feel alright about the injections today.'
She nods, I continue, 'Do you want to go ahead?'
She hesitates but says yes. She looks distracted, to engage her again I continue, 'How many grandchildren do you have?'
Her face softens, 'I love seeing them.'
'Does your constant pain get in the way when you see them?'
Animated she replies, 'Yes it's so uncomfortable when they try to climb on my lap.'
I reply, 'The pain probably adds to your feelings of wanting to die.'
Looking suddenly tearful she just nods. I ask, 'If we could lessen your pain do you think it may impact on you wanting to die?'
She looks thoughtful and thinks it might. I let the topic rest. She stops me before I leave, 'There is one thing. I am concerned the injections will hurt. Can I have pain killers before them?'
I feel elated and want to shout, 'Eureka, she does understand!' Instead I just say, 'What a good idea I'll arrange that.'

Journal reflection

Pam is Mabel's power of attorney and will sign the consent form. This period of lucid conversation with Mabel and her request for analgesia pre procedure is reasoned and logical; it reminds me of the importance of engaging people with cognitive impairment in the decision-making process even if they are medically deemed unable to consent to treatments.

December supervision

CJ asks if I checked how Ed and Cathy were feeling, did her statement shock them?
His question transports me back to the moment and how drained I felt as the conversation drew to a close. I realise I had not considered the needs of my colleagues; I only directed my energy towards Mabel and myself. I must be mindful of connecting with them, to ensure we all can remain available to Mabel. Alternatively I could have considered debriefing with them either later that day or on another day.

CJ and I discuss the issue of obtaining consent. As my experiences with Pete, Jay and Mabel demonstrate, to participate in decision-making they require continuity of staff and repetition of information. Obtaining consent is a process (Gelling 2004) rather than a one off task of receiving information and signing a form. CJ and I detail issues to consider when involving individuals with cognitive impairment in the consent process, they need:

- Repetition of information and consistency of details from all team members.
- An agreed treatment aim.
- Time to assimilate what is going on.
- Flexibility of information provision to maximise time when they are able to understand and ask questions.
- Clinicians to be alert for such opportunities.
- Documentation that reflects the ongoing nature of their engagement and the different clinicians involved in the consent process.[72]

Trial and phenol injection

The trial was positive in reducing Mabel's pain and enabling better positioning both in lying and sitting. Mabel and Pam agree that this would improve her current lifestyle and want to continue.

As the anaesthetist starts to position the blue procedure sheets over Mabel, she starts to cry. Despite my direct and indirect questions, I am unable to establish what is wrong. She sobs harder. Even though the environment and personnel are the same as the trial, I wonder if she is scared and maybe unclear about what is going on.

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[72] Subsequently the department of health (DOH 2005b) have reviewed the Consent procedure and documentation. It encourages recording more description of all the discussions that have been had, moving towards obtaining consent being dealt with as a process.

Burrowing under the sheets I hold her hand she grasps it tightly. I start to stroke her hair. I repeat details of what we are doing and emphasise that she is safe. She starts to settle. I wipe her eyes and nose with a tissue, simple things that she is unable to do. The doctor asks me if she is Ok and could he go ahead. Mabel was still crying, but not so hard, I ask again, 'Are you crying about the injection?' She gives a definite shake of her head. 'Is it your situation? Are you fed up with how things are for you?'
She nods but through her sobs she says, 'Carry on.'
I continue to hold her hand and stroke her hair, guiding her through each step of the procedure.
We make her as comfortable as possible in the side lying position that is necessary for the twenty minutes wait as the phenol takes effect; she is much calmer now. I ask her about her mood, 'Do you feel low all of the time?'
She nods and says, 'Of course wouldn't you in this situation?'
'I guess I would; do you think it would help to talk to someone about how you feel?'
'Not really; not much they can do.'
'Can we review your antidepressants?'
'Oh I forgot I was on those, maybe that's an idea.'

The nursing home manager confirms it has been some time since Mabel's drugs have been reviewed, she states, 'Oh Mabel yes she does cry a lot, but with the care assistants she knows well, they soon pull her out of it.'
I wonder if interacting with people she knew was enough, perhaps removing her continuous pain will go someway to improving how she feels. The doctors discuss Mabel's antidepressants with her and decide to try a new regime.

I am reminded how easy it can be to overlook depression as a symptom to manage in a person with a long-term disability and the need to be mindful of appreciating a person's whole pattern (Cowling 2000).

Journal reflection

Despite her tears I felt Mabel knew what was happening with the phenol injection and did want us to proceed. I felt her emotional response was in reaction to her experience of the measures and trial; where we asked her to focus on her body and in particular its limitations. This was similar to when we were measuring Tina's spasticity and how challenging it was for her and her husband Leon.[73] I feel Mabel was experiencing a transition from living with disability (illness) in the background to living with disability (illness) in the foreground (Paterson 2001, Figure 3.11.1).

[73] Reflective Text 11, p173-176.

Outcome

Following the second injection Mabel is sat up in bed smiling and more actively participating in conversation. I ask her if she feels having no pain is contributing to her improved mood. She states, 'It must be and I am looking forward to going home and seeing my grandchildren at Christmas.'

Pam

After Mabel was discharged, Pam telephoned, 'Thank you for looking after my mum, I am so glad she went ahead with the injections they have made a real difference... It was a pleasure to meet you.'

I was touched by her final comment and surprised she had used such an intimate statement, as our interactions had been seemingly quite functional with little exchange of emotion. I wonder if Pam felt able to be intimate with me, as she had witnessed my intimacy and concern for her mum; similar to the letter from Ben's parents. This suggests that my intimacy and concern for a person can make an impact on their family even if they have only observed my interactions or exchanged functional dialogue with me; subsequently it can result in them demonstrating intimacy towards me. Perhaps intimacy helps to dissolve the 'guarded' part of alliance – moving to a therapeutic alliance. This could be added as a 4th stage to the model of Thorne and Robertson (Figure 3.14.0).

Naïve Trusting	A passive interaction where individuals believe that healthcare professionals will work with them in collaborative ways negotiating and mutually making decisions.
Disenchantment	The individual and their family realise collaborative relationships are not happening. This leads to a risk of adversarial relationships, disengagement and needs not being met.
Guarded Alliance	The ongoing nature of chronic illness often requires the individual and their family to re-engage for health care. However they are now enlightened from previous experiences and proceed with caution.
Therapeutic Alliance	An ongoing relationship where there is a collaborative partnership based on honesty, intimacy, mutuality and thick trust.

Figure 3.14.0: Model of Therapeutic Alliance (based on Thorne and Robertson 1988).

Reflective text 15: **Supervision session 25**

Saturated

November 2003

Journal entry: Tuesday night

In big letters down the middle of the page I write:

'I feel saturated with looking at the issues associated with bringing people with chronic illness into hospital but feel I'm only scratching the surface'

Monday: Cliff's admission

Cliff and Julie have been having a tough year. Cliff had pneumonia that necessitated a prolonged stay in his local hospital and his superficial sacral pressure sore that we first noted in August 2001,[74] developed into two large grade 4 sores that now extend to both his hips.

As Cliff no longer has audible speech I regularly discuss his spasticity management with Julie; it is worsening. Although they are reluctant for another hospital admission they agree with the spasticity team that ITB is no longer managing his spasticity and he needs an IP trial.
I know his complex needs are going to be a challenge for the ward nurses to meet and I consider how I am going to challenge and support the nursing team.

Julie and I detail to the nurses on the morning and evening shifts Cliff's care routine and what is 'normal' for him. I encourage them to write what we discuss in their own words in his care-plan. Cliff and I show the nurses how he communicates to direct questions by nodding his head for yes and shaking his head for no. Cliff is now dependent for his complete nutritional needs on PEG feeding. However he finds it difficult to manage his oral secretions and requires up to four times an hour oral suctioning. Julie is reluctant to use hyoscine patches, as Cliff's major response to drugs seems to be drowsiness. Julie shares that at times the gurgling of secretions in the back of his throat can make his breathing sound a lot worse than it is. We discuss this with the nurses and Julie describes and points out noises, which are normal for Cliff. We emphasise that he regularly sweats necessitating his sheets and clothing to be completely changed.

Julie asks how we will manage his resuscitation status. When Cliff was in his local hospital Julie had tearfully rang me, as his doctors had wanted to put him, 'Not for resuscitation'. She was concerned this meant withdrawing all treatment. I supported her to express what she and Cliff wanted.

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[74] Reflective text 3, p120-121.

I ask Julie if their views have changed. She explains, 'We do not want the heroics of resuscitation but Cliff wants to be kept comfortable and if he gets an infection he wants antibiotics.'
We discuss this with the doctors and their wishes are documented in his notes. When I leave to go home I feel Julie and I have communicated with as many people as possible about the best way to care for Cliff as expertly refined by Julie and his team in the community.

Tuesday morning

I am deflated; overnight the nurses have unnecessarily recorded Cliff's oxygen saturations. Unsurprisingly they are low. He then had one of his 'sweats'; concerned the nurses called the doctor. At one o'clock in the morning Cliff was sent for a chest x ray and was commenced on IV antibiotics. He was apyrexial.

Back in my office I reflect on the night's events I feel we have let Cliff down. Frustrated and angry I mumble loudly, 'Why oh why can we not care for people with chronic illness in the acute setting?'
Two colleagues ask me to explain. As I do, they admit to only looking at health care from an acute model, but they understand my perspective. One asks, 'Do these people need to come into hospital at all?'
I reply I ask myself this question repeatedly but as the intrathecal procedures carry significant health risks it is only safe to perform them in hospital. I conclude, 'Although it feels today that Cliff is at greater risk from health care professionals who cannot care for him as an individual, then the procedure itself.'
I discuss my views about the care Cliff received overnight with the ward nurses and the junior doctors working with the spasticity team.

Tuesday night journal entry

Having scrawled my opening statement down the page, I sit back and reflect and can see the wider picture. The on-call doctor had a duty to ensure the safety of Cliff, he probably took what he thought was the safest option. It is frustrating that however much I appreciate a person's life pattern and share it with others, health care is so bounded by 'rules' that doctors and nurses do not (or feel unable to) care for people in an individualised way however much information they have. I ask myself how I would have responded if I had been in their situation. I admit to myself I may have acted in a similar way.

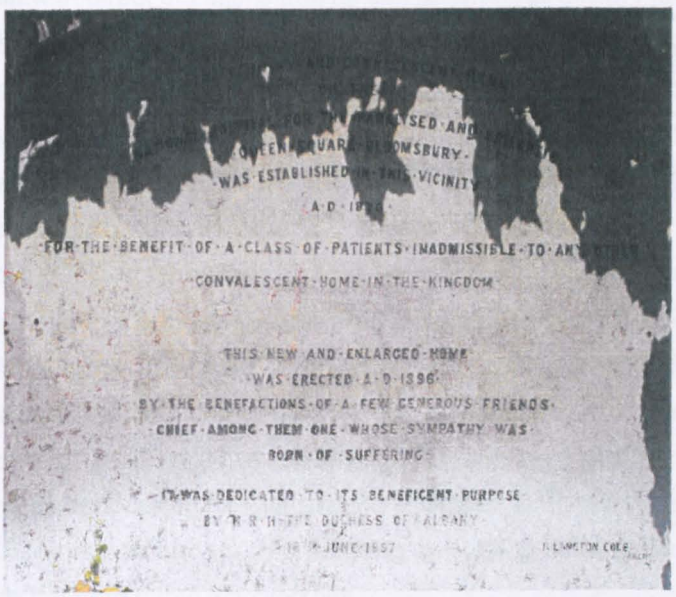
Wednesday

On the ward round the junior doctor concludes her summary by saying, 'Lou feels the x-ray and antibiotics were avoidable.' Her tone is tentative but not patronising she seems to be wrestling with the idea, but relaxes as the consultant agrees. I share my frustrations but in a calmer manner than yesterday. We discuss how we could prevent it from reoccurring. We recognise we can improve our documentation and oral communication with the on-call teams to enable them to make appropriate management decisions in our absence. This feels positive.

I wonder if yesterday I had pricked people's consciousness, got them to view people with complex disability differently. Certainly the junior doctor appeared to have thought about our conversation.

Thursday: Supervision

I ponder the best place to care for people having intrathecal treatments. In the past I have felt they need a dedicated ward where the team work within a chronic illness philosophy? But now this makes me feel uncomfortable, placing people having intrathecal treatments together in one place is similar to hiding them away. It feels akin to the way disabled people have been treated through history marginalized and separated away from mainstream society. It reminds me of how sombre I used to feel whenever I read the plaque inserted into the exterior wall of the rehabilitation unit to commemorate its opening way back in 1870 (Figure 3.15.0).



Inscription

The country and convalescent home
of the
National Hospital for the Paralysed and Epileptic
Queen Square Bloomsbury
was established in this vicinity
A.D. 1870

For the benefit of a class of patients inadmissible to any other convalescent home in the kingdom

This new and enlarged home
was erected A.D. 1896
by the benefactions of a few generous friends
chief among them **one whose sympathy was born of suffering**

It was dedicated to its beneficent purpose
by H.R.H. The Duchess Of Albany
18th June 1897

Figure 3.15.0: Photograph of the rehabilitation unit commemorative plaque.

I discuss with CJ that I feel exhausted and mentally drained or 'saturated' and show him the line from my journal.

> 'I feel saturated with looking at the issues associated with bringing people with chronic illness into hospital but feel I'm only scratching the surface'

He asks, 'Why are you feeling like this. Is it because there is such a gulf between the two issues in the sentence?'

I reply, 'I'm afraid of uncovering more and more issues and not being able to positively impact on them. I feel it's just not possible for people with complex disability to pass smoothly through an acute hospital admission. I feel like I am trying to merge two paths; the patient's journey of needs and the hospital's route of care provision (Figure 3.15.1). Each pathway is littered with obstacles that prevent the person's journey being in synergy with the way care is organised in hospital. I am in a constant struggle to smooth the person's pathway in, through and out of hospital.' (Figure 3.15.1).

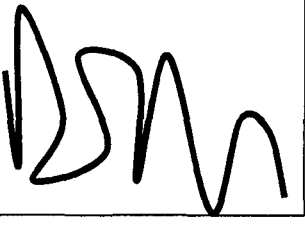
	Actual Journey In Dissonance	Ideal Journey In Synergy
Person with complex disability ° Individual has refined methods to manage symptoms o Health 1st illness 2nd o Person can contribute to ascertaining best ways to manage whilst in acute model		
Acute hospital model o Disregard for the person's current practised care strategies o Illness 1st Health 2nd o Ritualised practice o Unsuitable Environment		

Figure 3.15.1: The actual and ideal journey for people with chronic illness through an acute admission

Small steps

CJ reminds me that I did manage to facilitate a successful admission for Ann.[75] He suggests that to meet my aim of working in synergy, perhaps I need to take smaller steps. He asks me to plot my spheres of influence (Figure 3.15. 2)

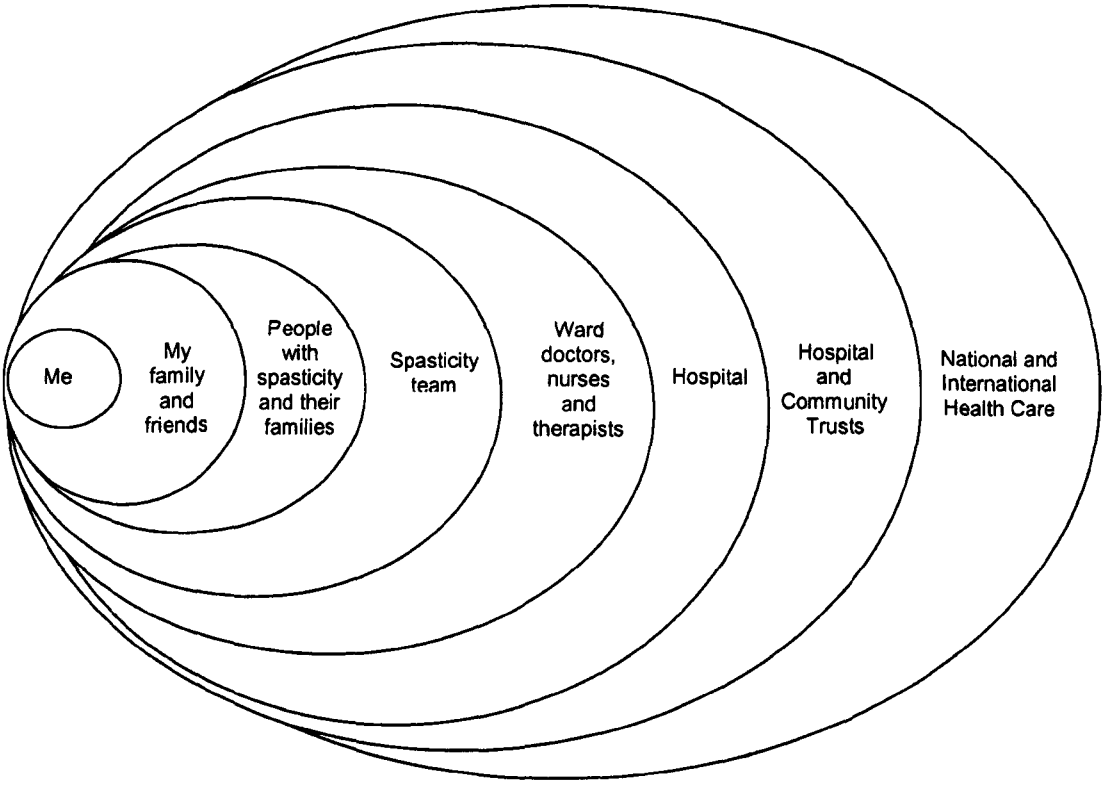


Figure 3.15.2: My spheres of influence on attitudes towards people with complex disability

CJ suggests by paying attention to getting it right in my immediate circle perhaps positive attitudes and practice will self perpetuate and radiate out toward the wider circles. I feel a surge of strength, I

[75] Reflective text 9, p157-161.

have to try and positively influence attitudes towards disabled people and the care of patients coming into the neurology wards, after all many of these individuals have complex disabilities not just those with spasticity.

CJ reminds me of the praise and thanks I received from Ben's parents and Mabel's daughter; through showing concern and intimacy to their family member they reciprocated with intimacy towards me. They were within my spheres of influence.

Friday: Refilling Cliff's pump

Cliff agrees to my suggestion of refilling his pump to save him a journey to outpatients. I ask the nurses if anyone wants to watch, two nursing students are eager to observe and Cliff agrees to them watching. One of them is helping to care for Cliff on this shift. I carry out the procedure and involve Cliff with direct questions that he can answer yes or no. I feel mischievous and seek his opinion as to whether I am questioning the students too much he vigorously nods his head. I tease him about how he has confessed to me in the past about skipping school lessons preferring to be out on his motorbike. Cliff continues smiling and laughing, at one point he laughs so hard, he needs suctioning. Nearly finished I turn to the students and ask what year they are in? They reply together, 'It's our 1st year and 1st ward placement.'

I put my hand to my face in mock horror I have assumed they were in their 3rd year (our normal level), as they have effortlessly answered tough anatomy questions. I have to raise my voice to apologise as Cliff is laughing so hard, we all giggle and then I suction Cliff. I look at him and realise he has watched the scenario unfold, fully aware of the students status and my lack of awareness.

As the students and I walk away from Cliff, I say, 'I hope you found that useful?'

The student caring for Cliff said, 'The biggest thing I have learnt is how easy it is to communicate with Cliff. I just watched you two laughing and joking, I had been at quite a loss this morning as I worked with the staff nurse washing him.'

Suddenly I remember the image when I visited Cliff that morning; the curtains were around his bed and I could only hear his chest noises, I thought he was alone. I peeked through the curtains and was surprised to see two nurses with him changing his dressings. Ironically Cliff with the least verbal communication was perforating this deadly silence of non-interaction with his 'gurgling', yet such a prompt yielded no reaction from his 'carers'.

This episode clearly demonstrates to me the importance of deepening my knowledge of someone over time, so as I can continue to communicate, when speaking or interacting becomes difficult for them. It also emphasises the value of role modelling communication skills as well as teaching about technology and demonstrating the skills of an aseptic technique.

A few days later a clinical practice facilitator said, 'I have been thinking it would be great to video you and the way you communicate with patients, you have such a fantastic way of talking to patients I think all levels of nurses could learn from you.'

I have never worked closely with this person but she recently observed a pump refill clinic. Perhaps I do not know all my avenues of influence.

'Just kill me.'

March 2004

Ali

Ali is 22 and left India two years ago to seek work in England. Eighteen months ago he developed tuberculosis (TB) meningitis and is now tetraplegic, cognitively impaired and in severe pain. He has been transferred to us from another hospital for a review of his spasticity.

First few days

Ali is very restless; it is difficult for the physiotherapist and I to assess him. He cries most of the time and screams if you touch him or his bed. As we spend time with him we start to be able to move him, he screams less, but loudly pleads, 'Please don't touch me.'

I ask him to tell me why, but he just closes his eyes, I am reminded of how Jay[76] used this technique to disengage. Other team members think his screams are related to pain but I am not so sure. When I ask him where the pain is sometimes he can localise it on other occasions he retorts, 'What pain?'

After a few days I ask, 'Does it feel odd when we touch you?'

He forcefully states, 'Yes.'

I continue, 'When you are touched does it send off other sensations around your body?'

Again he replies, 'Yes.'

As I get to know Ali I am less convinced his mild spasticity is contributing to his pain. I think he has a dysaesthetic pain that is exacerbated when he is touched or moved. I think he screams when in pain but also as an expression of his frustration. He has minimal spasticity and spasms. The doctors still feel we should do an intrathecal trial; the physiotherapist and I remain unconvinced.

Trial day

I am in Ali's room with the physiotherapist, a ward nurse and the registrar preparing to do the first ITB trial. I explain to Ali what we want to do he pleads, 'Please just let me die, kill me.'

Instinctively to show concern I place my hand on his arm he roars, 'Don't touch me just kill me.'

I quickly remove my hand. I sense space around me and feel alone in the room with Ali. I think how odd there is no one in my line of vision but I continue, 'Ali, I am a nurse I cannot kill you.'

He replies, 'But I'm asking you, pleading with you to kill me.'

I repeat, 'Ali, I'm a nurse I cannot kill you. We are not allowed to kill people in England. Perhaps if we can try and minimise your pain you will not feel like you want to die?'

He replies, 'What pain?'

Later he asks his sister, 'Am I in England? I thought I was still in India.'

[76] Reflective text 10, p165.

He questions her as to why he cannot move his arms and legs. She recounts the events of the previous months and he begins to piece together what has happened and why he is in this current situation.

Journal reflection

Much like when Mabel stated she would be better off dead, I felt my colleagues melt away from the bedside, the situation – the discussion of death. Were they scared with what he would say next or what I would say? I felt relieved that he replied with another plea about wanting to die, it justified to me that he did want to talk about it, I had heard and interpreted what he had said correctly. Why did I doubt myself? I felt uncomfortable and it was effortful to engage in this conversation; to talk about death was exhausting my energy. This together with the image of the others moving away made me question myself as to whether I had made a mistake by answering him, but it felt appropriate to flow with the mystery of what was unfolding and to answer his questions confidently and clearly. Subsequently he started to engage in conversations to piece together what had and was happening to him.

In neurology as opposed to other specialities we do not have to face death as often with our patients. They have long-term conditions and often die at home or in care homes, less frequently in hospitals. The spasticity team and I rarely confront people or ourselves about how we feel about death.

The challenges of caring for Ali

As I walk onto the ward I can hear Ali, he sounds tuneful, one of the nurses disagrees, 'Dreadful noise isn't it.'

I reply, 'Oh I don't know sounds as if he is chanting.'

She looks unconvinced.

The next day I notice Ali has been incontinent of urine, it's clear from the semi dried stain and the newer wet one on the sheet that this has occurred several times and he has not been changed. With a heavy heart I try to understand why this has occurred. I touch the bed, Ali repeatedly screams in a high pitch tone, 'Leave me alone. Leave me alone.'

His voice ricochets down the length of the ward.

As he continues to cry out I match his volume and state firmly, 'Ali, today I cannot walk away you are in a wet bed, I need to wash you and change the bed to protect your skin from breaking down.'

I have his attention in a softer tone I ask, 'Is that Ok?'

He quietens and replies in a similar gentler tone that I can wash him.

I feel slightly uneasy. I do not like raising my voice but feel to preserve working *with* Ali rather than *against* him, I have to be paternalistic and controlling, but mindful that I am using this approach. I strive to respond appropriately, lowering my voice was key to demonstrate I was not angry, I was listening to him and wanting him to listen to me too, so as we could work together.

Although leaving a person in a wet bed is indefensible, I can see how his behaviour would have led nurses to resist changing him. Afterwards, mindful to strive toward a collaborative style of

communication,[77] I discuss with his nurse how I had gained his co-operation to enable me to change his bed in a hope that he wouldn't be left in a wet bed again.

Medical Outcome

Cerebral spinal fluid (CSF) from one of the ITB trials was analysed and unexpectedly showed raised protein. This did not correspond with a subsequent CSF sample taken from his cranial shunt. He had an MRI of his spine, which demonstrated active TB. Ali did not require intrathecal drugs for spasticity management at this stage but further treatment for his TB and steroids to reduce the swelling around his nerve roots which would have been causing him pain as he was touched or moved. He was transferred back to his referring hospital.

March supervision

The interactions I witnessed between other health care professionals (HCP) and Ali demonstrated that everyone found it difficult to manage his screaming and crying. Some were better at making a calm environment, using distraction and engaging him in dialogue. Others ineffectively communicated by continually apologising whilst quickly doing what needed to be done or worse still some HCP avoided interacting with him, silently carrying out tasks with no discussion or negotiation. I summarised the factors I felt were influencing Ali's care:

- His loud repetitive screaming disturbs staff, patients and visitors on the ward. This is intensified for the nurses by other patients and their families complaining about the noise. Several carers of patients (astute to understand the infection control precautions being taken by staff) even stating he was infectious and should not be on the ward. This put the ward nurses under great pressure.
- Team members disagree about the origins and hence the chosen treatments for his pain.
- His pain is not just physical. A multifaceted program is required to address it not just drugs.
- Having control over ones environment is of fundamental importance to individuals (Robertson 1986). Ali has lost control and needs help to redefine his locus of control (Rotter 1954 cited in Eachus 1991). His environment is being controlled by external influences he can only express his internal locus of control verbally.
- He challenges HCP perceptions of what is acceptable behaviour of a patient.
- He challenges HCP perceptions about death and dying, but also perhaps what level of disability they personally would find acceptable to live with. He illustrates the fragile line between being alive without health problems and becoming severely disabled. Although not verbalised I think HCP felt he would be better off dead, perhaps why they could not address his requests to die.
- Why do HCP resist Ali?
    - Caring for him is emotionally and physically draining.
    - Lack of understanding about his culture.
    - Because he is young and now profoundly disabled.
    - Perception that there is little they can do to change the 'tragic' situation.

[77] Influenced by my interactions with Carla's nurses pages 179-181 and with Olive the agency nurse pages 186-187.

- Because they need to address their own views on death and disability.

CJ asked me what it was about Ali that made his care such a challenge.

I sense the tragedy of his story creates an emotional response in those who come into contact with him. They become preoccupied with their thoughts, which are compounded further when they minimise their interactions or use phrases to reassure themselves not him, such as:

'It will be ok Ali.'

'We will just do this quickly – sorry we need to do it'.

As I discussed with Janice and Ann[78], glib reassurance serves to reassure the professional not the individual (Sullivan 1954 cited in Teasdale 1995), it erodes rather than builds trusting relationships. Similar to how physical disability can be a barrier to get to know a person,[79] so can emotional outbursts such as screaming. Both the screams of Carol[80] and Ali generate emotions difficult to deal with for those trying to care for them. Whilst I try to flow with the situation and realise I cannot 'fix' their individual predicaments, I feel I have to keep addressing the emotions of others or 'breaking down their barriers by saying, 'Yes this is a tragic situation but....'

I try to get them to focus on what we can achieve and to engage in honest communication with the person not glib reassurance.

[78] Reflective text 9, p155-161.
[79] Reflective text 13, p183-187.
[80] Reflective text 6, p135-136.

Three years have passed since commencing the narrative. I feel the need to draw it to a close. CJ suggests reflecting on five consecutive days at work to illustrate the continuity yet variability in my day to day practice. 'The week' becomes theory in action as I draw my insights together forming a prelude to chapter 4...

Reflective text 17: **Supervision session 29**

July 2004: A week in my working life

Monday: Spasticity clinic

Sue and Phil are due in clinic today. They have cancelled previous appointments, concerned that because of Sue's cognitive impairment and severe disability they would be forced to have treatments, particularly ITB which they do not want. I have had lengthy telephone calls with them about our approach and philosophy and finally they have decided to come.

I know the pattern well, individuals (Janice, Ann and Cliff) can fear admission; for Sue and Phil even an outpatient appointment increases their anxiety to a level that they consider refusing input.

Phil telephones, the ambulance is late picking them up. Knowing they are anxious I encourage them to come, I fear if they miss today they will never attend. They arrive at the end of clinic. I try to put them at ease by saying we are used to people being late and it isn't a problem. They remain nervous and the start of the assessment is uncomfortable. Sue states she has no problems. Phil looks exasperated, scoffs and shakes his head in disbelief, but he tries to prompt her. Sue asks. 'You tell them Phil, tell them everything.'

It seems tense between them, but Phil smiles at her and cautiously starts to tell us their story. He is co-operative but guarded with his responses to our queries. I 'tune' into his wavelength and sense he is desperate to give an impression of coping and that they have a good life. Cowling et al (2008) describe this as,

> 'attuning to dynamic flow...It is the vibrational sensing of where to place focus and attention and involves attuning to the subtleties that present themselves in the moment, being sensitive to self and the other. It is following the lead of the other, going where that person is leading' (Cowling et al, 2008, p47)

Phil says, 'People keep saying we need a bigger care package but we don't.'

I respond, 'It seems you both cope really well but perhaps there are ways we could make things slightly easier?'

Phil's posture starts to relax. It didn't take us long to agree that ITB was unlikely to have a significant impact on Sue's very severe spasticity. We start to broach the idea of IP.

After the team assessment I ask Phil and Sue what their reaction is to IP, Phil thoughtfully replies 'I am very unsure as it seems so final.'

I state, 'Is it hard to know whether to proceed with the injection as it's difficult to imagine the outcome.' They both nod in agreement. I emphasise how the trial is a useful time to explore whether its impact would be significant on their daily lives, and how people in the past have found the trial really helpful

to decide whether to continue with the permanence of phenol. Phil replies, 'It's the permanence that makes it so difficult I mean damaging her nerves.'
I gently reply, 'Other people have found it odd that we talk of destroying nerves, when MS is already doing this.'
They nod, 'The difference with IP is that we try to target the nerves causing the spasticity and spasms.'
Phil replies, 'But research is going on all the time...'
I surface what I think he is meaning and say, 'Are you thinking, so what happens if a cure is found and we have already damaged Sue's nerves?'
'Yes exactly.'
I gently reply, 'Yes research is ongoing and yes a cure maybe found, but it would be difficult to predict if such a cure could help Sue as she is right now.'
I am very conscious of watching Sue throughout this exchange I am not sure how much she is understanding and what her thoughts are. 'Sue what do you think?'
She replies, 'I am not sure. It doesn't sound like I have much choice.'
This gives me the opening to reiterate again that this session is not about making choices or decisions but to gather information, to go away think about it, speak to other people and then to get back to me. I emphasise, 'One option is to have the trial, if you do not like the outcome you do not have to go ahead. We will not force decisions on you or leave you to make decisions on your own. We will strive to work with you both so as you feel you have enough information and time to make the right decision.'

I pick up their anxiety about a hospital admission, in particular the length of time, potential worsening of her pressure sores and who would help her smoke. In response I describe how I can work as an advocate for them during the process liaising with the different teams ensuring they are kept informed of the ongoing plans and participate, as they want in the decision-making. I detail what interventions will be planned for each day of her admission, how I will organise for the provision of a pressure-relieving mattress, liaise with her community and ward nurses to continue the management of her pressure sores. We discuss, as she is currently unable to use a wheelchair, she would not be able to access the smoking areas. Phil states, 'She gets low in mood when she doesn't smoke.'
I suggest we could consider using Nicotine patches. They think this is a good idea.
I pursue the side effects of phenol, but as with Pete, I avoid discussing the potential impact on sexual function. It seems inappropriate at this stage.

Reading their lifestyle pattern, Phil is heavily involved in all of Sue's daily care needs; they do not like to accept help. I sense they are a couple that strive to maintain their privacy. Our relationship still appears fragile and I do not want to jeopardise it by addressing this potentially sensitive issue. After a long clinic I feel sapped of energy and concerned I may not be able to find the words to address this issue sensitively enough.

Tuesday

Last week whilst I was on study leave, Ann had been urgently admitted for a problem with her pump. She telephones and her opening comment is: 'Where on earth were you last week; haven't you written that book yet?'

I laugh loudly and retort, 'I don't need a supervisor with your close monitoring. How did the admission go?'

'Very smoothly.'

I smile and say, 'See you didn't need me.'

She replies 'But it's nice to know you're around'.

Later journal reflection

Ann's reference to me studying caught me by surprise and made me consider how patients view nurses 'studying'? Research takes time to develop and complete maybe it seems an eternity to patients. This highlights a tension with practitioner research although my research is steeped in my practice and directly affects it, demonstrating this to users may not always be readily apparent.

Phil telephones; he explains that having discussed IP with Sue and their MS nurse they wish to go ahead with a trial. Phil is businesslike in his manner and leads the conversation to discuss managing her admission. I feel unable to disrupt his efficient management style; I miss the opportunity to talk about the impact of IP on sexual function. I share this with their MS nurse. She admits to also struggling to discuss sex and interestingly shares that she has received feedback from people with MS and their partners how intrusive they had found the previous MS nurse because she had always asked about sex. This counteracts a study by Rubin (2005), where 20 men with MS and a rehabilitation team expressed the importance of discussing issues relating to sexuality.

I reiterate to the MS nurse why it is important to discuss with Phil and Sue and she said she would see what she could do. I feel relieved to share this with a colleague.

Later supervision

CJ challenges me that I seem to be burdening myself with addressing the potential effects of IP on a person's sexual function, maybe I should pay attention to when it is appropriate to discuss or omit such a discussion. Maybe it is enough to be mindful of these issues, flow with the situation, introducing the information as appropriate.

Wednesday

Cliff is in his local hospital with pneumonia and septicaemia. His doctor's have advised he is too unwell to travel for a pump refill and suggest it is unnecessary, as he may die soon. Our team feel it's important that ITB is not stopped now as it could potentially cause him seizures, pain and discomfort as he nears the end of his life.

I tell my manager that I will be off site for two thirds of a day to refill his pump. She immediately queries why I have to go. I concentrate on the technology and how it's important not to cease treatment as this could lead to side effects. I stress there is nobody locally who can refill his pump. I don't emphasise the close working relationship I have developed with Cliff and Julie over the last seven years, that we have shared several critical periods with his health and I want to visit in case I can offer them psychological and emotional support. Why is this? I'm afraid my manager will say I can do such support over the phone and do not need to visit. To secure her agreement I manipulate the situation by emphasising the technical over the emotional.

Julie seems really happy to see me, she shares that Cliff has slightly improved. He smiles at her. The previous week he had not been responding. His nurse caring for him is keen to watch the refill and I discuss ITB therapy in general. As we slightly lower the bed head, Cliff grimaces with discomfort. I ask, 'Do you want us to raise the bed a bit?

He nods. It feels good to involve everyone. Once finished I leave the room to empty the dressing trolley his nurse follows me. I ask, 'How is Julie holding up?'

She replies, 'She seems Ok,' and then quickly changes the subject, 'MS it's such a devastating disease isn't it, I mean he is so young and so disabled.'

Despite being aware of such attitudes in nurses throughout my research, I am shocked that she moves the discussion so quickly away from Julie and Cliff onto the disease. I don't comment. She continues, 'If I was in that situation I would want someone to shoot me...'

I am speechless and throw her an incredulous look, regardless she continues, 'I'm serious that is what I would want!' Another nurse in the room affirms what she is saying by nodding agreement. I mumble, 'They have a good life together' and rush back to Cliff's room.

The room is bustling with activity one of Cliff's friends is reading him the newspaper and showing him the pictures and his brother has just arrived visiting on his lunch-break. I reflect how these activities encompass a more caring response than what I had just encountered in the treatment room.

As I leave I feel it is important to arrange when I will next see them, I don't want to imply that we will see what happens. Julie seems to hang onto the date and I say I'll call in the meantime. Julie walks out with me, I ask, 'Do you fancy a coffee?'

'I'd love one' she says smiling.

She questions, 'How long do you think Cliff will live.'

I reply, 'It's difficult to know we were in a similar situation last year and he is still with us!'

We laugh and agree how strong a fighter he is. I emphasise the importance of his loving family around him and praise her skill at looking after him. She states, 'It is so hard to see him in hospital and not interfere in his care.'

I reply, 'The nurses may appreciate your input, have you thought of asking the ward sister what they are happy for you to do and what they aren't?'

'It's a good idea Lou, but if I do too much the nurses will get reliant on me and then I worry when I'm not here, you know would they be caring for him. I know it sounds bad but I am treating this admission as a rest especially as he now doesn't have respite.'

I appreciate a tension for long term carers of balancing giving care, letting others give care and taking time out for a rest. Despite this Julie shares, 'It is much easier not sending him to respite. The nurses were forever ringing me thinking he was unwell or stating they were unable to manage his care. But now with Macmillan night nurses, three times a week and paid carers the situation is much better.'
We smile as I say: 'He always hates being away from home, look at how I have had to coerce him into hospital in the past, I am sure he is much happier with this arrangement.'
I ask, 'How are you coping?'
'I am pleased he is on active treatment even though he is not for resuscitation. I learnt from the past and was very clear with what I wanted. It was much easier to negotiate this time.'
'How is your teenage son coping?'
'I'm worried he is having lots of headaches and always phoning me to find out how his dad is. He has said to me we should stop treatment and let Cliff die.'
I reply, 'That must have been quite difficult to hear.'
'Yes very.'
'Do you think he is doing it to protect you?' Julie looks at me, I continue, 'I bet he is as equally worried about you as his dad. I expect it is very difficult for him to witness his mum going through this.'
Julie looks really surprised, 'I have never really thought of how he must feel about me that makes sense now.'
Julie discusses her future plans and getting a job, 'I feel I have no skills to offer.' I highlight what skills she has in all the years of caring we laugh as say, 'I could write your CV.'
Julie was thoughtful and states, 'Your right I do have all those skills.'
Completely changing the subject Julie muses, 'I think some of the nurses on the ward feel Cliff's life is not worth living.'
Thinking back to my conversation in the treatment room my heart lurches, 'Have you heard that?'
'No I can just tell the way they speak and interact with Cliff and me.'
I reflect how perceptive she is and how important it is to remember that people can sense how we feel about them, by our very presence, the way we touch, speak or remain silent.
Julie states, 'I am finding it difficult to plan Cliff's funeral. My friend is a bereavement counsellor and has suggested that I might find it helpful to do this now.'
I reply, 'It is difficult, have you spoken to Cliff about it? With his sense of humour he would probably find it quite funny that you are agonising over this.'
She laughs in agreement, 'I have never thought about doing that.'
'I know he no longer speaks but you more than anyone can interpret his small facial expressions and grunts.'
She pauses and then suddenly claims, 'I've seen a dead body.'
I sense shock sweeping my body; I freeze my facial expressions to mask it. I don't want her to stop talking; she doesn't seem to notice and continues, 'An old man died on the ward. It was all so calm and nicely done; he just closed his eyes and died with family members holding his hands.'
I slowly realise she is utilising opportunities to prepare for Cliff's death and offer, 'It could be the same for Cliff, no drama just a calm ending.'
She smiles, 'I am so relieved; whenever you see it on TV it's always dramatic.'

She continues to describe how she watched the whole scene how the man died, how the body was dealt with and how the wife coped. She describes in detail how the wife went around the ward thanking everyone. Comparing this to herself she says, 'I am sure that won't be me I will be running around screaming.'
She continues, 'I needed to see a dead body. I asked his wife if I could, I peaked behind the curtains he just looked asleep.'
I listen intently but silently I battle with my thoughts, where were the nurses's to maintain the privacy for this dying man and his wife? I try to understand the relationship that had developed between the two wives, decades apart in age, and how Julie had used the situation to prepare herself for her husband's death.
In this moment I realise I have never given much thought to the power of transient friendships that can develop for carers in this way. This situation was very significant for Julie and could have only occurred between the two grieving woman, nurses could have perhaps facilitated but only participated on the peripheral of such an interaction. I wonder what I would have done if I was Cliff's or the dying man's ward nurse? I think I may have run around screening off the dying episode preventing Julie from rehearsing an important coping strategy and offering support to the other grieving wife.

As we leave the coffee shop, we hug and say goodbye.

Train journey home

All of the above points were discussed over one coffee, which lasted about 40 minutes, it was a powerful exchange and I think a very valuable use of time. I am not sure if Julie had a chance to discuss any of these issues with other people, or how useful she found it, but the conversation flowed freely, we had been honest and despite the situation we laughed and talked about the future. Our exchange highlights the importance of knowing the family and that I can still relate to Cliff as a person. This enabled Julie to talk about Cliff the person and perhaps to see that he could still help her to make difficult decisions. Julie and Cliff have taught me a lot about death and dying.

Thursday

Fred is Diane's husband and main carer, she is now dependent for all care and I have known them for nearly ten years. Fred telephones, 'Our marriage is at breaking point. We have discussed parting but I don't want it to come to that, I don't want her to go into a nursing home. We are ringing you Lou, because we don't want to talk to our GP. Diane doesn't want it in her notes that all her community team have access to. She is happy to speak to you though Lou, you know her.'
I immediately think I do know her, but is this within my role boundaries? How can I help this couple? If I do not open this avenue of dialogue as they are requesting I could potentially restrict them from seeking specialist help. Yet I need to tread carefully what if I open up an issue that I do not have the skills to deal with. He must have read my mind, 'We know you are not a marriage guidance counsellor but we would appreciate your help.'
Maybe I need to just listen with compassion and flow mindfully with the conversation.

Diane is only able to activate her 'hands free' telephone at certain times in the day and maintain her privacy from carers. It takes five times before we are able to speak confidentially. Despite my reservations Diane readily discusses her low mood and I acknowledge it is common for people to feel low about the restrictions their disability can cause them. She shares her main concern is that she will be classed as cognitively impaired for feeling depressed. I share how the two issues differ. She decides to speak to her GP about options to treat her depression. We revisit the benefits and disadvantages of respite and Fred regularly taking weekends off throughout the year. She agrees that I can liaise with her social worker about reviewing her care and to explore the possibilities of how she can have a weekly outing from her house without having to rely on Fred.

After the call I am relieved she is going to take action and that she is happy for me to contact professionals who are in closer proximity to provide practical help.

Similar to Phil and Sue's situation this scenario emphasises that people with complex disabilities fear seeking intervention in case they are labelled as cognitively impaired, which they then perceive would restrict their involvement in making decisions about their own health. Likewise this situation demonstrates a tension between the two labels; 'being depressed' or 'cognitively impaired' both can dehumanise and as with Mabel it's possible that cognitive impairment can mask depression and for it to go untreated.

Friday: Pump clinic

The clinic is overbooked. First we see Carla.[81] Her spasticity and spasms have not improved; she feels unwell and is barely coping at home. We all agree she is possibly having a MS relapse and urgently book her in to be reviewed by her neurologist and MS specialist nurse.

Our third person to refill is Colin he admits to having less relief from his spasticity and he has been having a lot of headaches. It is an unusually difficult refill. Suddenly his abdomen begins to swell. We admit him for an urgent surgical review. In theatre it is found that his intrathecal catheter has disconnected from his pump and CSF is filling his abdomen.

Molly is next and has a mild wound infection; she also needs a surgical review. The last patient Polly is disgruntled about the outcome of her ITB. I remind her of the original agreed goal. She replies, 'My physiotherapist feels the pump can achieve more.'

I know that her physiotherapist has already been forceful about her views on the telephone to our physiotherapist. I feel dispirited that a colleague is unrealistically raising this woman's hopes. In turn it increases the difficulty of our interactions.

As I tidy the clinic room I reflect that this clinic has been exceptional for the amount of problems we have encountered. I have managed to flow with the issues but recognise that the space to work in therapeutic alliance was constrained by the time available for each person. Although maybe working at such a level of honesty, trust and intimacy enabled me to use the time we did have more effectively. I make a note to reflect on each interaction on Monday and consider if I need to make any follow up calls to extend our interaction space.

As I review the past few days I realise it has been quite a week.

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[81] Reflective text 12, p177-182.

Postscript: November 2004

Cliff has died

Julie explains, 'He just went to sleep and didn't wake up. It was very peaceful and so good he was at home.'
I feel relieved, their greatest wish had been granted it wasn't dramatic and had happened at home.
Julie continues, 'Lou, it was really difficult to see him at the undertakers he was just skin and bones, it was somehow emphasised in the coffin. Even though I had been active in his care, I had become less involved in washing him, you know the sores were so big, in the end they stretched right across his bottom, bone could be seen. The carers said I didn't need to see them. I didn't realise how thin he was...'
She takes a deep breath and continues, 'People keep saying I should get back to normal and get rid of the hospital bed from the sitting room. This confuses me I am finding it hard to know what normal is. For me normal is Cliff in bed in the sitting room.'
I reply, 'It's going to take time to adjust to Cliff not being around. He will always be a big part of you; after all you did start dating at school and carried on through all your formative years. You really don't know adult life without Cliff in it.'
I share with Julie how I have always admired them as a couple, not letting MS dominate but integrating its management into their daily lives. How it was such an asset that they could read each other so well often negating verbalisation, which was so valuable as time moved on and speech got difficult and then impossible for Cliff. I remind Julie how she courageously took on each next step of Cliff's care becoming his expert. She explains, 'It was difficult to watch some nurses suctioning him as they didn't know Cliff and I knew I could do it better, sometimes it was difficult not to tread on toes.'
She continues, 'I know it's the suctioning that kept him alive for so long and I am trying not to be bitter, but the pressure sores were his major problem and caused him the greatest distress and discomfort.'
She recounts how on at least three occasions Cliff had spent 24 hours waiting in hospital for a mattress, 'In that time I know the damage to his skin was already done and it would never heal. I really wish they had never happened. In a couple of months I may do some fund raising to buy the A and E department a pressure relieving mattress.'
I respond, 'Putting your energy into such a positive project is one way of fending off the negativity about the sores whilst highlighting in a constructive way to the hospital the impact they had on Cliff's life and end of life.'
I am reminded of Carla's pressure sore and realise my frustration with the nurses ambivalent attitude towards it is driven by stories such as Cliff's.

Julie changes the subject 'I am concerned how I am going to manage financially. All the care benefits stopped as soon as Cliff died, and because I am under 45 I am not entitled to a widows pension, just job seekers allowance of £50 a week.'

She laughs and continues, 'Despite twenty years of caring I have no national insurance payments to show for it!'

These comments jar me for I have never considered the financial implications of ending a period of long term caring. Somehow the abrupt stopping of the allowances seems insensitive when Julie is trying to adjust to her new life and think about a career.

As we say goodbye Julie says, 'You know Lou, wherever Cliff went people always seemed to warm to him.'

I reply, 'He had a twinkle in his eye and was always honest about what he thought.'

Julie laughs, 'He was a bit of a devil really.'

'But lovable.' I reply, 'With a great and often wicked sense of humour.'

Periodically along my journey with Cliff and Julie I have said to colleagues that I will feel sad when Cliff dies. But I don't. He was ready to die and it seems the right time. The day after this conversation with Julie having never written poetry before I sat up in bed and wrote the following poem as I remembered working with Cliff and Julie.

The Look

Piercing, bright blue eyes
Full of mischief, fun and cheek
Making others want to know you
they spoke a million words

You had special looks for
those who knew
But the one I dreaded became
known to Julie, you and I as 'The Look'

As time moved on you never had to say
that you didn't want to come into hospital
You would just throw me 'The Look'
Or Julie would say careful Lou you'll get 'The Look'

We would laugh it always eased the tension
As the time approached for you to leave
Julie fought so hard to keep you
where you always wanted to be – at home

She jumped many hurdles,
ignoring well meant advice
All the time striving to keep your wish
of staying in at home

I admire how she managed this
and know we all feel glad,
as not only did you get your wish
you'd taught us well and no longer used 'The Look'

3rd Analytical Pause

Insights

Within each of the preceding texts I find myself dwelling more deeply within the therapeutic space and the insights I have so far gained, most significantly a deepening appreciation of my role and the way I position myself in response to the other's precarious harmony.

Likewise I have become more mindful of the way my position within the team influences or threatens to dislodge the person's precarious harmony and my struggle for them to be seen and treated as a person. My insights are summarised in figure AP3.0.

My position: Intimacy and poise

My experience with Carla takes me deeper into the meaning of intimacy, not just through the use of imagery but also by recognising that to be intimate requires a sharing or giving of self, for instance when I hug her. I recognise that through intimacy I can build on my appreciation of a person's precarious harmony.

This degree of intimacy can be emotionally draining and I use my guided reflection sessions to manage my feelings. Through dialogue with CJ, I move closer to an appreciation of poise, to balance my vulnerability as I let go of the need to control the therapeutic space and engage with the other's suffering.

The process of engaging a person in intrathecal trials and measuring their spasticity creates a space where I can build on my appreciation of their pattern, but it can also confront both the person and their family with the extent of the person's disability and can lead to a change in their precarious harmony. Being skilled at measuring goes beyond the task of producing numerical scores and involves considering the whole person and how the experience is impacting on them, their family members and their precarious harmony.
To further consider how I can position myself to get the most from collaborating with others, I return to Barbara Hepworth for inspiration.

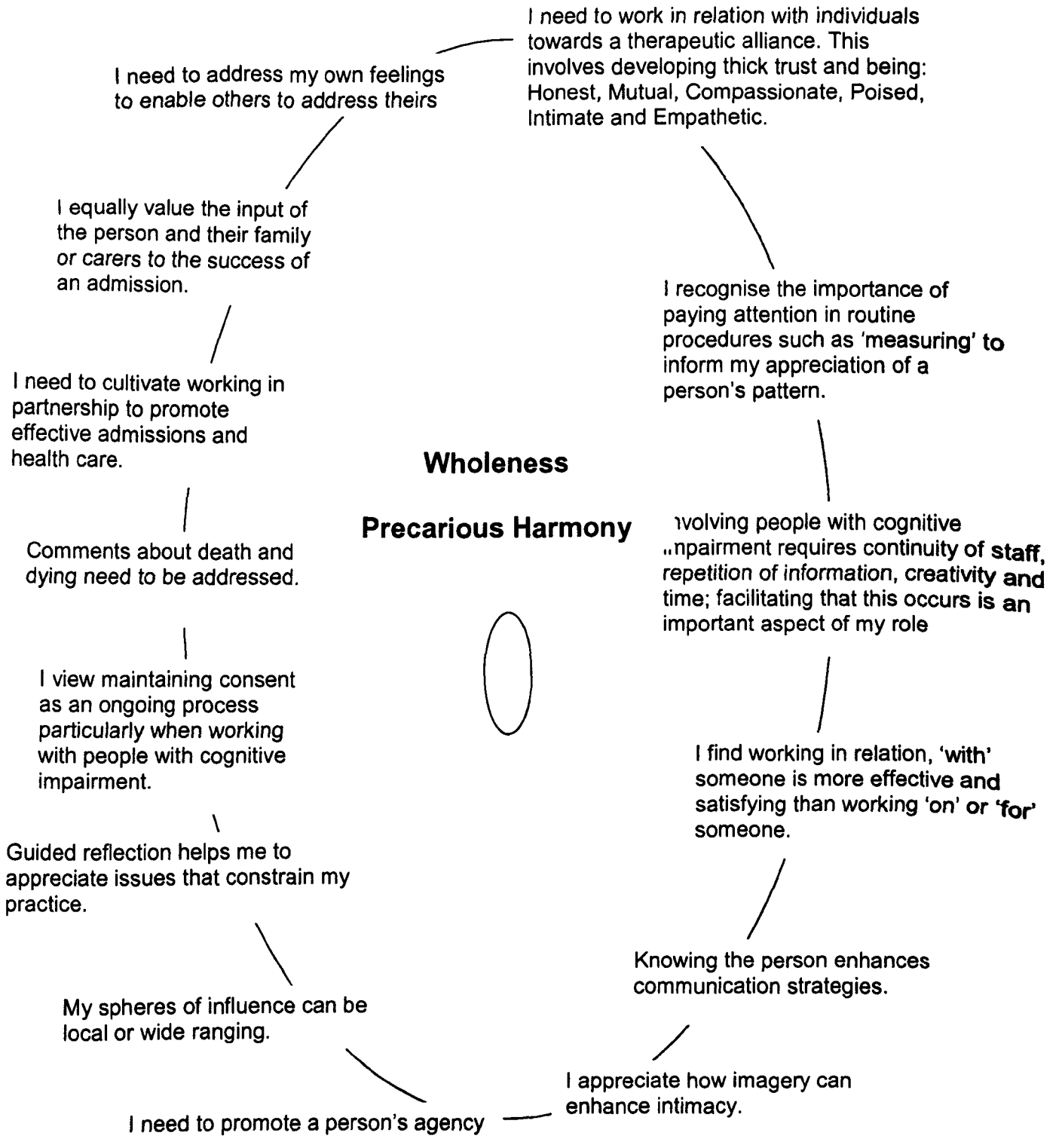


Figure AP3.0: Insights from texts 11-17

Barbara Hepworth and Health care

In the late 1940's a surgeon who had previously operated on one of Barbara Hepworth's children invited her to observe and sketch whilst he operated. She made a series of drawings from these visits and Alan Bowness (1985) her son-in-law quotes how she described one such experience,

> 'At first I was scared, but then I found there was such beauty in the co-ordinated human endeavour in the operating theatre that the whole composition – human in appearance- became abstract in shape. I became completely absorbed by two things: first the extraordinary beauty of purpose between human beings all dedicated to the saving of life; and secondly by the way this special grace (grace of mind and body) induced a spontaneous space composition, an articulated and animated kind of sculpture very close to what I was seeking in my own work. I wasn't trying to tell a story, but the experience proved a theory I had – that no matter how many people are involved – their action and poise and intention produced drawings rather like ballet; though the ballet is contrived, whereas in the operating theatre the action is not contrived but disciplined and at the same time intuitive. In a fearful emergency everybody goes into the right sort of place and the most extraordinary shapes are made.' (Bowness, 1985, p50-51).

From her observation Barbara Hepworth identifies that space is created and shaped between professionals and a person to carry out health care work. She highlights the need for collective grace, poise, intention and intuition. I identify with these issues in my interactions with people with spasticity, particularly in the stories of; Pete,[82] Ann, [83] Cliff,[84] Jay,[85] Carla,[86] Maud[87] and Mabel.[88]

Working in relation towards a therapeutic alliance

To create a therapeutic alliance I have identified the need to work in relation with others, a partnership based on honesty, intimacy, mutuality and thick trust. This involves actively communicating, listening intently and flowing with the dialogue whose direction is often led by the other person. For instance with Ali I followed his lead on discussing his wish to die, although tentatively I tuned into his wavelength, being sensitive to issues that concerned him. Likewise I was perceptive to Phil and Sue's [89] reasons for their reluctance to attend the clinic.

Intently listening, interacting and flowing with a person's conversation is more likely to promote trust than mechanically and silently completing tasks, assuming their needs or using glib reassurance. A person with a complex disability does not necessarily have a limited life span (Swain and French 2008). Further, my experience with Cliff and Julie in particular showed that someone can be in a stage of approaching death or a palliative phase for quite some time. I feel the palliative phase for Julie and Cliff started in August 2001 when they stopped looking for a cure, although he didn't die until November 2004. During this phase, effective communication with Cliff and Julie remained a key

[82] Reflective text 2, p112-119
[83] Reflective text 9, p155-161
[84] Reflective texts 3, p120-121; 15, p193-197; 17, p204-207, 209-210
[85] Reflective text 10, p162-167
[86] Reflective text 12, p177-182
[87] Reflective text 3, p121-123
[88] Reflective text 13 p183-185; 14, p188-192
[89] Reflective text 17, p202-203

priority, as Cliff became limited in the way he could express his needs, techniques to communicate with him were vital to role model to others.

Carla moved from agentic to victim; although she was empowered when working with the spasticity team this did not translate to other teams. I recognise that how I interact with a person does not always translate to how they interact when working with others. I could have been more proactive with teaching her about pressure area care and the use of anti-emboli stockings.

Knowing the person requires utilising all available resources, for instance I should have liaised with the nursing home staff more effectively about Mabel's coping strategies.

Mapping my spheres of influence was instructive in reminding me of how wide my influence can be.

To shape the therapeutic space I need to manage being in a continual flux, negotiating how I am going to position myself to be most effective. I need to be sensitive to the ebb and flow of being in relation with others so as to maximise engagement of all.

Developing my vision

Supervision July 2007

Striving towards my vision gives me direction and intent and I have learnt to flow with pressure and work within the unfolding moment, tentatively holding and evolving my insights as I practice. I share with CJ my reworked vision,

> **To tune in and flow with a person's experience; appreciating their ever evolving life pattern whilst we work together to integrate spasticity management strategies, the use of drugs and technology to promote their health and widen their life space.**

We talk in a poetic form as we discuss the insights that have led to this rewording of my vision.

I muse,
Tension between chronic illness and the medical model
Nature of relationship with the person
Shaping space

CJ takes the flow,
Sensing the connection with the whole
Positioning self
Finding the wavelength

I interject,
Sensing the wavelength

CJ responds,
Touching the wavelength
Flowing with the wavelength
Mindful of expectation
Poise threatened by the carelessness of others
Shaped through ignorance

I continue,
How do I move boulders that litter our journey?
Tripping not just myself but also the precarious harmony that people with spasticity seek to grasp

CJ summarises,

Lives in balance easily rocked

From this we expand my vision,

> **To tune in and flow with a person's experience; appreciating their ever evolving life pattern and how they maintain their precarious harmony, whilst we ethically work together and with other colleagues to integrate spasticity management strategies, the use of drugs and technology to promote their health and widen their life space.**

Developing the being available template

I explain to CJ, 'Although I have continued to evolve my insights (Figure AP 3.0), I feel the influence of the being available template is not explicit.'
CJ comments, 'The being available template[90] has already influenced how you construct your therapeutic space through your reflective texts and the emergence of your insights. Its influence is floating in your matrix of space and practice, it is dynamic and shifting; maybe it is time to distance yourself from it?'
I respond, 'It has helped me to maintain a sense of the whole in regard to my practice as opposed to fragmenting my work into pieces. This has been instrumental in maintaining my practice focus towards the person with spasticity and their family in parallel with my own self-development. This is unlike the participants in the action research study who only focused on their own development and rarely focused on patient care in their supervision sessions (appendix 2).'

CJ asks, 'How would you describe your use of the being available template to others?'
I respond, 'My use has evolved to consider that being available to others requires a sculpting of our practice space, working to maintain or regain an individual's precarious harmony.

[90] p82-85

4: Towards a 'spatial appreciation' of spasticity nursing

The previous chapter has demonstrated how I used guided reflection to develop insights that have enabled me to grow and develop as a specialist nurse. This chapter summarises my approach and details how I moved towards conceptualising my approach to be able to share it with others.

Defining my approach

At the outset a potential outcome from my narrative was to define a model for spasticity nursing but as I have progressed I have become uncomfortable with the idea of 'telling' or 'suggesting' to others what they should do or be doing. For instance in text 13,[91] I feel my efforts of being direct with the agency nurse had little impact on her immediate practice. Similarly in the book I co-authored (Stevenson and Jarrett 2006) I highlight the profile of a specialist nurse and issues to consider when nursing people with spasticity. I detail competencies and protocols for specialist nursing practice and care-plans for the invasive treatments. However, as my texts with Janice,[92] Cliff,[93] Jay[94] and Carla[95] reveal, they do not ensure a high quality of nursing care. I prescribe how to safely 'do' spasticity nursing, whereas a key thread throughout my narrative is 'being' not doing. I want my resulting model or approach to embrace 'being' a specialist nurse that builds on this earlier publication.

To expand the models depicted in Figures AP1.3, AP2.0, AP3.0, I try to be more explicit about my insights by writing individually about each of one, incorporating other literary influences into a text to accompany the diagrams. After several revisions I stop as the text isn't flowing and is not easy to write or read. It feels stifled. It is reminiscent of one of the stages I went through in constructing my narrative where I lost the essence of the story and hence the meaning of what I was trying to express.[96]

Supervision August 2007

I lament to CJ, 'By writing individually about each of my insights I feel I am minimising my approach to practice, I lose its essence and meaning. The emerging text remains laborious to write and to read; it does not flow and follow the narrative form. I am imposing an order rather than flowing with what is inherent.

CJ responds, 'Within the disorder of your practice context there is order. Each insight is fluid, ever changing and cannot be shaped. You need to work with your insights as they are, albeit in apparent disorder. Metaphorically you flow with the creative edge.'

I continue: 'This links with chaos theory where order is implicit within; I do not need to impose an artificial order but allow it to manifest. I need to create the right conditions for it to be discernable. Holding each insight as a potential influence yet allowing each interaction to define its own pattern.'

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[91] p186-187
[92] Reflective text 9, p155-157
[93] Reflective text 3 p120-121; 15, p193-197; 17, p204-207,209-210
[94] Reflective text 10, p162-167
[95] Reflective text 12, p177-182
[96] Shaping the narrative form, page 98-100

CJ excitedly shares that he feels this discussion represents a moment of co-creation. I sense this and feel these ideas are in tune with my narrative but my enthusiasm is tinged with uncertainty, a mist is starting to descend, blocking my view of the horizon, my way forward. I try to clarify, 'So we are saying that within my chaotic practice context, order is inherent and I can be a catalyst for people with spasticity to self organise their lives and social worlds; to promote their precarious harmony. My role is to mediate, to help others to find a sense of balance in their lives.'

CJ replies, 'Yes all these aspects will contribute to the 'strange attractor' of your practice.'

Wheatley (1999) discusses how in chaos theory a system never behaves the same way twice and within the system's apparent chaos is an inherent orderliness. The 'strange attractor' (a mathematically generated computer image that traces a systems evolution)[97] is formed in what is known as phase space. Within phase space, the system can explore millions of possibilities that could contribute to the form of the strange attractor, but the process is not infinite, within the system is a boundary, the shape of its wholeness. This is not created externally and imposed by others but is inherent within the system (Wheatley 1999). I link this to the different dimensions a sculpture can portray within its environmental space; Bowness (1985) quotes Hepworth,

> 'I think that the necessary equilibrium between the material I carve and the form I want to make will always dictate an abstract interpretation of my sculpture – for there are essential stone shapes and essential wood shapes which are impossible for me to disregard.' (Bowness, 1985, p53).

I deduce that the material and the intent of the carver limit the sculptural form, as in chaos theory the limitations are evident with the system.

From these observations I realise why I struggle with being prescriptive to others, there are many variables, but I do not need to impose structure for there is an intrinsic order within my practice space that I need to flow and align with.

What impacts on the shape of the space?

The shape of my practice space is influenced by power, tradition and embodiment as barriers to rational change (Fay 1987).[98] These issues are enshrined within the fabric of how systems and individuals function. My practice shape is a fluid, dynamic space constantly shaped by these relational patterns and by the wider political agenda. Examples of these issues thread through the narrative and are particularly revealed through my discussions on conflict,[99] oppression[100] and people with complex disability being in hospital.[101] Through these issues my practice space is always under the threat of being altered or influenced, often curtailed, such as when my manager tried to prevent me from visiting Cliff.[102]

Widening the living space of the person with spasticity.

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[97] Chapter 2, p 79
[98] p51-52
[99] Reflective texts 4, p125-130; 8, p150-154
[100] Reflective texts : 4, p127-130; 7 p147-148
[101] Reflective texts: 2, 6, 8, 9, 10, 12, 13, 15, 16,
[102] Reflective text 17, p 204-205

A major effort throughout my transformation has been to work towards widening or maximising my practice space, revealing the potential of individuals as I strive toward my vision. This parallels how I envisage the widening of a person's life space as they manage their spasticity.

This appreciation was influenced by attending a collage workshop (appendix 7) at the reflective practice conference in 2007. Through dwelling with this collage, my previous piece of art[103] and my reflective texts, I realise that I describe spasticity in a similar manner; limbs are involuntarily held in angular positions and can move spontaneously. This can be painful and associated with a feeling that the limbs are heavy. In addition, to get to know a person with spasticity and their pattern requires time and effort. Health care professionals, health care organisations and societal attitudes can oppress people with spasticity. However another less obvious but perhaps more important similarity emerged. With the unfolding art I take the opportunity to see Jay, the person, not just her disability. As I strive to get to know a person with spasticity and appreciate their life pattern, together we become open, relaxed, more able to be ourselves and the space we share widens. Similarly, on the collage (appendix 7), as the depiction of our journeys join up and unfurl, the pictures become less busy and complicated, symbolising space and calmness as we refine the optimum way to work together. The following description of 'nursing' by Newman (1999) resonates with the way my collage flows to depict my evolving relationship with a person with spasticity.

> 'Nursing intervention is derived from a relational paradigm that directs the professional to enter into a *partnership* with the client, often at a time of chaos, with the mutual goal of participating in an authentic relationship, trusting that in the process of its unfolding, both will emerge at a higher level of consciousness.' (Newman, 1999, p97)

Through my texts and constructing a collage, I have moved towards situating individuals with spasticity and myself as a nurse in a wider context of the practice environment. As we work we move towards a higher level of consciousness, the inherent order within the chaos of our practice space reveals itself.

Integrating health and illness

Newman's (1999) view that health and illness are a pattern of the whole resonates with how the majority of people with spasticity I work with approach their lives; health and illness being integral to their lives not separate entities.

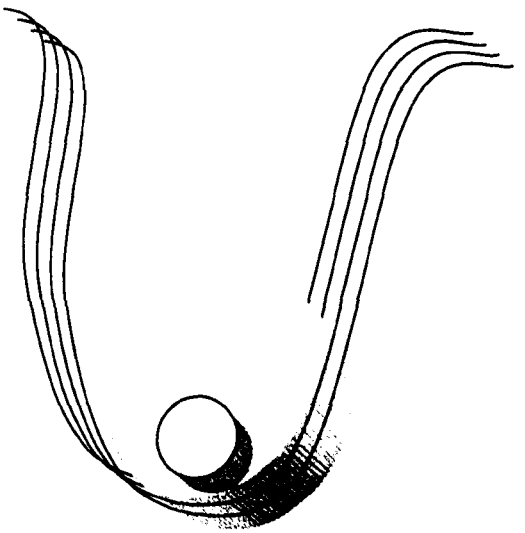
I strive to appreciate a person's approach to health and illness so as I can work in relation with them to manage their spasticity. We consider the advantages and disadvantages of utilising treatments and technology in their lives; exploring the choices they may or may not want to make to alter their existing life pattern and precarious harmony. I am mindful of engaging them actively in the decision making process. By responding to their wholeness through appreciating their pattern, they can see themselves in relationship to life and health factors. We begin to create new spaces or put another way, we expand our consciousness. Our therapeutic space could be said to have a creative edge as we explore these options. To be mindful, I need to hold this creative edge, flowing with the tension as we explore new spaces. CJ suggests I try to capture this summation in a new single image.

[103] Reflective text 10, p166-167

Further representation and development of my approach and vision

Guided Reflection: September 2007

I share with CJ figure 4.0 as a representation of my approach as a whole.



To sculpt the therapeutic space I share with a person with spasticity, their family members and other health and social care professionals, I need to tune into the other's wavelength to understand, connect with and flow towards maintaining and improving the balance of the person's precarious harmony.

Figure 4.0: A conceptual model for spasticity nursing

I explain that as I practice, I visualise this image as representing the influences on sculpting my therapeutic space. Working with a person with spasticity, their family and other team members is fluid, a floating space where I hold insights as potential influences, which move in and out of dominance and hence impact on the person and their precarious harmony. The strings represent my insights and hold the ovoid shape (the therapeutic space) in perpetual motion; its piercing reminds me to think of the potential and actual aspects that are influencing a person and their family. The potential space between the strings and ovoid represent the creative edge of sculpting my practice space.

My thesis is that to work effectively with people with complex disabilities requires appreciating their precarious harmony, whilst striving and flowing to sculpt the practice space with all those who share it. As I state this to CJ, I finally see a potential way of communicating this to others, and suggest, 'Of course I need to write another story, an exemplar text, of how I now approach my work as a result of my study. This will follow the narrative form and allow the reader to make his or her own interpretations; I do not need to be dictatorial.'

CJ smiles as he directs me towards his computer and suggests, 'Why not try and start to write it now. Think about how I have constructed 'RAW'[104] and dialogued with the literature.'

I write a poem and later use it as headings as I weave reflections and insights from recent experiences into a text that depicts the precarious harmony of individuals and my current approach to sculpting the practice space.

[104] RAW is a performance narrative written by CJ. I have participated in presenting RAW with CJ and two other students, Maria Fordham and Bella Madden at the Reflective Practice Conference in Denmark June 2007 and on the 17th July 2007 at Bedford University as part of CJ's inaugural professorial lecture.

Sculpting my practice space

August 2007

Travelling to work my mind turns to what the day may hold,
Something's known and others unknown.
A mystery play unfolds,
I plan my day,
Mindful that I will encounter and flow with as yet unidentified issues.

As I leave Waterloo station and head for Waterloo Bridge I feel a tinge of excitement, as I will pass 'The Hayward', the gallery currently hosting an exhibition by the sculptor Antony Gormley.[105] Some of the figurative works are positioned on pavements and rooftops and my husband Jon and I spend the five minutes crossing the bridge counting how many we can see (Figure 4.1).

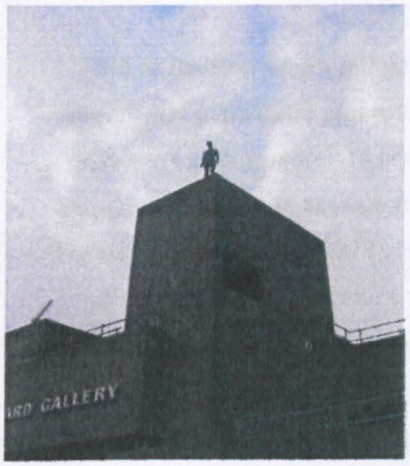


Figure 4.1: A figurative sculpture by Anthony Gormley on the roof of 'The Hayward'

(Photographed 25th May 2007).

As I touch the sculpture on the bridge, I remember the quote attributed to Anthony Gormley,

> 'Sculpture reminds every one that we are human and we are embodied, incarnate, that all your sense of self and being comes through the body, which is only fully itself when placed, connected to an elemental world.' (Gormley, 2001 cited in Exhibition Guide, 2007, p17)

I am reminded to work in relation with people with spasticity, to tune into their wavelength, to be creative if they have significant cognitive impairment, to work towards keeping individuals engaged whilst I strive to appreciate their precarious harmony and the environment they live in.

Environmental space

Arriving at my office desk always acts as a prompt to check my voicemail. As I punch in my numerical code I ponder, will there be urgent voices to attend to or the telling of a life transition, such as a new job or the birth of a grandchild?

I will sense how to respond.

As I listen I am simultaneously logging into my computer to check my emails. The plethora of ways to keep in contact with others has so many guises in our technological world; effectively managing

[105] 'Blind Light' Anthony Gormley 17th May – 19th August 2007. The Hayward, Southbank Centre, London UK. I attended the exhibition on 25th May 2007.

technological communication so as it compliments and does not dominate my daily practice is a challenge. Using a computer is often difficult for people with severe spasticity; I rarely receive emails from people with spasticity so I know my emails will be management orientated. The telephone is my most important tool in maintaining communication and my availability to people with spasticity. From the telephone and email messages there are no urgent issues to attend to today, just a few clinic queries and a colleague asking me to do a lecture. I feel relieved that unexpected issues will not as yet encroach on my space; I will have enough time to visit Connie, an in-patient, and to prepare for the afternoon pump clinic.

Colleagues arrive shaping the tone of the office space.
Some are in conflict with self, others or me,
What time have I to respond to their needs?
Striving to maintain the balance of my practice space,
Focusing on my vision,
I respond to hold the harmony of the team in the few moments available.

How I respond to my multidisciplinary colleagues has been influenced by the modernisation of the NHS pay structure (DoH 2004). The claim of this national review is to promote equality of pay across all non-medical professionals in the NHS. My therapy colleagues working at an equivalent level job have been graded two levels higher than I am. I have formally appealed against my band and despite significant support from my general manager I remain on one band lower than my therapy colleagues. This inequality persists throughout the Trust between nurses and other allied health professionals. However, unable to muster support from my nursing colleagues I have not pursued the issue. Having raised my head above the parapet once and been knocked back I do not feel strong enough to continue to fight this battle on a wider Trust basis, especially as I have received careless comments from my medical colleagues, 'Surely you knew when you became a nurse you wouldn't be paid well.' I respond, 'I think you are slightly missing the point. The drive for this review is equality of work carried out, not what profession you are part of.'

I wonder why I respond, in the past I would have remained mute thinking any comment was futile, but through my research process I have become more assertive which helps to maintain my sense of self worth, at least locally even if not Trust wide. Considering the conflict grid (Thomas and Kilmann 1974, Figure 4.2), I visualise my position.

Managing conflict is considered interplay between how assertive and co-operative individual's are. This can lead to five interaction states; a person who is highly assertive and co-operative is collaborative, with low assertiveness and co-operation a person avoids conflict, with low assertiveness and high co-operation conflict is accommodated, high assertiveness and low co-operation can cause competitiveness, and a similar regard for both can lead to compromise. If I had ignored my colleague's comment on nursing pay, I would have been unassertive and had a low concern for self, I would have avoided conflict. However by answering my colleague's question I visualise myself moving up the assertiveness axis, although I am aiming for a collaborative relationship the risk is I could become competitive.

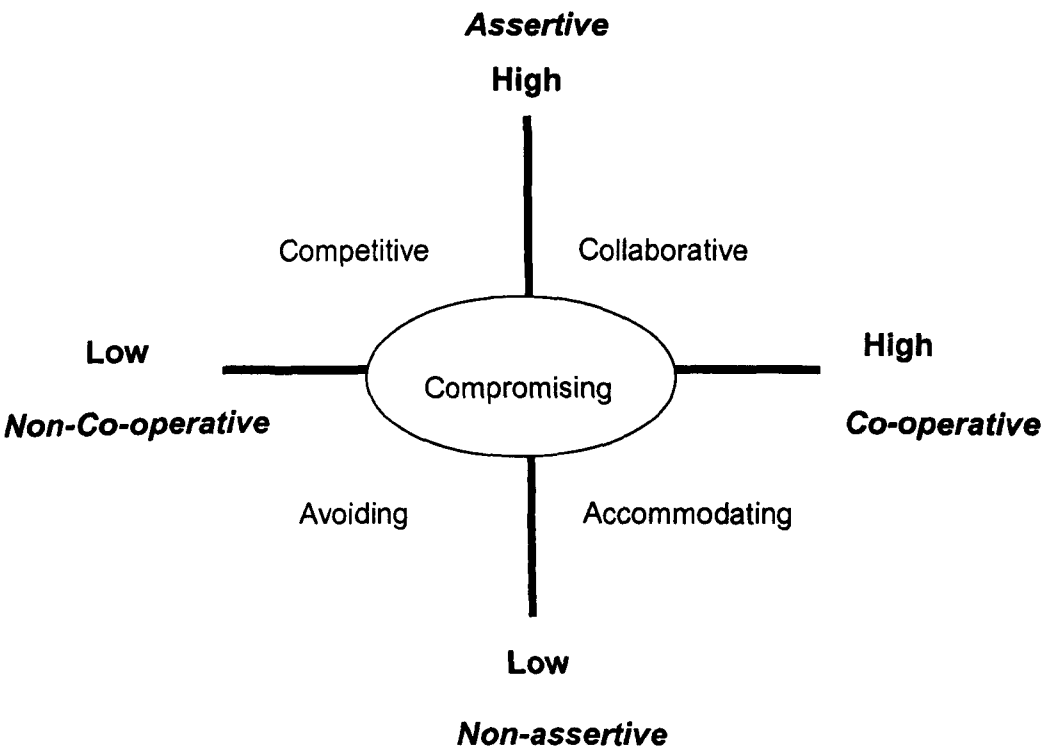


Figure 4.2: Adapted model of managing conflict based on Thomas and Kilmann (1974) cited in Cavanagh (1991)

The pay review process has been a brutal reminder to me of how nursing continues to be an oppressed profession. The knowledge and skills of nurses are financially valued less than those of other disciplines working in equivalent level jobs across the Trust. In one of my attempts to query this discrepancy a co-ordinator from the Trust's pay review implementation team said, 'Your job description could not be judged alongside physiotherapists, for they 'treat' and nurses 'care'.' No amount of discussion would change her opinion; I sensed she was voicing a mandate from higher sources. The irony of her statement is that my job description emphasises the technical side of my job, this was done to demonstrate the 'treatment' aspect of my role as it carries significant risk to people with spasticity and hence responsibility for me; notwithstanding the risk to the smooth running of the organisation if mistakes are made. The wrong placement of a needle as I refill a pump could result in baclofen being injected into the wrong port and could kill someone. I know this and have written and published protocols to safe guard against it (Jarrett 2006). No therapist in our department takes such risks. My manager thought the technical emphasis would support my job description to be assimilated with those of the therapists; reinforcing the view that technical skills are valued more highly.

In response to my explanation I am told by the co-ordinator that my title has 'nurse' in it, therefore I will be banded with the other nurses.

Her response is at odds with how I have interpreted the meaning of 'equality' in the new pay scheme. I feel wronged that I am financially penalised when I take such responsibility, but my energy is spent I

can no longer fight the system. I am outwardly passive, yet raging inside. Each time I walk into the building I feel my insides being torn into shreds and I want to turn around and run home.
Roberts (1983) describes three ways that oppression is maintained; only behaviour preferred by the oppressor is rewarded; the oppressed are taught the oppressor's values; if the oppressed threaten a revolt, token rewards are given to stem the challenge, which often leads to further dependency and powerlessness.

I view my appeal outcome as a token reward, especially as my pay did not increase. I was moved to a higher band but as the pay scales overlap I remain on the same level of pay. My advantage (token reward) is that I now have more annual increment points than if I had remained in my initial band.
The appeal process was long, required detailed paperwork and I was not kept informed of the progress. This illustrated to me the oppressors (Trust managers) preferred values, they want a docile workforce not a challenging one.

I accommodate the potential conflict by having low concern for self whilst I strive to have high concern and co-operation with my immediate colleagues. I try not to let the situation cloud my relationships with the 'junior' therapists who are on the same pay as me, yet seek leadership and constantly ask for advice and guidance, but I know it does. When I hear, 'Lou can I just ask you something...'
I feel unease in the bit of my stomach, but I smile and try to stifle my cry of, 'Why do you not ask your discipline leader, the one paid higher than me?'
I don't cry out, I know the answer. They ask me, as I will be able to discuss a solution with them, whilst their leaders will not.

My manager has presented me with a potential opportunity, 'a dangling carrot'. She states there is potential to restructure the team, disestablish and create new posts that existing team members could then reapply for. Such a process *could* lead to me having equal pay, although there is a risk it will not. Eventually I see no way forward than the plan she presents. I summon the energy to raise my head over the parapet once again and positively respond to the call for interest in the potential new jobs. I get no response. When I respond for the second time I am told, 'Oh that plan is not happening at the moment it has to go on hold, as another review has to occur first.'

Yet another token reward thwarted and I remain powerless.

Johns (2000) warns that the effort and energy required to maintain relationships between team members can become the dominant driver in practice, restricting space for developing therapeutic interactions with patients.
Whilst I feel an equal and valued member of the spasticity team and have been financially supported to attend conferences and courses by my department I am not financially rewarded on an equal basis with my colleagues for the day to day work that I do. My loyalty is dented; I know I am being used. I am relieved I can see it now, for too long it has been clouding my therapeutic space.

Returning to Kieffer's model,[106] I remain in the third phase, the era of incorporation, as I recognise and confront my position within the team, the department and the wider organisation. I realise my narrative could be viewed politically; a statement of a specialist nurse's value and contribution that challenges the accepted norm across the Trust. Whilst for me personally this is an unexpected outcome of my narrative it demonstrates the role of guided reflection and supervision in realising the empowerment of individuals.

As I take a deep breath I remember the diagram to flow with pressure.[107] I need to focus on my vision and sculpt my space to nurse.

Protecting my therapeutic space

My vision is my safety line I return to it again and again; it is why I am here. I leave the stifling row of offices full of dishonest memories and unfilled promises. Immediately the clouds hanging over me disperse as I make my way toward the neurorehabilitation ward[108] where Connie was admitted yesterday.

Shaping our space,
Finding a way forward.
Working with the ward team,
Shaping and sculpting the day.

I dwell with Connie, reading the signs, her pattern. I ask myself do we manage her spasticity effectively. Mindful of my concern for this woman battered by her spasticity and spasms, I look at her body searching for clues to how she is managing within this ward environment. I know the ward can be insensitive wrapped up in its rigid structure and process, I become the protective mother I smile and ask, 'How's things?'
I am ready to confront incongruent care. She responds, 'I am good, I slept well I am ready for the ITB trial.'

Listening to her response, I silently question, are there any cues that I need to pick up? Is she disclosing all her concerns? What help does she need? How is her precarious harmony being challenged by this admission?
She must read my mind as she says, 'No truly I am ok it's better than I expected. I just told the nurse last night how I liked to be positioned and they were able to achieve it.'
I am heartened that the moving and handling skills of the rehabilitation nurses in contrast to the skills of the acute nurses are beneficial to people with spasticity. I notice my deep breaths and regain my poise as I realise I do not need to take responsibility for Connie. She can make her voice heard above the medical din. As Boyd (2001) notes,

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[106] Figure 3.4.2, p129
[107] Figure 3.5.0, p133
[108] As a result of a bed usage review across the hospital, people with spasticity undergoing intrathecal trials are now admitted to the rehabilitation ward as opposed to the acute wards. Whilst this was part of a larger restructuring I was able to share my experience to support the move and to illustrate to the rehabilitation nurses where their unique skills would be of benefit.

'...some individuals with perceived disabilities may in fact be healthier than other individuals without perceived disabilities- not simply because, subjectively or existentially, they regard themselves as healthy, but also because they have sufficient physiological reserves to be equal to the environmental challenges they face. And that, after all, is perhaps the most that any of us can hope for.' (Boyd, 2001, p362)

The measuring space

Today we measure Connie's spasticity.
It can be a time of deep fear,
Others take it in their stride.
Being sensitive to her response,
We teeter along the edge of her precarious harmony.

Mary, the physiotherapist joins us and I explain to Connie, 'Before we do an intrathecal trial we like to try and understand your spasticity and spasms in more detail. We would like to move your limbs, stretching them to their fullest extent, within acceptable pain levels for you. If the pain gets too much you must tell us to stop.'

'I don't get much pain anyway.'

'That's good, but we will be stretching your legs to their limit this may bring on pain or discomfort, we want to stop as soon as that occurs, so let us know.'

I smile as I continue, 'I'll be watching your face as I have a sneaky suspicion you might not tell us if we hurt you?'

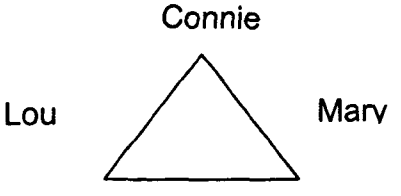
Connie smirks, 'I don't like to make a fuss.'

'We want you too if it hurts. We want you to work with us to minimise your discomfort. Its likely we may also bring on your spasms?'

She nods, 'Yeah Ok that may hurt. I'll tell you.'

Reflections on the measuring space

Mary and I stand on either side of Connie's bed; together we form a triangular shape, our space for discovering what Connie's spasticity feels like.



In her book on the 'Signs of Life', Angeles Arrien (1992), a cultural anthropologist, shares how she discovered that five shapes appear in the art of all cultures and they carry similar meanings. The circle represents wholeness, the square stability, the triangle represents goals and dreams, the cross relationships and the spiral growth. She states that,

'People experiencing the triangular process are intensely focused on identifying and pursuing a goal; attaining it is extremely important to them' (Arrien, 1992, p55).

The identification and attainment of a goal is most pertinent in the process of measuring a person's spasticity. We use many measures (protocol 2) but in a review of our ITB goals (Jarrett et al 2001), it

was measuring whether a goal had been achieved or not that provided the most reliable information on whether the treatment was effective.

I find measurement scores helpful as they form a baseline quantifiable judgement that can be easily compared pre and post intervention and communicated between disciplines across care sectors. The subjective perspectives; the person's description and my experience of the passive movements provide me with the greatest appreciation of the person's level of stiffness, and the force of their spasms and how they may be impacting on their life pattern. Communicating these subjective issues is difficult, yet it is these aspects that are most pertinent to the person and in assessing the overall success of an intrathecal treatment.

In December 2004 I attended an international conference: *Evidence Based Measurement and Treatment of Spasticity*. Whilst sitting through a workshop on, 'How to measure a 'patient', I recalled my experience with Tina and Leon and my insights that measurement can bring disability to the foreground and can have an impact on the person being measured and their family.[109] In the prevailing discussion I suggested that it was important when measuring to consider what it is like for a person with spasticity to be measured? The audience was a mix of scientists and clinicians, there was some agreement with my statement, but I felt it may have been a new perspective for some.
When we measure we concentrate on the detail of how much we can move limbs, how they feel when we do so, we get the individual to focus on what their main problem is and what would be the one thing that could improve their current lifestyle. Between the 'measurers', numerical scores are shared for example Ashworth (Ashworth 1964, protocol 2), often these have little or no meaning to the person with spasticity. In my clinical practice people have responded to the measurement process both positively and negatively. Positive statements include,
'It feels really good to be stretched like this it hasn't happened for years.'
'I am delighted you want to look in detail at my spasms.'
On the other hand we can also get other statements such as,
'Is it good or bad?'
'Have I passed the test – will I be able to get a pump now?'

When measuring, I listen for any such statements that cue me to appreciate how the person is feeling during the measurement process. For some people being measured can make them feel as if they are being tested or judged and that they are at the risk of failing. I have found supporting an individual through education, engagement and involvement can enhance the measuring process (Jarrett 2006b).
Education involves 'why measurement is required'; 'how it will help the team assessment' and 'what their role is in it'. That it is not a test and there is no right or wrong is stressed. How a person can actively engage in the measurement process is important. With people with high levels of cognitive impairment this may require creativity and flexibility to engage with them when they are most able; for

[109] Reflective text 11, p173-176.

example breaking the process down into small sections to ensure they do not fatigue. The close involvement of a significant other or main carer maybe helpful to provide a perspective on how the outcome may affect the person's lifestyle and care routine at home. Their involvement requires mindfulness, for it can impact on their perception of their family member's disability, as it did for Leon. [109]

Measurement tools that involve self reporting for example visual and verbal analogue scales from the person or carer can help them to engage and feel part of the process. It also helps them to focus and be able to be more specific about the changes they feel in their bodies during the intrathecal trials.

Space for discovery

I continue to explain the process to Connie, 'As we stretch and move your limbs, Mary and I will be trying to measure your spasticity. We use different numerical scores, so you will hear us sharing numbers and writing them down. There are no right or wrong answers; it's not a test. The numbers do not mean much on their own, but they form a baseline so that after each trial we can repeat your measures and compare them.'

'Ok I think I understand; it's nice someone is taking such an interest.'

'I will continue to explain things as we go along. Firstly we need you to transfer from your chair onto the bed.'

Connie looks panicked. I respond, 'You look concerned, is it not as easy here as at home?'

She nods. We position equipment and Connie as best we can for the transfer. She manages it with little help from Mary and I, but it is not a safe transfer. I discuss with Connie that some of the nurses may feel they do not have the skills to assist her with her transfers and would rather use a hoist. She replies,

'I know they did that last night. It's Ok, it's safer for us all.'

The environment of a hospital needs to be arranged to promote the safety of the majority and not individuals. This can be a stark reminder to a person of their level of disability, and may emotionally force them to confront their illness in the foreground (Jarrett and Johns 2005).[110]

My hands start to move towards Connie's legs, I am eager to move her limbs through their available range so as I can compare what I feel, with my previous experience and knowledge. This is a vital facet to how I build up my interpretation of Connie's pattern. What I experience as I move Connie's legs builds on her description of how they feel. Yes, I can have a sense of how the movement feels by listening to a numerical grade from one of my colleagues, but it is no substitute to experiencing the movement, as Gadow asserts,

> '...in order to have access to the subjectivity of a silent patient, nurses must be re-embodied, must experience their bodies as part of their own subjectivity rather than as unfeeling instruments. Only through the re-inhabiting of the body does it become possible to experience the patient's body as a subjective being rather than a mere thing.' (Gadow, 1989, p76)

Whilst Connie is not silent it is difficult for her to describe how her legs feel, and terms can be confusing. For instance heavy can be used to describe either stiff or weak legs and distinguishing the

[110] Reflective Text 11, p176

difference is vital to establish the appropriate treatment. Only through feeling the passive movement can I gain an appreciation of Connie's description. I use my body to understand hers.
When moving Connie's stiff limbs that may violently spasm, I focus on both of our postures, my aim is to maximise the movement to promote safety for both of us. I watch her face, looking for positive and negative signs of her well-being. As I flex and extend her limb I concentrate on the passage of movement and what I can feel. Is the movement fluid? Is there resistance? If it resists does it abruptly stop or slow the movement, does it slow then release so the limb passively moves more freely again? If a spasm is triggered I focus on my grip and the way I have moved the limb. I question, whether the spasm is as a result of my handling of her limb or is it in response to the stretch or occurring spontaneously and how could this correlate to how Connie moves and functions in her daily life? Sometimes to flex or extend a limb I have to use as much strength as I can summon, when measuring I use my body as a 'feeling instrument'. I feel it is more sensitive to change than any outcome measure.

Connie tolerates the stretching of her right leg, but as Mary reaches end of range at her left knee, Connie lets out a sharp yelp. Mary releases the stretch, Connie grabs my hand and together we do some deep breathing.
We pause with the stretches.
Connie says 'Carry on, I am Ok now.'
I respond, 'Why don't we have a rest from the stretches and just talk.'
Connie shares that her spasticity and spasms are with her throughout the day and night. She is woken at least once a night by strong extensor spasms and she dreads the possibility of kicking her husband Stuart.
Angeles Arrien (1992) expands on people experiencing the triangular process,

> 'They have the innate gift of vision and their greatest need is to follow their dreams. Their worst fear is that there will be no dreams to pursue.
> They will persevere despite substantial obstacles and delays for as long as their goals have meaning for them. They need to avoid becoming so absorbed in their plans for the future that they accomplish nothing in the present.' (Arrien, 1992, p55)

I sense that Connie is hanging onto a dream. I need to unearth it, mindful that I need to be honest if I feel ITB cannot fulfil her dream.
Connie looks distracted and I note a glassy film covering her eyes, she manages to say with a quivering voice, 'Stuart and I are thinking of having separate beds.'
I offer, 'And you really don't want that.'
She turns and fixes on my face with a pleading look and nods. Her dream uncovered, not to loose the intimacy of sleeping with her husband.
I must remain in the present and consider if we can achieve this goal? I am torn I want to explore how she feels, but feel inhibited with Mary there and the pressure of time to finish the measures.
I have learnt the importance of addressing sexuality.[111] I know I will discuss sexual issues with Connie but I need to do it at the right time. In a study exploring intimacy using semi-structured interviews and

[111] Reflective text 2, p118-119.

diary analysis with ten nurses, Williams (2001) found that to be intimate required reciprocal personal disclosure that could vary in intensity from superficial sharing of information to personal secrets. It requires time and the presence of a nurse being with the person to appreciate their experience. I want to give Connie time and the privacy to discuss this on a one to one basis; this is to address my need for privacy as much as hers.

Connie's tears are flowing. I ask, 'Would you say disturbed sleep is your biggest problem?'

Through her sobs she states, 'Well my movements are the biggest problem for Stuart, his sleep is disturbed most nights.'

I recognise this is potentially a key element that could jeopardise their precarious harmony and I inquire, 'A lack of sleep then causes tension during the day?'

She chews her bottom lip as she nods, but is more composed. I ask, 'Describe to me a typical day?'

As Connie talks other tensions emerge between her and Stuart, 'He helps me to get dressed in the morning before he goes to work. Recently it has been taking longer because my spasms are more severe. He has been late for work. His boss isn't very sympathetic.'

Another threat to her precarious harmony revealed.

We continue to talk as we finish off the other measures. Mary and I think we can suggest ways to improve her night-time posture and dressing techniques in conjunction with using ITB. We agree a potential goal, to reduce her night-time spasms and to ease the effort of getting dressed in the morning.

Connie's mood is lifted.

Changing space

As we finalise the goal Stuart arrives he looks tense but smiles at Connie as he kisses her. She asks Stuart, 'Did you sleep well?'

Stuart's face flushes red and he looks embarrassed as he nods.

Space shifting,
Space for them to be together.
Should Mary and I go?
We all dwell together.

I am conscious of my presence in this our shared yet changing space as Stuart joins. I remain available I read the signs waiting for the moment when he will turn and signal my presence in the space. He looks at me, I respond, 'Hi how are you?'

He replies 'Just fine.'

I wait. No more comments. I discuss what we have done today. Connie shares with him the goal. He looks excited, visibly pleased. He gets animated as he talks and his posture relaxes. I start to discuss ITB, the plan for the trials and ask if he has any questions. He replies, 'Not really, well just one.'

Then the questions flow.

We are now in dialogue.

The living space

Off to pump clinic.
I know who I am expecting to see,
But I prepare myself for unexpectedness.
Living with chronic illness is always precarious; order is an illusion,
Family conflicts, transport difficulties, pump problems, spasticity out of control,
Crisis and chaos fill our space.
Holiday snaps, new pets, work promotion,
Lives being lived to the full, lives in transition,
Transforming the clinic into a living space.

Diane is late for her appointment it's most unlike her. We get a message that an ambulance is unable to pick her up. I am confused she doesn't use hospital transport, Fred her husband always brings her. I ring her home telephone number there is no answer. I wonder if she unable to activate her 'hands free' telephone or maybe they are on the way and caught in busy traffic. We continue to see other people.

Neil looks really happy. He has recently moved into a nursing home for young people and is full of stories about what he and his new friends are getting up to. He has nothing but praise for the nursing home staff. I am relieved when I refill his pump; as I can detect no new cigarette burns on his abdomen skin just a few fading scars. I make a note to mention this to the matron when I call her after clinic.

For Neil moving into the home from living on his own has provided opportunities to improve his health in all the areas that Lindsey (1996) identified as important to feeling healthy when living with a chronic illness; honouring the self; seeking and connecting with others; creating opportunities; celebrating life; transcending the self and acquiring a state of grace. When initially thinking about the move Neil had asked my opinion, I gave him a balanced view on the pros and cons for him as I saw it; this was a far cry from the negative attitude towards nursing homes I used to hold.[112]

Clarissa is finally managing her spasticity and spasms with the pump increase from the previous clinic, but she's unhappy and shares, 'My mum has fallen out with my best carer, you know the one who can move me properly, and now the carer won't come to the house.'
'I am sorry to hear that, what's happening now how are you getting care?'
'Well I don't blame the carer; my mum was very rude and shook her walking stick at her. I have other carers now although I'm scared mum will frighten them off too.'
'Is there anything I can do to help?'
'No just sharing it with you helps, I'm in contact with my social worker I am sure we can work something out, maybe I'll move out. I'll call you if I need to.'
I feel deep compassion for Clarissa and recognise how fragile her precarious harmony is. Four years ago she was independent, working and walking but she then experienced a severe MS relapse and spent two years in her local hospital. Once home it took a further two years to get the council to build

[112] Reflective texts: 1, p107-111 ; 7, p146-149

a ramp so as she can independently exit her flat rather than be dependent on four ambulance men. Now my concern is heightened as she is considering moving away from her mother, but also the environment which has been adapted and enables her a degree of independence. A major consideration, but how valiantly she seems to be coping. I take energy from her strength and continue to work through the clinic.

Both Neil and Clarissa illustrate having experienced aspects of a loss of self (Charmaz 1983); through living restricted lives, being socially isolated and having had to reconstruct definitions of self as their levels of disability increased. They also show growth; Neil in socialisation and Clarissa in considering moving house and taking action through liaison with her social worker. This resonates with moving from extraordinariness where individuals confront life with illness and their losses to ordinariness where they transform and reconstruct their lives with illness (Kralik 2002). I feel Neil had recently achieved this transformation and Clarissa was considering entering such a transition.

The chaotic and supportive space

Diane didn't make it to clinic, returning to my desk I get a message she is in her local hospital with pneumonia and could I ring the senior registrar. He was clearly panicked 'Diane says that her spasticity has got a lot worse since the pneumonia started, she reports her legs are stiffer and although not visible are jumping more. We do not know what to do? I am not familiar with the intrathecal pump.'

I ask, 'Are her legs stiffer from your perspective?'

He replies, 'Oh I haven't felt them, I am just relying on her report.'

I suggest, 'It's good to listen to her report, but it is not uncommon for spasticity and spasms to worsen with a secondary illness. We need to support her through this period it may mean increasing her spasticity management drugs, but importantly it also means sharing the evaluation of how her legs feel. Anxiety is likely to worsen her spasticity. I have checked her records; you can reassure her she still has enough baclofen in her pump reservoir for a further three weeks. Treating the pneumonia and working with her to assess if an increase in drugs is required maybe enough to settle the spasticity.'

As I replace the telephone receiver I reflect how common it is for the use of technology such as ITB therapy to raise the anxiety of other health care professionals unfamiliar with it, the focus becomes the technology and not assessment skills. Whilst it was appropriate for the doctor to telephone for specialist advice, it was clear he was not in relation with Diane. He distanced himself by not feeling her legs and sharing his perspective with her. This could have increased her anxiety, as she felt isolated making decisions about her spasticity in this situation. Woodward (1998) discusses how paternalism can be seen as something we should avoid, however she advocates that at times it can be appropriate to prevent the person feeling abandoned.[113] By encouraging the doctor to exert his perspective with Diane, by listening, sharing, jointly assessing and making decisions, I was attempting to maintain the agency (Polkingthorne 1996) of Diane within a supportive environment.

[113] Similar to how I reacted with Pete. Reflective Text 2, p117.

There is a troubled message on my voice mail from Carla. I call her mobile telephone number, she gushes, 'I have broken my toe, the bone is sticking out through my skin, I am in my local A&E. My spasms are all over the place.'

She continues to rant; with a calm, strong voice I respond in a sensitive but firm manner as I talk over her, 'Carla... Carla... I can hear you are upset.'

She stops talking, 'Oh I'm sorry Lou, am I ranting?'

'A little.'

We laugh, and I continue, 'Well done for going to casualty, that was the right action. You are in the right place, work with them Carla let them advise you about your toe.'

'I tried to phone you, but when you weren't there I imagined what you would say.'

I smile, 'You mean I would be bossy and say you need to go to casualty.'

'Exactly, once I have seen the doctors I'll ring you back. I'll tell them about my pump and give them your details in case they want to discuss anything with you.'

Two hours later she rings, 'I have had an x-ray. They have cleaned the wound, repositioned the bone and I am in a bandage.'

'How are your spasms?'

'They are still going but less intense, probably as I'm calmer now. Although I still feel I may come out of the chair.'

'Will you be safe tonight?'

'Oh yes.'

'We may need to increase the pump dose a little whilst your fractured toe heals, do you want to come and see us tomorrow?'

'No I think I'll be ok, I am coming to clinic at the end of the week I'll call you tomorrow and let you know how I am getting on.'

'That would be great – just another hurdle safely jumped then?'

Laughing she says, 'Too right, I don't do things by halves. Glad you are on the end of the telephone, speak tomorrow. Bye.'

Momentarily I reflect on my interactions with Carla and how today I feel we jointly sculpted the practice space to maintain her threatened precarious harmony. Woodward states,

> '...the inappropriate imposition of patient autonomy represents the antithesis of caring and asserts that a caring relationship, which balances respect for patient values and beneficent guidance based on the practitioners clinical expertise, protects the moral integrity of both patient and practitioner.' (Woodward, 1998, p1047)

I scribble a line in her medical notes,

Broken toe, treated in A&E. Carla noted an increase in spasms, settled once toe realigned. Will keep in telephone contact. Review in clinic at end of week.

As I slam the notes shut to signify the end of my working day, I think this entry hardly captures the crisis, her fear and my caring response. It's merely procedural. I chide myself; no wonder nursing remains invisible, oppressed and not valued. Despite my studies I still do not document the essence of caring.

Friere (1996 [1970]) shares that the major characteristics of oppressed behaviour stem from the ability of dominant groups to identify the norms and values as the 'right' ones in society, the values of

the subordinate group become negatively valued. This proceeds so that the oppressed hide their traditions, past or their origins. My entry resembles a medical way of writing. However when developing this text I do capture the sense of compassion, intimacy and partnership. I need to strive to keep narrative style notes of my conversations and interactions, so as the reality of my intervention is accessible in the notes to enhance others knowledge on a person's unfolding pattern and my nursing input.

Reflective Space - Journey Home

I can hardly write in my journal. I feel so drained. I do not have the energy to telephone any family or friends tonight, which I recognise as a sign that I have given a lot of myself today. I ponder whether there is any issue from today that I could take to supervision next week? Maybe I should explore the feeling that I took strength from Clarissa, the reciprocal nature of working in relation.

Henderson (2001) shares,

> 'It is clear that nurses not only experience strong emotions in the context of work but also consciously use those emotions to hone, refine and improve their practice. This is a high level skill and one, which requires great honesty, tenacity and perseverance.' (Henderson, 2001, p135).

Supervision has been instrumental in my quest towards desirable practice, I have used the space to explore and manage my emotions and the issues contained in the text that have arisen when working with people with complex disability. Without such a space, I feel I would not have remained in this job for as long.

As I touch the Antony Gormley figurative sculpture on my way back over Waterloo Bridge I am reminded of his words,

> 'There is part of me that feels that a lot of human nature is about trying to reinforce the illusion of our certainties. Art can undermine that. Losing the bonds of certainty about where or who we are seems to me to be very important' (Gormley, 2007a, p 56).

Similarly I have used supervision and my research process to identify and explore the uncertainties in my practice, I have been able to appreciate and flow with issues as they unfold, ultimately transforming and sculpting my practice space.

The essence of my approach

Sculpting space to work in relation

I hold uncertainty confidently

Whilst we transform

The space shapes its own order

5: Reflecting on my journey of being and becoming

The aim of this thesis can be stated as to improve knowledge and understanding about nursing and caring, through guided reflection, when working with people who have spasticity and complex disabilities. Through this process of guided reflection to transform self, I conclude that to work effectively with people with complex disabilities requires appreciating their precarious harmony whilst striving to sculpt the practice space with all who share it.

In this concluding chapter I will initially discuss the research methodology and the process of guided reflection. Secondly, I will discuss my conclusions, relate it to other work in this area and highlight implications for future practice.
hen discussing the research methodology I will:

- Place it in context with other narrative research methodologies
- Highlight its benefits and challenges
- Explore related ethical issues
- Describe how I used art to prompt and enhance my form of expression
- Discuss the transferability of findings

When discussing my conclusions and their implication for practice I will highlight:

- The uniqueness of the person with complex disability and the importance of appreciating their precarious harmony
- The factors affecting interactions with people with complex disabilities and the impact of 'self'
- The need to sculpt the practice space
- The role of art as a process of gaining knowledge and understanding

The research methodology

Placing my methodology in context with other narrative research methodologies

I describe my methodology (chapter 2) as a form of narrative inquiry that draws on influences from reflective theory, critical social science, autoethnography, hermeneutics and chaos theory. Within this thesis I detail my bricolage (Kincheloe 2001, 2005, Denzin and Lincoln 2005), a detailed description of the network of tools and methods I used to develop an understanding of my practice and how I try to convey that understanding to others.

Narrative inquiry is a broad term and currently encompasses different approaches, for example narratives are sources of data for phenomenologists, discourse analysists, and grounded theorists and cover different disciplines; sociology, psychology, anthropology, education, nursing and medicine (Hurwitz et al 2004, Holloway and Freshwater 2007a).

Since the work of Benner and her colleagues (Benner 1984, Benner et al 1996) there has been a continued interest in the use of narrative in nursing research (Frid et al 2000, McCance et al 2001, Frost and Cliff 2004, Holloway and Freshwater 2007a). Outside of the work of Johns (Johns 2004,

2006) and his students (Johns 2002, Fordham 2008), the approach I used of constructing my narrative through guided reflection and co-creation is not readily discussed in the literature. Instead the texts referenced above describe collecting stories from others through written mediums such as diaries or more commonly narrative texts are created from transcribed and analysed interview data. Holloway and Freshwater (2007), highlight that the process of collecting narratives through interviews is different to a more traditional qualitative interview of question and answer. With the narrative interview, the person is asked to tell their story, by use of a 'trigger or stimulus question' (Holloway and Freshwater, 2007 p708) on a topic that is personal and relevant to them and not the researcher. This, the authors claim, minimises the influence, although does not eradicate the power of the researcher. I described previously the argument that narratives are 'coached' and therefore constructed in a particular form. [114] In support of this McCance et al (2001) describes the difficulties they encountered in framing the questions to capture the person's experience, and I deduce, in the particular form that they wanted to capture that person's experience. In the narrative interview the researcher remains powerful over the researched by setting, or at least initiating the research agenda and shaping how the stories are revealed.

Being the researcher practitioner in my study at first glance negates this issue of the researcher having power over others, as I am researching self. However, throughout my interpretation I was aware that how people are represented in my texts are my interpretations and that they may have reflected and viewed the experiences in very different ways. Therefore, in my style of narrative inquiry, whilst I do not use trigger questions or try to 'coach' particular stories, the impact of self on the formulation of the narrative could be viewed as a form of power.

It is clear that all narratives are an interpretation of events; they do not capture the entire reality of an event. Narratives are an interpretation of an individual's perceptions (Taylor and White 2000). It is a constructed text based on reality; it cannot make claims of how others would interpret it. For instance, precarious harmony is my interpretation of how I view a person interacts with their living environment to manage their chronic illness; a harmony that can be easily rocked and disrupted by my actions or those of the team or organisation. Perhaps as a narrative researcher the best one can ever do is to be mindful and transparent, about their evolving forestructure of understanding (Heidegger (1962[1927]) and its' influence on a developing narrative and hence understanding.

The form of narrative inquiry I used does not just rely on appreciating, interpreting and developing an understanding of an experience, but extends its purpose through my intent to transform and improve my future practice. Captured as this is in a continual reflexive spiral, my narrative develops and unfolds as do my practice skills. Therefore, at the outset there is no defined question or set agenda, my research is driven by my intent to transform and improve my practice. Further, through the interpretation of the narrative by others, there is potential for their practice to be influenced.

[114] Chapter 2, p55

Does my narrative adequately reflect my transformational journey?

To plot my development I suggest the being available template[115] as a possible framework for readers to use. Czarniawska (2004) states,

'To become a plotted story, the elements, or episodes, need also to be related by transformation.'(Czarniawska (2004, p125)

I believe each of the being available template's interrelating factors ripple through my narrative and provide markers of my development and transformation. For instance, as my narrative progresses I become more aware of the importance of creating an optimum environment to practice in, or as I term, to sculpt and shape my space to practice. I had wondered if I would need to amend the being available template, but I feel there is no need. I have used it metaphorically as a springboard to delve into the essence of spasticity nursing, from which I have felt able to shape my insights and develop an approach.

The being available template is used as a marker to plot my transformation. This transformation is explicitly seen in my evolving vision that threads through and permeates the narrative as I strive to develop into the practitioner I want to be. The image that my vision is always tentative, ready for refinement is, I feel, inspiring as it suggests an ongoing, potential space for growth and transformation.

The benefits and challenges of my method

Certain benefits of reflective practice are detailed throughout my narrative and are supported by the work of others. In summary reflective practice and narrative can make the work of nursing explicit (Holloway and Freshwater 2007); transform the way nurses think of self, others and how they approach their practice (Johns, 2000, 2004, 2006, Taylor 2003); be empowering to the individual (Smyth 1992, Heath & Freshwater 2000) and produce local, context specific meaning and knowledge (Johns 2006, Holloway and Freshwater 2007).

A key strength of this methodological approach is it allows a continual evaluation of my practice and to test influences from other patterns of knowing; empirics, aesthetics, personal and ethical knowledge (Carper 1978). Other important benefits from this methodology which I discuss further in this section include that;

- The use of guided reflection and co-creation has provided support and developed my skills.
- There is a parallel development of both the supervisee and supervisor
- Being a practitioner researcher is less stressful than being just a researcher
- People with complex disabilities are not marginalised from being involved in research using this methodology.

Benefits

[115] p82-85

The use of guided reflection and co-creation has provided support and developed my skills.

The narrative and its meaning has been constructed through a process of guidance and co-creation.[116]

Guidance

Guidance is required to enhance learning through reflection and is a two way active process. As stated *in chapter 2* [117] *guidance was significant to me for multiple reasons, it has:*

4. Challenged my assumptions and insights leading to the co-creation of meaning
5. Opened up my perspectives on how I view individuals and situations
6. Picked me up when I felt demoralised, supporting me to take action as necessary

Guidance has been pivotal to the success of transforming my nursing practice. In particular, without guidance I would not have been able to see beyond the quantitative practice environment I worked in. Further, without guidance I would not have been able to develop my skills such as journaling and revealing contradiction in my practice.

Seeing beyond the quantitative work environment

My work place was steeped in a quantitative research culture, the randomised controlled trial being viewed as the gold standard of research methods. At times my language and approach have reflected this culture, for instance by finding it difficult to write in the first person. Guidance has helped me see and shift these social patterns in order to progress with this study and utilise a methodology directly related to my practice. Whilst the quantitative environment did not create an arena where issues relating to my form of methodology were formally and informally discussed to enhance my research knowledge, it did instil in me the importance of a rigorous research approach and the dissemination of knowledge to others through publications and conference presentations (appendix 6).

Journaling and learning to pay attention

Guidance to support me and persevere with developing the skill of journaling has been beneficial as I now pay more attention to my practice, which makes it more enjoyable and satisfying. Initially my stories focused on critical incidents of right and wrong, I concentrated only on the masculine perspective; I did not capture the nuances of care, the feminine perspective. As Johns states, 'The real drama lies not in heroic acts but in the fabric of relationship.' (Johns, 2006, p58)

Gilligan (1982) describes that a woman's moral development is focused on responsibility, care and being in relation with others. I believe these issues are what can make a difference to the essence of nursing; I initially had to work hard to reveal them so as I could develop and refine them. Through paying attention to my practice I now notice such details, register positive feedback and try to relate previous knowledge to the unfolding situation. I feel my approach is 'active' and ready to flow with the

[116] Figure 2.3, p60
[117] P78-81

developing situation, encompassing the views and concerns of all involved. I feel in harmony with my vision of working in partnership, tuning in to the wavelength of others.

The value of revealing contradiction

Being challenged through guidance allowed me to appreciate my values and continue to evolve my vision. It was also important to highlight when my practice was out of kilter with my vision. I now use my reflective space to nurture contradiction, to understand it for what it is and to chisel my embodied responses so as I can mindfully, carve and shape my practice space. I am aware of the gulf between understanding something and embodied practice. Indeed my whole journey could be framed as traversing this gulf (Figure 5.0).

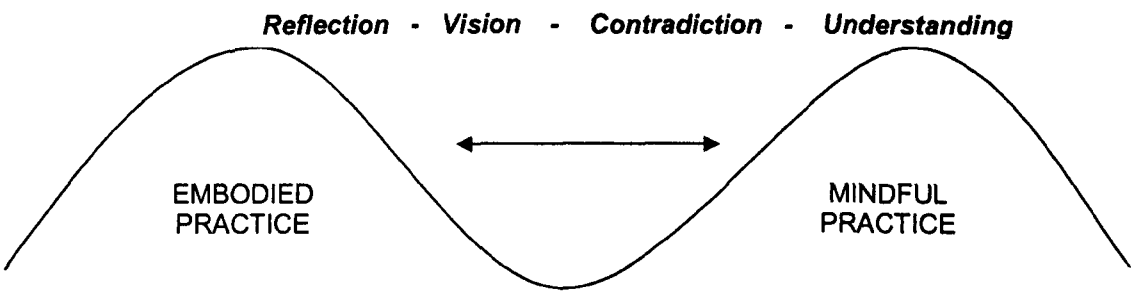


Figure 5.0: Traversing the gulf between embodied and mindful practice

Guided reflection as a way of being enables me to continue to explore my embodied contradictions continuing my quest toward desirable practice and my vision. In Kieffer's (1984) model[118] this resonates with his last phase, towards participatory competence within a community, the 'era of commitment'. He describes in this phase how people continue to struggle to integrate new personal knowledge, always looking to meaningfully apply it in their lives, leading and working within communities to improve them. I am excited about the challenge of continuing to develop self through narrative.

Co-Creation

I view guidance and co-creation as a two way, dynamic process. The act of co-creating has predominantly occurred with CJ, with influences from my other supervisors, people with spasticity and their families, my colleagues and fellow PhD students. Guidance focuses me to consider aspects of self in relation to my practice and it enables me to refine my insights, whereas with co-creation there is more interdependence between the guide and supervisee to evolve new meaning. The guide may not divulge aspects of self in guidance, however with co-creation the contribution of self to refine meaning is a more equal endeavour.

I have captured exchanges that represent co-creation in the previous chapter by detailing conversations between CJ and me, as I moved towards developing an approach as opposed to a model. We became poetic, perhaps tangential, yet strived to remain related to the issues. Guidance is

[118] 'Attainment of participatory competence through four phases of involvement. Figure 3.4.2, p129

a precursor to co-creation, but the process is not always strictly linear, guidance can occur in parallel to co-creation (Figure 5.1). For instance whilst CJ and I co-created aspects of my approach, I continued to require guidance as to the best way to present the thesis as a whole, demonstrating a parallel process between my clinical and research practice.

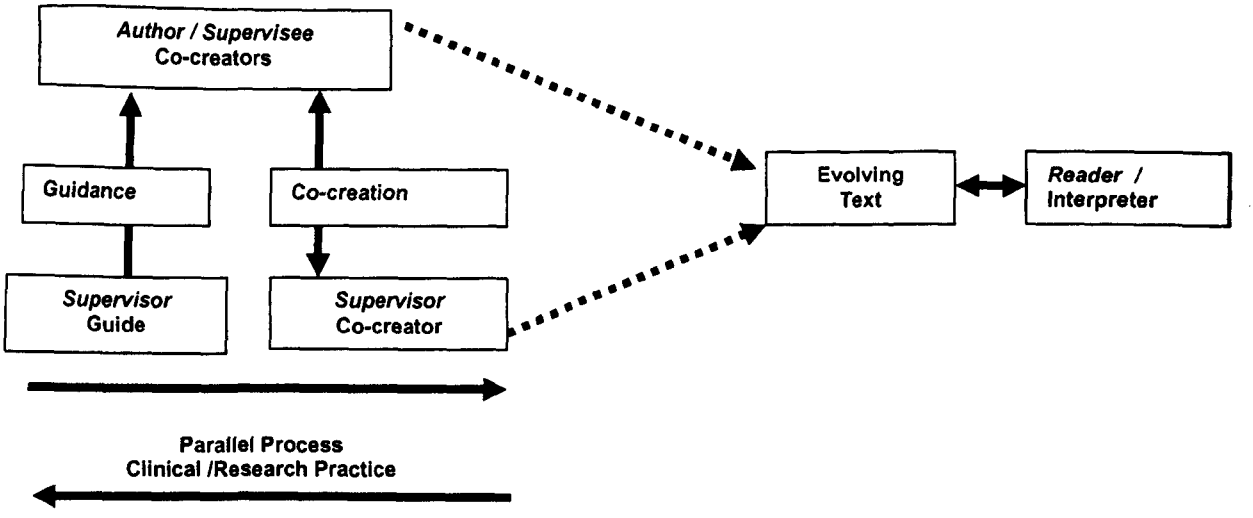


Figure 5.1: Relationship between guidance and co-creation

Readers of my text and those listening to my presentations at conferences have asked if I ever disagreed with CJ. Whilst this did happen it is not detailed in the thesis as in the spirit of co-creation we continued to dialogue and develop meaning that included our different perspectives. I have included in my narrative and continued to develop into my approach those aspects that made me think differently and informed my future actions.

There is parallel development of both the supervisor and supervisee

CJ stated that as I have developed my practice through supervision he has enhanced his approach and skills at being a supervisor. Similarly, as I have developed the skill of writing narrative, I have felt a shift in self to not only integrate reflection and being mindful into my practice but also to view the world as an unfolding narrative. Mattingly (1994) describes the work of occupational therapists in this way, simply as narrative. In supervision CJ shared how he has also shifted from describing this methodology as, 'guided reflection is a journey of self inquiry...' to 'narrative is a journey of self inquiry...'

This demonstrates that through this research process a parallel development of the supervisor and supervisee can occur.

Being a practitioner researcher can be less stressful than being a researcher who refrains from being a practitioner

Kidd (Kidd and Finlayson 2006) writes poignantly about the stress she went through when data collecting from nurses who had experienced mental illness. She goes as far as to suggest such research can cause harm to the researcher,

> 'Engaging with participants for whom the nurse-researcher also feels a professional ethical commitment increases tension and creates a heightened risk of harm to the researcher. (Kidd and Finlayson, 2006, p428)'

When reading her account I questioned why my data collection didn't lead to such similar levels of stress. I concluded that Kidd is listening to the narratives of others but she is not 'part' of the story. She feels frustrated, as she is unable to intervene as a mental health nurse, she has to remain as a researcher, detached and listening. Whereas I am part of my stories not just as the author or editor but also as a character, I can intervene and change the course of events. I can take action. This may not always be as effective as hoped, but I am not constrained by 'rules' that certain research paradigms impose on researchers.

Similarly, Lalor et al (2006) describe how a researcher, the interview transcribers and the research supervisor all experienced emotional distress during a grounded theory study, exploring the experiences of women carrying babies with a foetal abnormality. The researcher reported the least stress, as she adopted an approach of sharing information and her knowledge with the interviewees at the end of each interview. The supervisor and transcribers reported that only having the opportunity to read or transcribe the painful transcripts and not be able to intervene was distressing. From these studies and my experience I wonder if being a researcher/ practitioner is not as stressful as trying to be one or the other.

Good (2001) warns of the danger of being the practitioner to someone who is also in your research study, she talks of the imbalance of power and that there must be no risk of a reduced, eliminated or compromised service to the person. I acknowledge that vulnerable people need to be protected from being coerced, or doing something they may not want too. However, this must be balanced against giving them the opportunity to be engaged in the process, supported if necessary by a practitioner who knows them. I recognise a need to guard against vulnerable people being unduly influenced by powerful others, and feel ethical frameworks need to be developed which stretch throughout practice, research and even perhaps life itself.

Kidd and Finlayson (2006) suggest researchers need to engage in regular supervision to explore and challenge their role. I would support the position of guided reflection in both enabling me to uncover the ethical issues in my practice and my research but also as a supportive space for me to explore how to manage them.

People with complex disabilities are not marginalised from being involved in research using this methodology.

My narrative captures my interpretation of dialogue exchanges that I had with people with complex disabilities, who often had major difficulties in communicating. To maintain a sense of flow, my narrative does not detail the time it took for people to convey their meaning, or the physical and cognitive effort, or the number of times we abandoned sentences only to pick them up when the person was able, maybe minutes sometimes hours later. A benefit of this occurring with this methodology was I could revisit these issues with the person, when they were most able to communicate. I was not so bounded by time constraints as an interviewer might be. Taylor (2003) privies conversational analysis as a method to analyse narratives, with the people I work with, obtaining the conversation to analyse would be time consuming and possibly impractical whereas my reflective texts were at least able to capture my interpretation of our exchange.

Corker and Shakespeare (2002) in their writings on embodying disability theory value the plethora of research approaches within post modernism methods, which aim to capture the complexity of lives, lived and further societal understanding. The disability movement has in the past favoured the social model of disability as opposed to the medical model (Swain et al 1994, French 1994) as one way to challenge the thinking of others. In essence the medical model confines the problem to the body, often just the part that is affected; the impairment. This locates the issue as a problem of the person. The social model moves to look at the whole person, not just its affected parts, and firmly states that problems occur because the environment is not set up to allow people with disabilities to function. For instance public transport and buildings have limited wheelchair access. Such issues are viewed not as the problem of the individual but of wider society. More recently both the medical and social model have been challenged as creating universal models that,

> '...end up creating, totalizing, meta-historical narratives that exclude important dimensions of disabled peoples' lives and of their knowledge. The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas.' (Corker and Shakespeare, 2002, p15).

Corker and Shakespeare (2002) state future research needs to continue to aim for the emancipation of disabled people and the development of inclusive societies that embrace the diversity of disabilities that people may experience. I believe that narrative construction is one such methodology that could be used to actively involve people with differing levels of disability.

Barton (2004) discusses a co-participation approach to narrative inquiry with Aborigine people she had previously nursed. She describes a process of facilitating the sharing of stories between her and the participants, through interviews, where ultimately their dialogue and interactions created new stories. Barton (2004) created a new environment through the process of carrying out the research interviews, whereas I see potential value in not altering the context from practice to research, but integrating the two or as I suggest earlier, viewing narrative as a way of being in practice. I see the potential for nurses to learn about self, their practice and ultimately improving the experience of people being nursed, by nurses narrating their everyday practice encounters and encouraging

individuals to narrate their experience back. I envision new horizons, narratives that are co-created between two or via a group. This would create joint, contextual narratives where all participants have agency and power, as together they sculpt the practice space.

Challenges

In the spirit of a reflexive narrative I have highlighted the difficulties I have encountered as the chapters have unfolded. For instance in chapter 2[119] I tried to convey my personal challenges in being able to write in a coherent and readable style that is both accessible and credible to my readers. In this section I revisit the challenges of:

- Embarking on a novel methodology and the potential of my work and findings not being accepted by others
- Managing my time
- Dialoguing with the literature

These challenges could be viewed as potential criticisms of the methodology or even as warnings to future researchers considering using this approach.

Constructing my narrative: A novel research approach

From the outset I needed to acknowledge the influences of the quantitative environment that I worked in. I needed to embrace writing in the first person and to disclose my feelings. There was an excitement but also trepidation in being a practitioner researching self, through the use of a reflexive narrative, a developing area of research methodology (Rolfe 1998, Clandinin and Connelly 2000, Freshwater and Rolfe 2001, Johns 2004). Would such an approach be accepted as research, did it matter if it wasn't, if it helped me to improve my practice? I wrestled with these thoughts throughout the process and as I dealt with inevitable challenges from others.

In the beginning with the absence of rigid methodological rules to follow I felt a sense of freedom to carve my own research route, yet overwhelmed by the different philosophies and methods available to inform me. Not following a well-trodden methodological path felt a potential risk that the research would not be recognised by health care professionals as legitimate and therefore able to inform their practice. Further, I was concerned as to whether its style of presentation would be accepted at a PhD level by the university. So what maintained my motivation and commitment? Intuitively my methodological approach felt 'right' and the process, as it progressed, was a catalyst for change. As Pinar (1981) states,

> ' Autobiographical method offers opportunities to return to our own situations, our 'rough edges', to reconstruct our intellectual agendas. The focus in such work is the felt problematic; its method is intuitive. One falls back on oneself -rather than upon the words of others - and must articulate what is yet unspoken, act as a midwife to the unborn.'(Pinar, 1981, p184)

[119] p62-64

At times constructing the thesis was arduous as each part or section had the potential to impact on other sections. It was a challenge to keep the whole thesis in perspective. There was an ongoing demand to rewrite and review sections in light of new insights. Until the last word of the last chapter was written I couldn't say that any part of the thesis was complete. To remain in the hermeneutic circle of being and becoming, using the six layers of dialogue required discipline and patience. At times I just wanted to write the text, to finish my thesis, but the text was not always ready to reveal its order. Much as a midwife prepares a pregnant woman for the birth of her baby, I had to nurture the growth of the text, gradually layering insights until it was ready to be born. This produced a tension between the time constraints to gain a qualification and the time needed to dwell with the texts to reveal understanding. Guidance was crucial at these stages to give support and encouragement.

One l criticism of this methodology could be to question whether guidance and co-creation allows one to develop as an independent researcher. Through this narrative research process I have become a reflective practitioner, incorporating lifelong learning into my practice and research. My thesis is a moment in time, but my research is a continuous process. Through journaling I continue to change experiences into story text, extending it through reflective to narrative text. As my exemplar text in chapter 4[120] demonstrates, I am still in the ongoing hermeneutic spiral of being and becoming. Layer 6 encourages the researcher / practitioner to become hermeneutic readers, to stand back, consider everything as tentative and pursue deeper understanding and meaning. Narrative research is a way of approaching lifelong learning, a co-creation process with another person or a group. To become independent is to be mindful in relation to self; it is a way of being. Further, independence can be highlighted by the ability to transfer these skills to others by being a supervisor and co-creator or participating in group supervision.[121]

To draw my narrative together I needed time away from my practice

Drawing the narrative together so as it adequately represented my journey I found the most challenging part of the process, it required patience and time. One of my difficulties was that having struggled to refine the skill of developing story into reflective text I needed to further develop my writing abilities to produce a narrative text. This was challenging to do whilst still in full time practice, as I was continually drawn back to layers 1, 2 and 3 to reflect on my experiences and refine my skills as the process was by now integral to the way I practiced.

Receiving an educational bursary[122] enabled me to take a secondment from my job and allowed me the space to consider my narrative as a whole. Returning to practice after the year, I was more mindful of moving between all the layers as my practice unfolded.

As I am sure it is with many long term periods of study, my personal commitment to this process, that of my supervisors and the support from those family members close to me, my husband in particular,

[120] p221-234

[121] Throughout the research process I have continued to supervise others and participate in the PhD research group facilitated by CJ at Bedfordshire University.

[122] MSTrust Educational Bursary Aug 2006 – July 2007 - £12,000

also has to be acknowledged. This process has demanded copious amounts of energy and time as well as the management of my personal emotions and finances.

Dialoguing with the literature: Evidence based and reflective practice

A further challenge is that the chronic illness literature seemed to have limited applicability to my practice. Significant papers (Charmaz 1983, Loveys 1990, Kralik 2001, 2002 and Paterson 2001), referenced through the narrative specifically helped me to expand my understanding of living with a chronic illness. Literature related to 'being' a nurse working with people with complex disabilities is scant, although I found the work of Thorne and Robertson (1998, 1998a and 1989) particularly helpful to gain greater insight into my interactions with people with spasticity and their families, which led to an expansion of their model.

The relatively low number of influential papers may reflect a difficulty with evidence based practice; that the current nursing literature is not directly applicable or transferable to nursing practice, an idea supported by other authors (Greenwood 1984, Holloway and Freshwater 2007a).

Evidence based practice can be defined as a systematic process of reviewing, appraising and using research findings as a basis for making clinical decisions (Rosenberg and Donald 1995). It aims to provide the best possible evidence at the point of clinical (or management) contact (Dawes et al, 2005, p4). However one of its main contentious issues is it privies quantitative research outcomes, in particular the randomised controlled trial, over other forms of knowledge (Dawes et al, 2005, Holloway and Freshwater 2007a). Evidence based practice has been described as hindering the development of nursing knowledge in four main ways, it medicalises the health care environment, values quantitative forms of knowledge over others and does not value personal or aesthetic knowledge (Carper 1978, French 1999, Holloway and Freshwater 2007).

Reflective practice is concerned with the thoughts and feelings of the individual and the detail of everyday practice, whereas evidence based practice is concerned with devising protocols and procedures, to objectify and standardize practitioner's performance rather than developing the individuality of the practitioner. Narrative challenges the dominance of evidence based practice by embracing the voice of the researcher within a local context.

The process of reflective practice, and in particular the research process I utilised, aims to use knowledge that is specific to practice. The process demands continual evaluation and testing of research outcomes in the local context of care, it does not privy research generated by one methodology over another. The process demands that the research is evaluated within its own paradigm boundaries, and assessed as to whether it is appropriate to be applied within the local practice context.

I remember my early attempts to construct the narrative were hindered by my embodied response to show what I had read by inserting lots of references. In reality though their influence on helping me to reveal insights within the text was small or non-existent; they merely restricted the flow of the text. The real demand was to dialogue with significant literature, carefully reading it to see if it could help me understand my practice further. This involved critically reviewing the methodology, process and outcome, but crucially, reviewing the significance of its outcome to my practice at a time that was clinically relevant.

Related ethical issues

I have detailed in chapter 2 some of the moral and ethical issues that I encountered and how those experiences have led me to believe that to be an ethical practitioner one needs to engage in ethical practice at all times not for a one off task such as completing a research ethics application form. This section considers two further ethical dilemmas that I faced; did I specifically choose stories where consent would be easy to obtain and how did I resolve the issue that some people did not want to be anonymous in my texts.

Sub-conscious selection of stories

I have never had a person ask me not to write about our interactions. I wonder if I sub consciously chose stories to develop into reflective texts where I thought individuals would agree to consent. Did I avoid those who were having extreme difficulties coping with what was happening to them, as I felt my research would be just another burden?

There are individuals that I have consistently worked with during the research period, who are not in the narrative but I would approach to be involved if I was starting out again now. Predominantly in the narrative where I do share the individual's distress and pain, are from people I had an established relationship with. They were easier to approach as I felt I knew them, we already had shared history. Maybe I did censor individuals, instead using key issues of what I had learnt from those interactions to make up composite, fictional characters in the narrative. If this did happen it is only now that I am realising it, I was not consciously engaged in protecting individuals, or choosing some and not others. I need to be less paternalistic and appreciate that individuals can make reasoned choices in times of stress. As an insight, I need to be mindful in positioning myself on the advocacy paternalism continuum in both my clinical and research practice.

Through the construction of my thesis I have noticed a shift in my practice and research from working 'on' to working 'collaboratively with' people. Being ethical in relation with others can lead to unforeseen ethical issues. As I developed mutuality with others in practice this simultaneously transferred to the research as the following incident illustrates.

Wanting to be known

When I approached two couples to consent them for my research, they were very shocked at my insistence that I would make every effort to keep their details anonymous. To the extent that one couple would only agree to participate if their real names were used. The wife stated;

> 'If you feel our work together is important enough to share with others, then we want the credit for that, we want to be known. This could be our only moment of fame.'

I was not expecting this response at all. It was a revelation why shouldn't they have their real names used if they wanted to. Who was I trying to protect? What is the role of ethics committees? Previously I believed ethics committees insisted on signed consent and maintenance of confidentiality to protect individuals. Now I question if this is the right way forward? Do people want this level of protection; perhaps they would prefer a choice? Christains (2005) states that ethics committee decisions protect institutions not individuals and goes on to state:

> 'This constricted environment no longer addresses adequately the complicated issues we face in studying the social world' (Christains, 2005, p148).

Johnson (2004) makes a claim that insisting on anonymity in nursing research is contributing to a distortion in what is harmful and beneficial in nursing research. He discusses that much of nursing work could be classed from a current research ethics perspective as 'harmful' e.g. giving an injection. Whilst I was keen to acknowledge this couples' wish, in future studies if people can choose to be identifiable, consideration needs to be given as to where the consent process should stop. For instance the above couple wanted to make this choice, but what about other close relatives who may also be identifiable by the couple's disclosure in the text. I feel this is particularly pertinent when working with vulnerable people. My interactions are often with the family unit, disability rarely impacts only on the individual. It is for this reason, to protect the identity of close and extended family members that I do not identify where in the text I am using real names or pseudonyms. In addition details of family and friends have been altered. This was a considered decision, discussed in my supervision sessions, as I feel I have a duty to not only represent the individuals who want to be known but also to protect those around them, who may not have had the choice to be involved in the study.[123]

The use of art to prompt and enhance my form of expression

It was liberating to remain open to influences outside of what I was previously conditioned to accept, essentially published literature, but it was also daunting as there were no barriers to what I could be influenced by. My ability to write and persevere with this thesis has been enhanced by my appreciation of art, sculpture in particular, reading and attempting to write poetry. These processes were particularly helpful because I found them novel and a fun way to learn. I was able to detach

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[123] Since 2005 the spasticity team use a specific consent form (Form 4) developed by the Department of Health (DOH 2005b), that details the health professionals decision-making process (Leyshon and Clark 2005) and the significant others involvement in discussions. Although not available when I was gaining consents, such a form could easily be adapted for use in future research studies.

myself from the story or stagnant text, view issues from different perspectives, which then helped me to reconnect with and evolve my texts.

My skills to engage in the narrative construction were further enhanced by participating in art workshops, albeit I was initially reticent. It was liberating not having to write grammatically correct prose. Particularly significant is how I continued to dialogue with the art pieces long after they were finished.[124] Similar to how I have dialogued with literature, I have subsequently read deeper meaning into the art I produced. This process was significant as together with my appreciation of the work of Barbara Hepworth, I isolated the importance of 'space' in my work with people with spasticity. Maybe that to develop practitioner research through narrative requires the inclusion of aesthetics, to help the person tap the unknown, to reveal deeper meanings of self and as for me, to help remain engaged in the process.

Transferability of findings

Sharing my stories with others affirmed the narrative approach

I doodle in my journal;
'My nursing narrative is unique...its beauty though, is that for many nurses its uniqueness will be familiar.'
Holloway and Freshwater (2007) state that,

'Narrative then is not only bound up with individual identity formation but is also connected to large-scale identities such as nations, cultures and subcultures.' (Holloway and Freshwater, 2007 p43)

Referring back to Heidegger, by interpreting, understanding does not become something different it is revealed as itself. My narrative reveals aspects of being a specialist nurse, aspects of which other nurses in particular but possibly other health and adult social care professionals will resonate with. Thompson et al (2008) state for research to be utilised a person needs to know about the research and be able to make decisions with regards to its' implementation. In an effort to show the logical flow of my decision making, my narrative demonstrates the identification of issues and how I used different ways of knowing to enhance my understanding. For instance how I expanded the Thorne and Roberston (1988) model or used Kieffer's (1984) model of empowerment and how I have included the analytical pauses to demonstrate the development of my understanding.

Writing and presenting my texts in narrative form I feel makes them more accessible to my health care colleagues as Abma (1999) states,

'...stories are appropriate for conveying the complexity, concrete details, and context of lived experience; they suit our common knowledge, speak to a public, and are open for social negotiation.' (Abma, 1999, 193)

Initially I was nervous to share my stories with others informally or formally, for instance through publications and conference presentations (appendix 6); although once I did, their positive feedback

[124] Reflective text 10, p166-167 and the collage, appendix 7

and at times visible emotion, such as tears in their eyes,[125] affirmed to me the value of my narrative.

Aita et al (2007) suggest that one way to ensure effective research dissemination is to,

'Create opportunities for heathcare professionals to discuss and interpret research findings according to their local context.' (Aita et al, 2007, 152)

People have commented that, my work is accessible and listening to my stories has prompted them to consider their own practice. It's probable that the impact of such comments influenced my move away from a directive conceptual model, towards sharing an approach, which continues the narrative style and invites others to dialogue with the text. Taylor (2003) suggests that narratives tend to only,

'...focus on the individual reflector and their individual reflections, and thus reflection as a social activity is denied.' (Taylor 2003, p249)

The form of narrative enquiry that I have used encourages a sharing and deepening of knowledge as it privies guided reflection, co-creation and in particular in the 6th layer dialoguing with others. Scullion (2002) discusses how researchers often simply report their findings, make recommendations and opt out of any further engagement to see whether the findings are translated into and are effective in practice. He describes researchers as passive and never engaging with the user. Within my process I am continually testing the appropriateness of research findings to my practice. As well as describing my approach to practice[126] I have tried to illustrate my approach through a further narrative to appeal to readers who may prefer that form of expression[127]. However, as Scullion (2002) points out, just because research is disseminated it does not show that it has been translated into practice. In the future when I am using this methodology I will pay more attention to how people respond to my reflective texts and probe them further to appreciate how the text had influenced their sense of self and their practice.

Discussing my conclusions and their implication for practice

Bishop (2008) suggests that,

'The nursing profession needs to identify, unapologetically, its unique contribution to heath care.' (Bishop, 2008, p5)

She claims clinical supervision has the framework to achieve this, but does not detail how. The development of my narrative through guided reflection does demonstrate a method, depicts my nursing interactions, highlights insights and details my approach to working with people with complex disabilities. It narrates my unique contribution to nursing.

In this section I highlight:

- The uniqueness of the person with complex disability and the importance of appreciating their precarious harmony
- The factors affecting interactions with people with complex disabilities and the impact of 'self'
- The need to sculpt the practice space
- The role of art as a process of gaining knowledge and understanding

[125] Page 102
[126] Chapter 4, p216-220
[127] Chapter 4, p221-234

The uniqueness of the person with complex disability and the importance of appreciating their precarious harmony

Several authors have highlighted the need to gain an understanding of living with a chronic illness in order to work effectively with a person (Charmaz 1983, Loveys 1990, Kralik 2001, 2002 and Paterson 2001). Their conclusions have come through the use of different methodologies such as grounded theory (Charmaz 1983). My own work concurs with these findings. In addition I have realised the importance of appreciating a person's precarious harmony. The concept of precarious harmony was developed and discussed in chapters 3 and 4 and may be summarised as a matrix of highly refined strategies, unique to each person with a complex disability and their family, which allows them to effective function as a family unit. It can be a fragile state, easily disrupted through life events, health and social care practices.

The concept of precarious harmony has two important implications for practice.
First, to work with someone in relation, towards a therapeutic alliance, requires an appreciation of their precarious harmony and therefore must form a cornerstone of one's initial and ongoing work with a person. Second, without acknowledging and working with a person's precarious harmony the uptake and ongoing use of novel technologies maybe limited as hitherto unforeseen life or personal changes impact on the process. This may have further implications in other fields using novel technologies, for example in the uptake of neurostereotactic surgery in Parkinson's disease (Limousin- Dowsey and Tisch, 2005) and implantable bladder stimulators in spinal cord injury (Gaunt and Prochazka, 2005).

As part of a wider drive to improve quality in the NHS, the UK's Chief nursing officer recently commissioned a report (Maben and Griffiths 2008) to investigate with nurses who also had experience of being patients and carers, what patient's value as important aspects of care. The report concludes that people want care provided in a, timely, safe and clean environment that is individualised and fits in with their life. They want nurses to be skilled, competent and knowledgeable. They want to be treated as individual people, not symptoms and for nurses to work in partnership, keeping them informed and involved in decision making. My research further expands on these findings. The need for the care environment to be individualised and to fit in with a person's life resonates with the need to appreciate a person's precarious harmony. To appreciate a persons' precarious harmony is an important skill a nurse needs to develop. This thesis demonstrates that becoming a reflective practitioner is a way of developing skills, competence and knowledge. A strength of this methodology is that it utilises and develops existing knowledge and patterns of knowing when it is clinically relevant. Finally, sculpting the practice space focuses the team to appreciate the individuality of each person and how they can influence the flow of the therapeutic environment and hence the person's experience.

The factors affecting interactions with people with complex disabilities and the impact of 'self'

My insights have highlighted that there are many factors that affect interactions with people with complex disabilities (figures AP1.3, AP2.0, AP3.0). Very broadly these factors include those directly affecting the person, factors I bring to the practice arena as well as environmental and social factors not only relating to the person's personal environment but also to the environment of the NHS and adult social care.

For example, as highlighted in the narrative, the revealing of my personal values towards nursing homes; the presence of oppression in the workplace and the influence of cognitive impairment have all been shown to impact on the practice space.

Holloway and Freshwater (2007) state,

'Narrative inquiry is an important genre within qualitative approaches, characterised mainly by its coherence and sequential form. These traits distinguish it from other types of research. Whilst much qualitative data collection results in 'fractured texts' (Reisman, 1993), narrative produces coherent stories'. (Holloway and Freshwater , 2007 p20-21)

In keeping with narrative methodology I do not reduce or collate my insights into themes. This is because I want to maintain the wholeness of my approach. Reducing my insights into a small number of themes not only runs the risk of producing a 'fractured' text but potentially could form an inadequate, static checklist that will not be applicable to the next individual with complex disabilities that I interact with. Further, I believe such "checklists" would not allow the building or layering of understanding of the whole: in order to appreciate a person's precarious harmony. As I practice I need to flow with the unexpected, be open to appreciating nuances that may give me greater understanding of how the person lives their life.

The importance of understanding and gaining insight into each individual's precarious harmony means that very person has to be approached afresh. Therefore, instead of generating an 'assessment checklist' this has required the development of a novel approach. This has been the ongoing need to sculpt my practice space over time.

The need to sculpt the practice space

My approach can be summarised as the need to sculpt the practice space, tune into the other's wavelength to understand, connect with and flow towards maintaining and improving the balance of the person's precarious harmony.

As my narrative shows the practice space can be comprised of different spaces, for instance; the person's actual position in space; the person's living space, the therapeutic space. Each of these spaces can be influenced in different ways, for instance by the person, self, others or external forces such as the Trust organisation or mandates from the Department of Health. I have learnt that this can create a disordered or chaotic feel to the practice space, but my appreciation of chaos theory, that

within apparent disorder, there is an order to be revealed, has led me to develop an approach that states the need to flow with the person to maintain or improve the balance of the person's precarious harmony.

As discussed in the previous sections the narrative approach can be used to tune into the other's wavelength that is to gain an understanding into the multiplicity of factors (physical, social, emotional, psychological, spiritual, etc.) that may contribute to one's precarious harmony.
Central to my approach however is my feeling that one must not only understand and connect with another's wavelength but to also flow towards maintaining and improving the balance of a person's precarious harmony.

By 'flow' I mean to convey the fact that we all live in ever changing environment, the crucial changes may not just affect the person e.g. a change in disease state or lifestyle but there may also be changes external to the person, such as changes in NHS staffing structure and resources, that affects their heath and well being and precarious harmony.

A rigidly defined best practice model is doomed to failure in the majority of cases because it doesn't have the flexibility to respond or flow with the changes that can confront the person e.g. changes in their disease process or a reduction of NHS resources. To 'flow with' is not a passive state, as my narrative shows it requires active engagement in dialogue and reflection to effectively journey with the person.

Recognising oppression

At the beginning of this study I did not recognise oppression. I knew I practised in a hierarchy but did not understand how this structure could be oppressive and impact on my space to nurse. Oppression can be difficult to reveal independently. Once guided by CJ and introduced to the work of Friere (1970), Roberts (1983, 2000) and Kieffer (1984), I more readily identified in my texts, at this reflection stage, as to when I was feeling oppressed. The situations were often complex and reasons for situations were multifactorial, in essence oppression could come from different directions; vertically downwards from my managers and government policies or horizontally from colleagues. These influences were vital to recognise so as I could continue to flow with situations, maximise space for dialogue and be in relation with others. I realise to enable others to be agentic; I need to resist being oppressed or the victim (Polkinghorne 1996).

The role of art as a process of gaining knowledge and understanding

The use of art as a process of gaining knowledge and understanding in the field of healthcare has been used before. Nursing lecturers for example have used art as a means to advance student's writing (Winter et al1999) and poetry as a mode of staff education (Peterson 2002, Biley and Chamney-Smith 2003). However, the use of sculpture to further extend knowledge, such as I demonstrate in my narrative, has to date been infrequently described. Navarro (2007) developed

knowledge of the physical impact of Alzheimer's disease by engaging in a pictorial study of his Father's progressing disease. This included sculptures of the whole and parts of the body. This approach clearly demands time, access to appropriate materials e.g. wood and the necessary skills to execute ones thoughts and wishes artistically.

The use of existing art such as I have demonstrated in my narrative to a certain extent circumvents some of these problems. Classical Greek sculpture for example has been used to gain an understanding into new dimensions of movement quality by physiotherapists (Skjaerven, 2004) and, as previously described (p132), Wynn (2006) describes how close examination of a sculpture depicting the sculptor and her dying husband, helped Wynn to develop a more receptive openness to her patients in palliative care.

My current work uses more contemporary and abstract rather than figurative sculpture. One advantage of the abstract form is the potential of conveying meaning to that form that was not previously envisaged by the sculptor themselves. Similarly, readers of the abstract representation of my approach[128] could also develop their own interpretations.

This method of using existing abstract sculpture by its essence requires the person to be able to see and ideally feel the sculpture first hand, for me this has required trips to Hepworth's museums and also to prehistoric sites which in turn influenced her work. Such an approach may therefore be criticised as expensive, time consuming and clearly not possible within the realms of current practice. Sculpture and art is something that is normally viewed in one's own personal time. In order for this method to be successful the person must therefore bring into their personal space and time what someone may call work related issues that is the precarious harmony of people with chronic disability that they are working with. The use of sculpture therefore involves personal commitment and time linking to the idea that practice is narrative, but maybe extending this to life is narrative.

One may say that this approach can be emotionally draining however I have found the use of narrative is less draining because I am an actor who can makes changes within the stories, rather than being a bystander such as other researchers can be, unable to influence the process of events in case of 'contaminating' data collection.

Future: Becoming

My narrative research journey has spanned eight years, in one way it seems a long time, but in another I feel only a little way into what I now appreciate as an ongoing process, with no definitive end point. Reflection and being mindful are now integrated into the manner that I approach my work; they have become part of how I practice. I have moved from an epistemological model of, 'knowing or learning how to do something', to an ontological way of being, where I view 'knowing or not knowing something' as part of the process of discovering and flowing with the unfolding situation.

[128] Figure 4.0, p219

What drives me to continue with the effort of narrative is simple, it makes my practice come alive and I see things that would otherwise go unnoticed, masked by issues relating to tradition, power and embodiment. By tuning into these issues I am able to personalise care and influence the experience of others. Working in relation with others towards realising my vision has been pivotal in enabling me to continue and gain satisfaction within a physically and emotionally draining job. It has enabled me to share with others the nuances and what I am thinking about in relation to my nursing practice. It has made me more able to articulate what as a nurse I am doing.

Despite these gains it has not always been easy to be so 'aware' in practice, I have needed to face issues of self and the way in which my work environment was managed, which in the short term would have been easier and possibly more comfortable to ignore. By recognising and reflecting on these issues I have changed my perceptions and this has influenced how I practice and interact with others. These influences will continue into my future practice and, through being a supervisor, into the practice of others.

Widening horizons

Following my presentation at the MSTrust Conference in November 2007,[129] I have been asked by a research unit to submit ideas of how this research approach could be used to explore, how people with severe cognitive impairment could be included into clinical trials (Appendix 8). The hope is to construct a research proposal to seek future funding for a joint clinical / research practitioner to develop these ideas. As others dialogue with my narrative I sense layer 6 in action.

The excitement
of potential joint narratives
propels me forward
in the spiral of being and becoming.

The essence of my approach

Sculpting space to work in relation,
I confidently hold uncertainty.
Whilst we transform,
The space shapes its own order.

[129] 5/11/07: 'You can miss so much when you just concentrate on the physical aspects.' Platform presentation: MS Trust International Conference. Leeds, UK.

Future therapeutic space

Joint narratives fill the space.
Feel the tingle of co-creation,
intentionality, mutuality, equality,
together carving and sculpting the therapeutic space.

Appendix 1: A model of coping: The transitional process of living with chronic illness (Jarrett 2000).

This model is the starting point for reconceptualising my theory of spasticity nursing.

The main premise of the model is that an illness episode is not always a distinct entity, which can be dealt with and then the person resumes their former life, although such a principle can form the basis of an acute model of care. This model evolved to encourage health care professionals to view illness as an event in a person's life, which has simultaneous effects on other aspects of their life. It has three main components, Life course, Illness trajectory and the Illness to wellness continuum. Figure A.1.0 is a representation of the model.

Life Course.

Events originating from developmental (puberty, marriage, pregnancy and retirement), situational (unexpected or untimely events suddenly loosing ones job) and health/ illness perspectives can occur throughout ones life (Shaul 1997, Murphy 1990). Such events could be described as transitional points, stimuli that cause people to re-evaluate their life course. Such events influence an individual's life course and can affect a chronic illness trajectory.

Knowing how a person perceives their own life course is pertinent to a nurse's assessment and ongoing care as transitional events can affect a person's priorities. For instance a person may wish to focus their energies on starting a new job rather than trying a new treatment regime. Appreciating the biography and lifestyle of a person can help the nurse to set realistic goals within the context of the person's life.

Illness trajectory.

Each illness has a trajectory, a course it will take, available steps are depicted by the phases: acute, stable, comeback, wellness, crisis, unstable, downward and death (Corbin and Strauss 1991). The trajectory is represented in a cyclical pattern as opposed to linear to represent unpredictability and how a person may jump back and forth between stages.

Adaptation and Adjustment

The model suggests that the work of moving through phases is carried out through the work of adaptation and adjustment. Some individuals will reach mastery while others will not and may require intervention from health care professionals, family or carers to realign their perceived aims or they will choose for others for example carers to work towards mastery for them. Failure to adapt or adjust will not stop or necessarily slow the illness trajectory down, but would mean that an individual does not reach their potential or chooses to remain at another functional level, or they may wish not to take an active part in managing their life course. Such wishes would need to be respected.

Nurses need to consider the values of the individual, their priorities, and their energy levels, assess their education needs, identify and facilitate particular strategies that may help them such as imagery and distraction. Nurses may need to give direct emergency care or to support, educate, advise or assist people to reach their own adaptation and adjustment goals, as they perceive them.

The 'at risk role'

The model relates the 'at risk role' *(Lovey's 1990)* to the stable, comeback and wellness sections. Where the symptoms are not evident but the impairment of chronic illness and threat of symptoms

and potential deterioration exists. The wellness section could also represent a plateau between health and illness.

An important nursing intervention would be to facilitate adequate education and information to ensure that individuals were able to identify when they may be entering into an 'at risk role' and when it would be appropriate to seek further advice and help.

Illness/Wellness continuum.

Individuals throughout their life span move along a continuum between health and illness. Wellness as perceived by the individual can be achieved at any stage along the continuum. If nurses and individuals living with a chronic illness view the illness trajectory as a cyclical pattern, realistic aims could be set to achieve wellness within the context of illness rather than aiming for cure. This could reduce feelings of failure, non-compliance and non-achievement and could encourage joint working, leading to collaborative goal setting.

This model attempts to incorporate the many dimensions that can affect the life of a person living with a chronic illness; by viewing chronic illness as a lifelong process with varying stimuli that affect the course of a chronic illness. Individuals, their family and carers are encouraged to maximise their potential, as they perceive it at each phase of their illness trajectory, rather than waiting for the illness to subside before getting on with their life. Adaptation and adjustment can be seen as stepping-stones in the process rather than as definitive end points that individuals have to achieve before they can be considered as well.

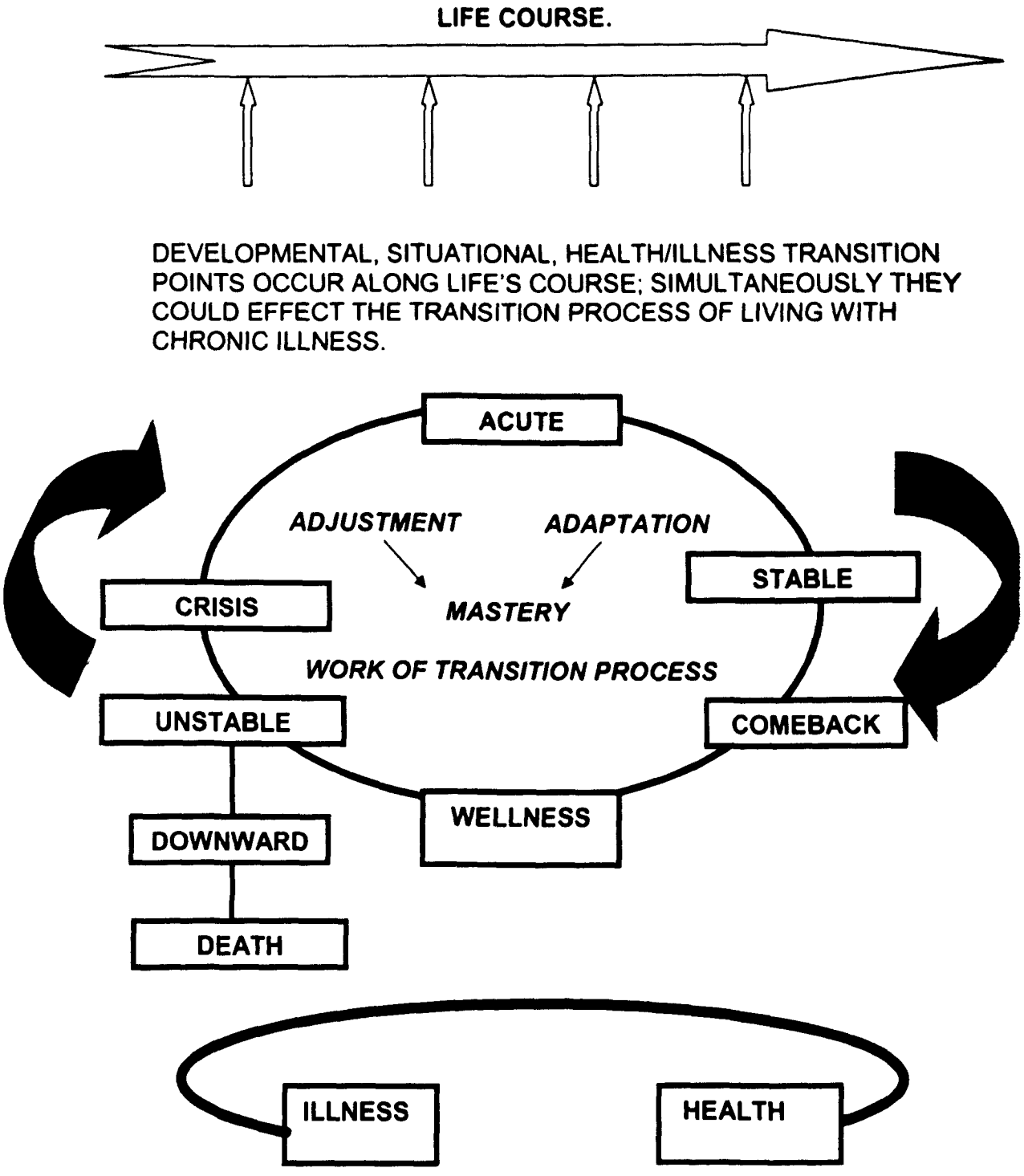


Figure A.1.0: Model of coping: The transitional process of living with Chronic Illness (Jarrett 2000).

Appendix 2: A summary of the action research project

Evaluating the implementation of a system of clinical supervision for nurses at UCLH Trust

Background

The last and current UCLH Nursing and Midwifery Strategies (1997-2002 and 2002- 2005) recommend the ongoing inclusion of clinical supervision into nursing practice at UCLH. Clinical supervision is viewed as a process that can potentially safeguard standards of care (DoH 1994b, UKCC 1996). The NHS Management Executive (NHSME) in the white paper: Vision for the future (DoH 1993) describes clinical supervision as a process where nurses can develop self-assessment, analytical and reflective skills.

Previously the Trust has provided resources to learn about clinical supervision through supporting local training initiatives and a university module, which I completed as part of my diploma[2]. In addition some areas employed external supervisors; despite this systems of clinical supervision have not been systematically implemented and maintained across the Trust.

A Trust wide steering group agreed that a work-based training was required that would promote the implementation of supervision as the training progressed and evaluated the implementation of clinical supervision systems. Professor Christopher Johns (CJ) provided a work-based training and facilitated an evaluative action research study to explore factors that promoted or constrained the implementation of supervision within the Trust. I led the evaluative action research project and this paper is a synopsis of the outcome and process.

Training Process

The work-based training consisted of three cohorts each developing 15 supervisors over a period of 18 months (Figure A.2.0). The training was separated into two sections; in the first six month training period the trainee supervisor's developed supervisory skills and during the subsequent 12 months, 6 support groups were offered as individuals strived to consolidate and further develop their skills whilst maintaining supervisory relationships (Figure A.2.0). The total estimated time to train each supervisor was 38.5 hours.

6 training sessions held monthly between	**Purpose of sessions**
Cohort 1: March 01 – October 01 Cohort 2: November 01 – April 02 Cohort 3: May 02 – November 02	For the supervisor to learn supervisory skills and to implement supervision. Tools were introduced to promote effective supervisory relationships (for example Record of supervision, Evaluation tool) and Theories to develop practice for example Assertiveness grid (Johns 2000), Conflict Management Grid (Thomas and Kilman 1974), Influences Grid and Ethical Mapping (Johns 2000) Decision corridor (Cope 2001) and Transactional Analysis (Stewart I and Joines V 1987).
6 support sessions held every other month between	**Purpose of sessions**

Cohort 1: October 01- August 02 (extended to May 03) Cohort 2: April 02 – October 02 (extended to May 03) Cohort 3: November 02 – May 03	For supervisors to further develop their skills and get support whilst maintaining supervisory relationships over time. As part of the action research these meetings were used as focus groups and the tools to promote good practice were used as data collection tools.

Figure A.2.0: An outline of the work based training.

Action Research Process

Action research involves systematic, group analysis of problems through the production of action research spirals (Lewin 1946 cited in Winter and Munn Giddings 2001). The spirals consist of sequential phases of planning, acting, observing, reflecting and re-planning (Kemmis & McTaggart 1988) or action, data collection and critical reflection (Winter and Munn Giddings 2001) (Figure A.2.1).

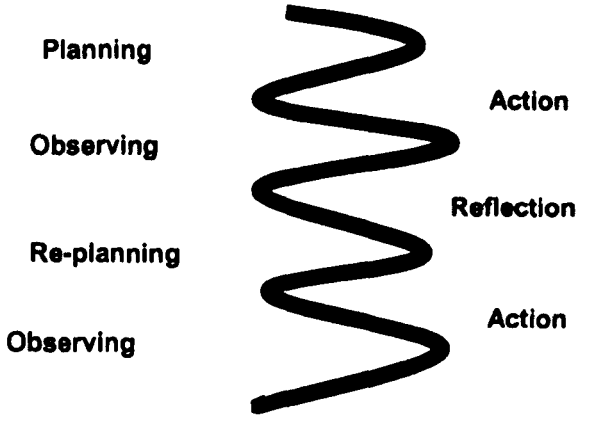


Figure A.2.1: An action research spiral

The NHS research and development health technology assessment programme defines action research as a,

> '... period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem focused, context specific and future orientated.
> Action research is a group activity with an explicit critical value base and is founded on a partnership between action researchers and participants, all of whom are involved in the change process.
> The participatory process is educative and empowering, involving a dynamic approach in which problem identification, planning, action and evaluation are interlinked.
> Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods maybe employed to collect data. Different types of knowledge may be produced by action research, including practical and propositional. Theory may be generated and refined and its general application explored through the cycles of the action research process. (Waterman H, Tillen D, Dickson R, & de Konig K, 2001 p iii –iv)'

The proposed training program mirrored this cyclical process.

Action Research Objectives

a) To identify factors that constrain and promote the implementation of clinical supervision within UCLH Trust and work towards resolving the constraints.

b) Relating to the DoH definition of clinical supervision,[130] to evaluate the impact of clinical supervision in nursing practice at UCLH by realising its intentions:
   - To enable the practitioner to develop competence
   - To enable the practitioner to sustain competence
   - To safeguard quality of care
   - To nurture practitioner responsibility for ensuring their effectiveness
   - To nurture self assessment
   - To nurture reflective skills

Role of the co-researcher

The supervisors in each cohort were invited to become co-researchers at the start of their support phase. The co-researchers were asked to:

- Consent to being a co-researcher.
- Participate in focus groups at each of the support sessions.
- To research self through their own supervision sessions.
- Explain the project to at least two of their supervisees and consent them to participate and provide anonymously:
   - Two reflective reviews scheduled at 4 months and 12 months of the support period.
   - Four individual supervision record sheets during December 2001 – April 2002.
   - One supervision evaluation questionnaire at the end of the support period.
   - A log of sessions attended and reasons for cancellations.

Appropriateness of this process

Relating to the above definition of action research (Waterman et al 2001) this style of inquiry suited the project for the following reasons:

- The co-researchers were part of a group learning new skills to implement and maintain systems of clinical supervision. They were looking to change and improve practice through critically reviewing what promoted and constrained them from implementing clinical supervision.
- It was specific to the current and future of clinical supervision at UCLH.
- The co-researchers were being encouraged to use reflective skills for both the process of implementing supervision and whist supervising individuals. Throughout this process they were receiving support and guidance from their fellow co-researchers to problem solve and act on issues.
- Both qualitative and quantitative data would be collected.
- The process could be integrated into the evolving work patterns of the co-researchers.

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Outcomes

The process

Twelve supervisors became co-researchers; I was one of these and the only person who took the opportunity to research self through supervision sessions with CJ. The outcome of which forms the main text of this thesis.

Attendance at the support groups was low; cohorts 1 and 2 were joined together allowing an extension to their period of support. This increased the potential training time to a maximum of 45.5 hours over 26 months for cohort 1.

Outcomes from the support groups

After each support meeting, from notes that I made during the session, I typed a record of what was discussed and agreed. A copy was sent to each co-researcher for verification and amendments were made as requested. I analysed the transcripts from the first two meetings and developed draft spirals for discussion with the co-researchers at the third support meeting. These were titled:

1. Doing supervision
2. Trust Strategy
3. Outcomes
4. Use/Abuse of the term
5. Using the Tools /Theory
6. Consent / Confidentiality
7. Data Collection

These formed the basis of seven spirals that were developed as the research progressed (Figure A.2.2).

Figure A.2.2: Summary of spirals; Denoting barriers and possible resolutions

Spirals	*Total Number of sessions spiral discussed (Actual sessions)*
1. DOING SUPERVISION	*11 sessions (1-11)*
Potential Barrier	Potential Resolution
'Is reflective practice more about breaking down the stereotype vision of supervision of 1 hour every month?'	We should be creative about how we can use reflection in practice, through dialogue, note writing, handover or debriefing.'
Internal Barriers-	
Fear of having to break confidentiality and or deal with poor practice. Even though in reality occurs rarely	Discuss at ground rule stage. Use examples to ensure people understand but be careful not to make ground rules too detailed as could stifle supervision ever getting started
What to do if poor practice is uncovered (NB: people do not always learn from experience, guided reflection can help them do so).	Encourage supervisee to discuss how they will deal with the situation. If needed use confronting probes: 'What do you think you need to do to resolve this issue?' 'You seem unable to take responsibility for this issue, so what do you think we need to do?' Supervisor would need to see if continuing the relationship was viable if they felt strongly about incident and supervisee would not disclose. Consider use of evaluation tools
Supervisees cancel sessions. Diaries unavailable; Off duty not sorted; Sessions not planned around leave	Consider using Influences grid (Johns 2000 pg 14) or keeping a log to assess why individuals keep cancelling. Emphasise it is their responsibility to confirm dates and use the time effectively.
Supervisees lack motivation and maturity. It was difficult to engage everyone in supervision, as it was not compulsory. Some people just did not see the need for it.	Need to acknowledge if someone finding supervision difficult. Provide high challenge with high support. Ask them to demonstrate how they are maintaining and developing their own practice.
Passive resistance 'Difficult to argue benefits of supervision against beliefs of off loading in the pub.'	If unchallenged will become part of culture. Highlight benefits of longer- term development and deeper learning against short-term debriefs. Also warn of danger of breaching patient/staff confidentiality by discussing things in the pub.
Need to promote ownership and responsibility of supervisees. Another way to engage them is to ask: Do you think you should be the most effective practitioner you can be? Do you think it's your responsibility?	Then sell the idea of supervision being the vehicle to enable them to achieve this
External Barriers- Environment	
Pressure of work / Busy wards means no time to do supervision	One supervisor's solution: 'If nurse too busy I tag along with supervisee and try to use reflective practice as we work together. To reflect people need to open their eyes, become curious and committed to learning, its good if it relates directly to their work'.
Restricted Time to do sessions	Strict about sessions lasting only an hour. They can be draining for supervisor's, who may need a break afterwards

Very pressurised environment on ward, CHI visit, staff changes, uncertainty of job stability Need to pace information giving and new initiatives but maintain supervision as can help address these issues	
Constant departmental changes and ongoing recruitment Need to ensure implementation strategy is workable to promote its inclusion into daily practice. Sisters are key in ensuring supervision accepted into ward culture	
Supervision can create questioning and challenging practitioners Managers and sisters need to want and encourage such staff development.	
Difficult to find supervisors Modern Matrons to be aware of who is available to supervise in each directorate	
2. TRUST STRATEGY	*10 Sessions (2-11)*
Supervisor to decide how many individual or groups to supervise not manager Need to negotiate with manager. Supervision needs to become part of off duty.	
Need to raise and maintain profile Present at hospital meetings; Study days; Public folders; Intranet; Article for inside story.	
Competing agendas: Leo, Competency program: Managing staff and pt care Reflective skills needed for all these initiatives. Integrate initiatives to ensure safe critical reflective practitioners.	
Need to clarify skills needed to supervise. Potential supervisors to discuss skills with their Modern Matron who will clarify if able or if they require further training	
3. OUTCOMES	*9 sessions (1-8, 11)*
Supervisees report able to: do a better job; understand issues more within a supportive framework; look at wider picture put things into context, tackle multidisciplinary unprofessional behaviours, deal with poor practice, improve communication when breaking bad news. Teams feel more able to work together and share issues. Guided reflection can help people to learn from experience in a way they may not have done. 'I noticed when stopped having supervision.' 'Can't be a ward sister without supervision.'	
Clinical supervision is being used as a corrective tool to manage poor practice Managers, Supervisors and Supervisees need to agree purpose of supervision, be aware of their roles and feedback mechanisms before the sessions commence	
4. USE/ABUSE OF TERM	**9 sessions(2-6, 8-11)**
Suspicious of term: valuable time wasted discussing term Use guided reflection as more readily transferred into everyday practice	
Once in supervision keener to continue. On the other hand individuals can abuse the supervisory relationship constantly asking for sessions – but not showing growth or development Supervisors need to protect themselves. Challenge the individual- surface the dynamics perhaps use an evaluation tool	
5. USING TOOLS/THEORY	**7 sessions (1-3, 5, 7, 10-11)**
Difficulty incorporating tools Start or finish sessions using record sheets to consolidate sessions and prompt to use theory	
Only use if tools felt to be useful May feel easier not to use them but are you maximising effect of supervision without them?	
If useful theory found after session Send it to supervisee to reflect on	
Difficult to keep supervisees focused Models maybe useful to keep their attention, help them to prepare or be more logical	
Starting to use supervision techniques in other situations Tools and theories can help people deal with new situations outside of supervision	
If unable to journal Bullet point 6 good things 6 bad things, less time consuming than trying to write text	
6. CONSENT/ CONFIDENTIALITY	*7 sessions (1-5, 6, 10)*
Uncovering poor practice and needing to break confidentiality can be a barrier to starting supervision. What if negligent practice is uncovered? Plan for it: Discuss at ground rule stage. Use example as individual may not truly understand what could occur until experienced supervision; discuss if/ when a supervisor would break confidentiality, when they may continue/ discontinue with supervision. Encourage individual to speak to managers.	
Still feeling of reluctance even though situation rare (CJ stating he has never had a supervisee who didn't take action.) Use questions for example, What do you expect me to do with the information? You seem unable to take the responsibility what do you think I need to do?	
What if managers ask about content of sessions? Supervisor needs to maintain confidentiality of sessions but should encourage individual to feedback to manager and be open about what they are learning.	
Is supervision about preventing gossip? Supervisors feel they share less with managers than they did before. This could be a barrier to managers accepting supervision. Discuss with individual at contracting stage how they are going to feedback their development to their manager.	
Do content of sessions need to remain confidential after supervisory relationship terminated? Yes. If confidentiality needs to be broken this has to be done in the knowledge of the supervisee	
If supervision is used as a tool to manage poor performance Supervisor needs to sensitively set clear boundaries with both supervisee and their manager.	
7. DATA COLLECTION	**7 sessions (1-6, 11)**
Difficult to complete record sheets /reviews. Use at end to summarise or at beginning to recap from previous sessions.	

Difficult for supervisee to summarise main points Not uncommon do together. Prompt by asking how they feel now? Why they feel better? Summaries can consolidate sessions and allow for ongoing deeper reflections after the session
Nurses enjoy the chance to not write notes. Do they have a choice? Concerns re confidentiality of written notes Some form of documentation needs to be maintained. Supervisee has control of what they write and wish to share with manager.
What about group evaluation Group verbalises what they have learnt, the supervisor records it and reads it back to group for clarification.

Outcome from supervisees

The co-researchers anonymously forwarded me copies of the records made with their supervisee's. I typed the text from each document and immersed myself in the content by repeatedly rereading it. I then compared texts to determine commonalities and variations (Silverman 2001).

Supervisees used clinical supervision to gain support and develop communication skills to predominantly improve and sustain their interactions with colleagues over time. Areas they developed awareness and skills in included;

- Assertiveness
- Transitions into new roles
- Role boundaries
- Communication with their managers and other members of the multidisciplinary team especially how to resolve conflict.

They demonstrated acting on plans made in supervision and a greater awareness of where to gain support when in practice for example Modern Matrons and personnel.

There was little evidence to assess whether supervision was used to improve the supervisee's competence and skills in patient care. Four supervisees used sessions to explore how best to address the poor standard of care of other nurses and one supervisee discussed the actions they needed to take following a drug error.

Only one team directly discussed developing their communication skills. They explored the concept of transactional analysis to try and understand how they were influencing one patients challenging behaviour.

Limitations of the study

Although supervision systems were developed and maintained throughout the study period the quantity of supervisors whom maintained systems were lower than predicted (supervisors = 18 (n=45) and there were a lower number of supervisee's (18 individual and 4 groups (n=90)).

The study was limited by the small number of co-researchers attending the support groups and contributing to the evolution of the spirals. There is little evidence of the spirals being developed through all the action research stages, in particular to observe if suggested plans were implemented and effective.

There was a lack of data submitted by the co-researchers from their supervisee's, limiting the opportunity to appreciate how sessions were used and the effectiveness of supervisory relationships.

Summary

Barriers to implementing supervision were evident and discussed below. Interestingly different perspectives on confidentiality, time and using documentation were also viewed as promoters to maintain supervision.

Misunderstanding terminology, lack of resources such as time and a suitable venue

The term clinical supervision caused suspicion and confusion for supervisee's and was seen as a drain on their time. The co-researchers suggested nurses should reconsider how time is utilised in their individual areas and the intent of existing meetings and work practices. From this it may be possible to reframe how time is utilised to incorporate systems of supervision, using an alternative name if preferred.

Perceived lack of management support

Supervision provided by managers was viewed as a form of surveillance and was not a preferred option. For the ongoing acceptance of non-line management supervision into practice the co-researchers suggested a need to develop feedback communication loops between the supervisee, manager and supervisor. Importantly each area needs to make explicit how systems (for example Clinical supervision, Leading Empowering Organisations courses and Competencies) are interpreted and integrated to provide an environment, which offers both development and support on a regular basis.

Concern in managing confidentiality and documentation

There was concern from both supervisors and supervisee's about the possibility of breaching confidentiality and how to manage uncovering poor practice both within sessions and through keeping documentation. Supervision was not felt by the co-researchers to be an effective mechanism for managing poor performance. The co-researchers recommended a detailed discussion on how such issues would be managed at the initial contracting phase and regularly reviewed as the relationship progressed. Reference to colleagues and patients in documents should be minimised and where needed pseudonyms should be used.

Supervisee's resisting supervision

This was demonstrated in various ways, by not attending, attending but not developing their practice or asking for extra sessions but still not demonstrating evidence of change.

Promoters of supervision

Positively supervisee's stated they preferred engaging with clinical supervision rather then relying on informal sharing of their progress between managers and colleagues. They also described that although finding the time for supervision was a challenge, once they did, it 'gave' them time to reflect

and improve their practice. Incorporating documentation, tools and models of reflection increased the effectiveness of supervision sessions and knowledge gained.

The nurses in this study used supervision to help them develop communication skills with colleagues and to consider or make the transition into a new post. Supervision was not used to develop their clinical practice skills or interactions with patients. This was the opposite finding to the large evaluative study across England and Scotland by Butterworth et al (1997), where patient related issues was the most popular topic discussed in supervision. However similar to this study, Ashburner et al (2004) found that supervisees tended to concentrate more on their interactions with colleagues than patients, she suggests this could be a defence mechanism so as to not get too involved in the patients' experience.

Recommendations for nursing practice at UCLH

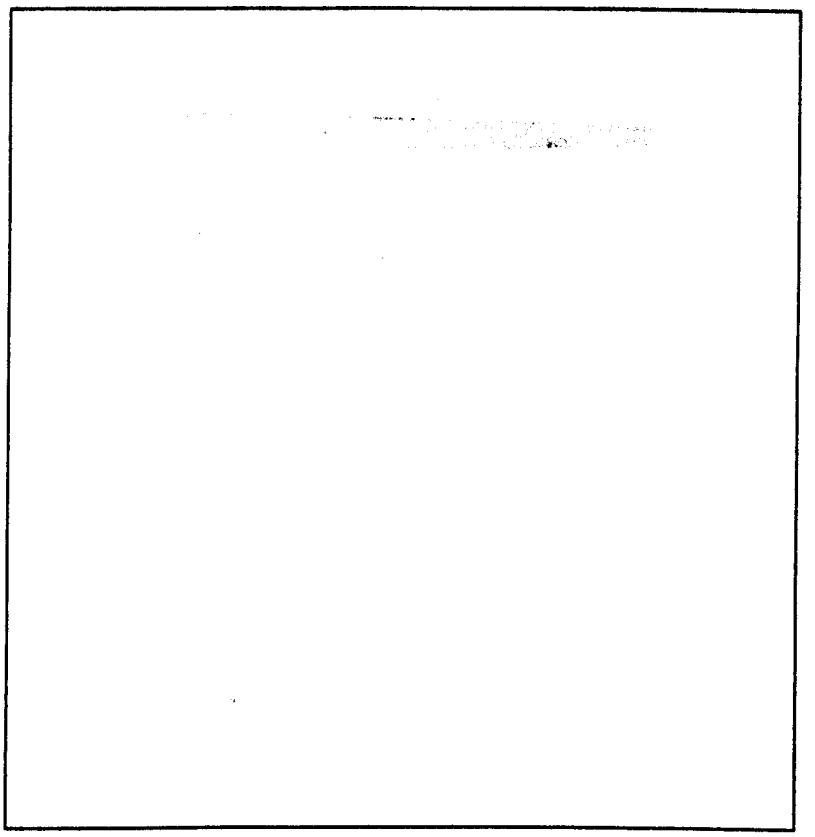
After discussing these outcomes with the chief nurse and an assistant director of nursing the following recommendations were incorporated into the development of the Trust Strategy for clinical supervision (2003).

	Recommendation	Action
Supervision aim	1. Supervision sessions should focus on issues relating directly to improving the nurses competence in patient care.	Supervisee's Supervisors Managers
Who can be a Supervisee ?	2. The minimum provision of supervision sessions should be access to: • 1:1 supervision for ward sisters, equivalent nurse specialists and above • Group supervision for all other nurses unless determined otherwise by the modern matrons. In addition ensure that clinical supervision is available as a priority for people making the transition into new jobs or acting up posts.	Managers Staff moving into new roles
	3. Clinical supervision should not be recommended as part of someone's poor performance management.	Managers
Role of the Supervisor	4. All Practice Development nurses, Clinical Nurse Specialists and Consultant Nurses are expected to supervise as they often have limited management responsibility of staff.	Managers
	5. The supervisor role needs to be acknowledged as challenging requiring the individual to not only have supervision themselves, but enough time to provide supervision. Only individual supervisors can assess how many individual or group sessions they can supervise at one time.	Supervisors Managers and Supervisee's
Process (Locally organised)	6. Individuals continue to be discouraged by the term 'clinical supervision'. Each ward or service needs to determine how clinical supervision is available in their area for example at handover, teaching sessions, 1:1 or group and how it compliments other systems for example appraisals and competencies and initiatives such as LEO. This would clearly identify how systems of development and support are provided and integrated both for the local team and the wider Trust.	Supervisors Managers (especially Ward Sisters) Supervisee's Ward staff
	7. When setting ground rules supervisors and supervisees need to specify: • How confidentiality will be maintained through out the supervisory relationship. • That if poor practice is uncovered than it is the responsibility of the supervisee to resolve and discuss it with their managers facilitated by the supervisor. • A clear pathway of communication between the supervisee and their manager so as the manager is kept informed of ongoing progress with the supervisee's development. • How sessions and the supervisory relationship will be evaluated • How they will take joint responsibility for organising the smooth running of sessions and effective use of the time.	Supervisors and Supervisee's
	8. Teams need to prioritise the importance of clinical supervision to their practice against other demands so as the decision to cancel sessions is carefully considered.	All
Process (Trust wide)	9. Supervisors and supervisees need to maintain some level of documentation and evaluation. At minimum an annual review of effectiveness of the supervisory relationship and a review of the supervisee's development should be completed. The expectation is that this will be done at the annual appraisal as part of an individuals' professional development plan.	Supervisees, Supervisors and Managers
	10. In order to maintain the number of supervisors available to supervise nurses: • Supervisors supervising other disciplines should only do so if reciprocal arrangements can be arranged. As each discipline approaches clinical supervision differently a shared definition of what clinical supervision is and its purpose needs to be agreed if the supervisor and supervisee are from different disciplines. • Supervisee's should be encouraged to start to supervise as appropriate.	Supervisors Modern Matrons
	11. Its important to maintain a system of co-ordinating clinical supervision such as the system now being used of the modern matrons being aware of who can and cannot supervise in their respective areas.	Managers Modern Matrons
	12. Managers at all levels need to actively be seen to support CS	Managers

Appendix 3: Model for structured reflection – 15a edition (Johns, 2007, personal communication)

Reflective cue	'Ways of knowing' Carper (1978)
• Bring the mind home	
• Focus on a description of an experience that seems significant in some way	Aesthetics
• What particular issues seem significant to pay attention to?	Aesthetics
• How were others feeling and what made them feel that way?	Aesthetics
• How was I feeling and what made me feel that way?	Personal
• What was I trying to achieve and did I respond effectively?	Aesthetics
• What were the consequences of my actions on the patient, others and myself?	Aesthetics
• What factors influenced the way I was feeling, thinking or responding?	Personal
• What knowledge informed or might have informed me?	Empirics
• To what extent did I act for the best and in tune with my values?	Ethics
• How does this situation connect with previous experiences?	Personal /Reflexivity
• How might I respond more effectively given the situation again?	Reflexivity
• What would be the consequences of alternative actions for the patient, others and myself?	Reflexivity
• What factors might constrain me responding in new ways	
• How do I NOW feel about this experience?	Reflexivity
• Am I more able to support myself and others as a consequence?	Reflexivity
• What insights have I gained from this reflection	Reflexivity

Appendix 4: Audio and visual presentation of the poem, Distinguishing between reflection and reflexivity.



Appendix 5: Analytical and Methodological Memos

Analytical Memos

1	Exploration of Chronic illness literature
2	Being measured, perspectives from people with spasticity.
3	What is my understanding of desirable practice?
4	Mutuality
5	Health as expanding consciousness (Newman 1999)
6	Sexuality
7	Empowerment
8	Spirituality
9	Death and dying
10	Intentionality
11	Revisiting 'Loss of self' (Charmaz 1983)
12	Pattern appreciation (Newman 1999, Cowling 2000)
13	Space
14	Existential Advocacy (Gadow 1980)

Methodological Memos

1	Understanding Wilber (Wilber 1998)
2	Conceptual model
3	Parallel processing
4	Guidance
5	Validity / Authenticity
6	Reflection
7	Significance to Insight
8	Creativity

Appendix 6: Publications, presentations and awards since commencing PhD.

Publications

Keenan, E. Dalton, C. M. Barry, C. Buckley, L. Jarrett, L. and Stevenson, V. L. (2007) Joined-up-care: neurological and obstetric services working in partnership. A case study. *British Journal of Neuroscience Nursing*. 3(4): 164-168.

Stevenson, V. L and Jarrett, L. (2006) *Spasticity management: A practical multidisciplinary guide*. Informa Health Care. Oxford.

Jarrett, L. (2006) The challenge of managing spasticity: the role of the nurse in the process of assessment and measurement? *Nursing Times*. 102 (15): 26-28.

Leary, S. Jarrett, L. Lockley, L. Rodriguez, L. Gilpin, T. Stevenson, V. L. (2006) Using intrathecal baclofen to improve dysphasia in a person with cerebral Palsy. *Clinical Rehabilitation*. 20(3): 228-231.

Jarrett, L. and Johns, C. (2005) Constructing a reflexive narrative. Chapter 12 in *Transforming Nursing through Reflective Practice*. 2nd edition. Johns C and Freshwater D (eds). Blackwell Publishing. Oxford.

Thompson, A. J. Jarrett, L. Lockley, L. Marsden, J. and Stevenson, V. L. (2005) Clinical Management of Spasticity. Editorial. *Journal of Neurology, Neurosurgery and Psychiatry*. 76: 459-463.

Jarrett, L. (2004) *Managing Spasticity. MS care in the community*. Distance learning module, level 3. Leeds Metropolitan University. UK.

Jarrett, L. (2004) The role of the nurse in the management of spasticity. *Nursing and Residential Care*. March 2004. 6(3):116-119.

Jarrett, L. (2003) Attitudes to long-term care in Multiple sclerosis. *Nursing Standard*. 17(17):39-43.

Jarrett, L. Nandi, P. and Thompson, A. J. (2002) Managing severe lower limb spasticity in multiple sclerosis: does intrathecal phenol have a role. *Journal of Neurology, Neurosurgery and Psychiatry*. 73:705-709.

Jarrett, L. (2002) *Care pathway: the role of the nurse in the Management of Spasticity*. Multiple Sclerosis Trust. Letchworth.

Jarrett, L. Leary, S. Porter, B. Richardson, D. Rosso, T. Powell, M. and Thompson, A.J. (2001) Managing Spasticity in People with Multiple Sclerosis. A Goal Orientated Approach to Intrathecal Baclofen Therapy. International Journal of MS Care. 3(2):10-21.

Jarrett, L. (2000) Living with chronic illness: a transitional model of coping. British Journal of Therapy and Rehabilitation. 7(1): 40-44.

Conference Platform Presentations

DATE	TITLE OF LECTURE	CONFERENCE
5/11/07	'You can miss so much when you just concentrate on the physical aspects.'	MS Trust International Conference. Leeds, UK.
8/06/07	From Significance to Insights	Reflective Practice Conference. Aalborg, Denmark.
7/6/07 17/7/07	RAW: Journeying with Gill through breast cancer. I participated in this performance narrative written and performed by Prof. Chris Johns, Bella Madden and Maria Fordham.	Reflective Practice Conference. Aalborg, Denmark. The Inaugural Professorial Lecture of Prof Chris Johns, Bedford University.
26/6/07	Researching One's Own Practice: Towards a Broader Ethical Framework. Joint presentation with Professor Sally Glen Pro Vice-Chancellor Academic	School of Health Research Day University of Wolverhampton. Theme Mind the Gap! Bridging the Research and Development Divide

24/10/06: Spasticity team ran study day on Spasticity Management. Approx 80 participants from different disciplines I did two lectures: Working in partnership with the individual and Using IP in the latter presentation I read a narrative.		
5/9/06	Developing my nurse specialist role through the process of guided reflection and the construction of art	Health, Illness and Representation Conference, Association for Medical Humanities, Kings College London UK
3/7/06	Understanding the relationship of 'space' to managing spasticity: through the process of guided reflection and the construction of art.	Reflective practice conference Cambridge.
1/6/05	Can nurses facilitate practical opportunities for carers to learn about death?	Reflective Practice Conference. Iceland
17/11/02	Using guided reflection to develop a nurse specialist role	MSTrust International Conference. Harrogate UK.
8/11/02	'Managing severe lower limb spasticity in multiple sclerosis: does intrathecal phenol have a role.'	RCN Nursing Rehabilitation Conference. Bournemouth. UK.
03/02	Workshop exploring nurses attitudes towards long term care. (Jarrett 2003)	MSTrust Nurse Specialist Conference. Birmingham UK.

Conference Poster Presentations

DATE	TITLE OF POSTER	CONFERENCE
5/11/07	Joined-up-care: neurological and obstetric services working in partnership. A case study. (Keenan E, Dalton C M, Barry C, Buckley L, Jarrett L and Stevenson V L).	MS Trust International Conference. Leeds, UK.
4/11/06	Constructing a Reflexive Narrative	MS Trust International Conference. Bournemouth UK.
16/ 10/06	Constructing a Reflexive Narrative	St Bartholomew School of Nursing and Midwifery part of the Institute of Health Sciences, City University 'A Celebration of Doctoral Research'.
12/5/06	Developing Spasticity Services (Jarrett L and Stevenson V)	Rehabilitation in MS (RIMS) Conference, Barcelona, Spain
15/11/05	ITB Therapy – Developing a new learning resource for nurses (Buckley L and Jarrett L)	MS Trust International Conference. Blackpool UK.
15/11/05	'Why am I here?' Individual experience as a driver for change within a specialist spasticity clinic. (Archibald K, Jarrett L, Buckley L and Stevenson V)	MS Trust International Conference. Blackpool UK.
9-11/12/04 7-9/11/04	Managing complex Spasticity is challenging – Exploring a model of spasticity assessment. (Jarrett L, Lockley L, Thompson AJ, Stevenson V)	SPASM Conference Newcastle. UK. MS Trust International Conference. Harrogate UK.
17-18/1/04	Using guided reflection to develop the role of the nurse specialist. (Jarrett L)	City University Mphil/PhD student research weekend.
2-4/11/03	Does the use of an Integrated care pathway increase the efficiency of a spasticity outpatient clinic? (Lockley L, Jarrett L, O'Connor R, Thompson AJ)	MS Trust International Conference. Harrogate UK.
23/6/03	Using guided reflection to develop the role of the nurse specialist. (including a 15 minute presentation) (Jarrett L)	Reflective Practice Conference- Mindful Inquiry, Cambridge, UK.
8/4/03	'Managing severe lower limb spasticity in multiple sclerosis: does intrathecal phenol have a role.' (Jarrett L, Nandi P, Thompson AJ)	World Rehabilitation Conference, Prague, Czech Republic.
5-9/06/02	'Managing severe lower limb spasticity in multiple sclerosis: does intrathecal phenol have a role.' (Jarrett L, Nandi P, Thompson AJ)	Rehabilitation in MS (RIMS) Conference, Chicago, USA.

Invited Lectures

DATE	TITLE OF LECTURE	CONFERENCE / VENUE
10/07	The management of spasticity focusing on ITB	Fairlie Nursing Home, London
6/2/07	The management of spasticity	Study day for pain management nurse specialists facilitated by Medtronic, Windsor, UK.
15/11/05	The use of intrathecal therapies to manage complex spasticity	MS Trust International Conference. Blackpool UK.
14/10/04	Titrating ITB to maximize function.	ITB Therapy International study day. Medtronic Ltd. Birmingham. UK.
4/8/04	Managing spasticity it's a team effort (Joint lecture with L Lockley)	Community rehabilitation team and social services. Peckwater center, Camden PCT, London.

28/2/04	Managing spasticity it's a team effort One lecture to people with MS and the second to health care professionals	Devon MS Society Study Day
9/7/03	Nurses role in the management of spasticity	Marie Foster Care Open day. Barnet. London, UK.
1/5/03	Managing spasticity	NANOT meeting Jacketts Field community Rehabilitation Unit, Abbots Langley Herts
29/4/03	The nurse's role in developing an Intrathecal Baclofen Service. Practical sessions on technique of refilling pumps	National Study organized for nurses and clinicians by Medtronic PLC, Watford, UK.
13/4/02	Managing Spasticity	Association of Chartered Physiotherapists Interested in Neurology (ACPIN). London Study Day
15/1/02	Managing Spasticity	Southend Hospital Multidisciplinary National Study day.
11/01	Managing Spasticity it's a team effort	MS Trust International Conference. Harrogate UK.
4/01	Developing the role of nurses in an ITB service	Nursing care committee of RIMS Conference. Copenhagen, Denmark.
3/01	The role of ITB and Phenol, illustrated with case studies	Spasticity Study Day, NHNN

Awards

BMA Book awards 2007: Commended in Neurology Section for Stevenson V and Jarrett L (2006) Spasticity Management: A practical multidisciplinary guide. Informa Health Care. Oxford

October 2006 NHS Innovations London 1st place in publications section for Stevenson V and Jarrett L (2006) Spasticity management: A practical multidisciplinary guide. Informa Health Care. Oxford. Grant of 2,500 awarded. We are considering using it to develop a spasticity management website.

Research Awards

August 2006 – July 2007: £12,000 Educational Bursary awarded by MSTrust to complete my Mphil/PhD.

Conference Awards

5/11/07: Runner up poster prize: Joined-up-care: neurological and obstetric services working in partnership. A case study. (Keenan E, Dalton C M, Barry C, Buckley L, Jarrett L and Stevenson V L). MS Trust International Conference. Leeds, UK.

17-18/1/04: Awarded best poster prize: Using guided reflection to develop the role of the nurse specialist: City University MPhil/PhD student research weekend.

2-4/11/03; Awarded 1st prize with co-authors for poster: Does the use of an Integrated care pathway increase the efficiency of a spasticity outpatient clinic MSTrust International Conference. Harrogate, UK.

Working Groups.

Member of European working party of the measurement of Spasticity. SPASM. From 2002-2004. Participated in five European meetings.

Appendix 7.
Reflective Practice Conference – Enlightened Holistic Care: Iceland June 2005.

Dr Rorry Zahourek facilitated a workshop titled, 'Intentionality: the matrix of healing: A collage experience.' After a brief introduction exploring the meaning of intentionality (Zahourek 2005), Rorry guided the group to explore the concept through the construction of a collage.

I doubted where this would lead. These feelings evoked memories of my unease at the start of the art workshop facilitated by CJ two years ago, where I illustrated my experience with Jay (Figure 3.10.1).[131] This earlier art workshop was beneficial as it focused my attention on working in relation with the person to appreciate their life pattern and it expanded my practice to consider the person's environment and how they may influence it. I found the process liberating as it provided me with a different way to express myself.

Overcoming my doubt with this memory, I diligently followed Rorry's instructions, to rip pictures from magazines that I liked or moved me in some way, subsequently arranging and pasting them onto a sheet of A1 paper.

The image I created (Figure 4.0) flows from the bottom left hand corner towards the top right hand corner. This symbolises the person's journey. My intervention is represented from the right hand corner until it meets the person's journey; we then flow together towards the top right hand corner. The pictures I chose relate to nature symbolising a move in my thinking, to consider my nursing practice and living with a complex disability within the wider environment and not just the hospital setting.

The pictures and their placement on the sheet have not been added to or altered since the workshop; however my interpretation has deepened as I have dwelt with and contemplated the images. Similar to how I have dialogued with other texts I have dialogued with the collage. For instance I choose a picture of shoes to represent myself, because I love shoes. It was some months later that I made the link to how people with spasticity often struggle to comfortably fit into different types of foot wear.

[131] Reflective text 10, Page 166-167



Person's journey

My journey

Figure A7.0: Intentionality Collage

Starting in the left hand corner, I paste a picture of ice with its sharp, straight edges and imagery of coldness creating a backdrop to a sculpted stone figure. These images represent a person whose body through spasticity has become held in straight angular positions; their limbs very stiff and difficult to move. People with spasticity often describe their limbs as being cold and heavy to move.



Pictures of mouths surround the figure these are crossed or defaced. This represents the struggle people with spasticity have to be heard as individuals. Not only to get their needs met in health and social care but also to be viewed as valued members of society.

I expand this issue by using pictures of cleaning tools to represent people with spasticity having their voices swept away by non-listening professionals or sucked up and not heard in today's business of health care provision. Leading to individuals feeling like 'rubbish', easily disposed of, not valued and not important.



I represent myself as shoes my favourite expenditure; but is this symbolic? People with spasticity often find it hard to wear shoes due to spasms, or swollen feet. This is often a reminder to them and others of their difference and difficulty with mobility. Shoes can become decorative or for warmth and protection, but not for walking.
I am reminded of Carla[132] *and her disappointment at not being able to attend her sister's wedding. In particular our distress at her missed opportunity to wear a style of glamorous shoe, which as ITB was now reducing her spasms she was hoping to be able to wear again.*



I represent the technology of spasticity management (Fact sheets 1, 2, 5 and 6), with pictures of gadgets. Before applying these pictures to the collage I screw them up. This is to symbolically reduce their power and to represent how in my role I value the judicious use of technology and drugs to enhance a person's lifestyle but not before knowing the person, their aims and aspirations and how the technology will be integrated into their lifestyle.
My aim is to value the person before the technology. To represent this I position myself on the college between the person and the technology. The light bulbs represent my current efforts to study, to understand and find meaning as I strive towards making desirable practice a lived reality. I symbolise meeting the person with uneven rocks. This represents how we jostle to get to know each other and how we both may be in a state of precarious harmony. It reminds me of the difficult journey or 'bumpy road' through health, illness and life the person and their family will have experienced.
The second picture of shaped pumice represents how we rub along to create smooth edges and to define a pattern of care and intervention that would suit the person and their chosen lifestyle. I feel the holes are important to show that we may not always agree, but we remain connected, open to suggestions, new and changing knowledge.





The final corner shows a meeting of horizons and a movement from dark into light.
For the person with spasticity I hope this symbolises they achieved their aims, were involved and felt respected as human beings.
For me this symbolises my quest to transform self into an effective practitioner through guided reflection as a research process of self inquiry and transformation.



[132] Reflective text 12, page179

Appendix 8: Future Research Ideas

Aim: To explore methods of effectively including people with marked cognitive impairment into research trials.

I propose three related strands:
To explore how,
1. Effective strategies used to engage people in clinical practice could be transferred into research methods.
2. People deemed ineligible for trials could be supported to participate.
3. The input from a significant other could be maximised.

Strand 1:
Focus: Can we transfer strategies used to engage people in clinical practice into research methods?
Dewing (2002) suggests in her research with people with dementia that considering how people consent in other situations is an important strategy to maintain a person-centered approach to the consent process. To manage the complexity surrounding consent she describes 'being with' a person, the need to be connected and engaged with the intent of being in relationship.
In my research I found that consent was an ongoing process of engagement that required repetition of information, continuity of staff and 'being with' a person, guiding and journeying with them through the process.
Method:
Identified practitioners will use guided reflection as a process of self-inquiry and transformation (Johns 2006) when working with people in their clinical areas. In particular they will reflect on the processes required to consent people with complex disabilities and to maintain them on treatment programs such as disease modifying drugs or long-term treatments such as ITB. In addition they will pay attention to the life patterns of individuals, how and where do they spend their time, how they mobilise in the community and who is significant in the way they live their lives. The study will consider the processes used to make decisions such as seeking support, information or health care and what cues or processes enable them to remain in a treatment program in the community?
Understanding a person's life context, how they integrate and participate in activities would enable strategies to be identified and refined to enable individuals with complex levels of disability to participate in research programs.

Strand 2:
Focus: To explore in more detail whether people deemed ineligible for trials could be supported to participate by utilising strategies used in everyday life.
Method:
The aim is for identified practitioners/researchers to appreciate the life pattern of individuals that have been judged as ineligible for a research trial. This would in turn allow an appreciation of how they currently manage their lives and whether there could be any strategies we could utilise to enable them and others to engage in a research study over time.
This research approach would need to integrate clinical work as it is likely by exploring issues in depth we could offer other management suggestions, support and changes to treatment.

My research has shown that such a process cannot be completed as a one off task; it requires time to get to 'know the person'.
I would suggest 6 sessions of contact over a 4-6 month period, with at least two face-to-face, more if they are unable to use the telephone.

Strand 3:
Focus: To explore the involvement of the significant other in research trials that want to include people with marked cognitive impairment.
The recent review of the Mental Capacity Act (2005), in use since early 2007, indicates a more formal involvement of family members and carers in the consent process for those individuals who lack capacity?

> 'Carers or nominated third parties must be consulted and agree that the person would want to join an approved research project.'(DoH,2005, p6)

I wonder if we can extend this to consider:
Is there scope to solely use significant others/ carers to report changes in the condition of a person participating in a research trial, particularly for individuals with minimal or unique communication methods.
Maybe to some extent this already occurs but can we develop this more formally?

This question has come from my research with people who had the most complex of disabilities (EDSS 8 or above), in particular those using IP. I noticed a pattern whereby I referred to the person and significant other as 'one'. I would refer to it as 'their' admission or treatment. This was not at the expense of seeking the views and participation of the individual but highlighted that the way the person lived and integrated into society occurred interdependently with their significant other.

There is evidence from other studies (Gelling 2004, Philpin et al 2005) that suggest support from families is invaluable to interpret responses from individuals in a vegetative state and with communication difficulties.

Plan:

- To visit the research unit in Cambridge and discuss how they carry out research with people with vegetative states and their families.
- To consider methods of engaging and evaluating input from a significant other.

Benefits of these approaches:

- They integrate clinical practice and research.
- Problems relating to transporting and managing individuals with a complex disability within the research arena (for example accessibility of room, availability of moving and handling equipment and toilet facilities) are not an issue as this work occurs in the usual clinical setting of hospital or home.

Fact sheet 1: Intrathecal baclofen therapy (ITB)

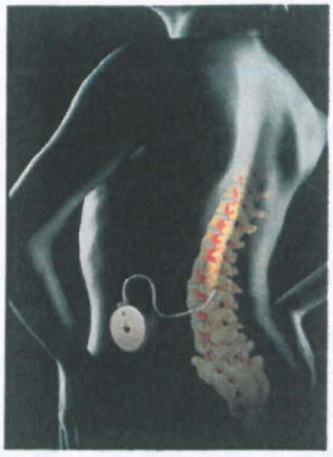
ITB was first used in 1985 (Penn and Kroin 1985) and is effective in the management of severe spasticity of either cerebral (Albright et al 1991, Meythaler et al 1997) or spinal origin (Penn et al 1989, Loubser et al 1991) and for specific conditions such as brain injury (Becker et al 2000) multiple sclerosis (Jarrett et al 2001) and hemiplegia (Meythaler et al 1999, 2001). The benefit has proved to be sustainable over time (Coffey et al 1993, Ochs et al 1989). More recently it has been used to improve specific functions such as the speech of a person with cerebral palsy (Leary et al 2006).

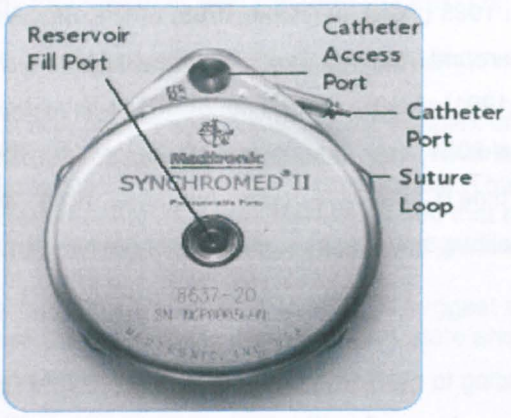
Mode of action

Baclofen acts by binding to gamma aminobutyric acid (GABA) receptors. It has a presynaptic inhibitory effect on the release of excitatory neurotransmitters (Fox et al 1978) and post synaptically it decreases the firing of motor neurones (Davies 1981). This results in inhibition of both mono and polysynaptic spinal reflexes (Davidoff and Sears 1974) with associated reduction in spasticity, spasm, clonus and pain. The purpose of administering doses of baclofen intrathecally is to deliver it directly to the GABA receptors; this accentuates its antispasticity effect while minimising the troublesome systemic side effects often associated with oral intake.

Mode of ITB delivery

For a short lasting effect, such as for a trial procedure, baclofen can be injected intrathecally via a lumbar puncture. For longer-term action, baclofen can be delivered intrathecally through use of a subcutaneously implanted pump. Each pump has a reservoir where the drug is stored and a catheter links the pump to the intrathecal space. The pump is surgically implanted into a subcutaneous abdominal pocket and the catheter into the intrathecal space with the tip situated at L2/L3 or higher, thus allowing the drug to be delivered directly toward the GABA receptors of the spinal cord (Figure FS1.0).





Dimensions of SynchroMed® II infusion pump		
	20ml reservoir	40ml reservoir
Depth	19.5 mm	26mm
Diameter	87.5mm	87.5 mm
Weight (empty/full)	165 / 185g	175 / 215g

SynchroMed® II Infusion System: Reference Guide. Medtronic. 2004

Figure FS1.0: Position of M

The people in my narrative used the battery dependent model (Medtronic SynchroMed® Infusion System, Figures FS1.0). This system is externally programmed using a hand held computer and telemetry (Figure FS1.1).



SynchroMed® II Infusion System: Reference Guide. Medtronic. 2004

Figure FS1.1: Medtronic SynchroMed® II Infusion System: The programmer

The prescription of baclofen over a 24-hour period can have up to ten different steps providing great flexibility in dosing to meet the individuals' needs.

Fact sheet 2: So why does spasticity occur?

The control and regulation of normal skeletal muscle activity involves a complex combination of descending motor commands, reflexes and sensory feedback both from the brain, spinal cord and peripheral sensation (Figure FS4.0). During normal movement, influences from the cerebral cortex, basal ganglia, thalamus and cerebellum, travelling via upper motor neurones adjust, reinforce and regulate the lower motor neurone which connects directly via peripheral nerves to the muscle to form smooth, co-ordinated muscle activity and maintenance of posture.

Spasticity and other positive features of the upper motor neurone occur when there is damage to certain upper motor neurone tracts (Figure FS4.0) this interrupts the regulation of spinal cord and lower motor neurone activity. This can result in enhanced lower motor neurone activity and an increase in muscle activity, in response to peripheral stimuli (for example muscle stretch, a urinary tract infection or pressure sore). In addition, there is evidence that certain motor neurons serving skeletal muscle are hyperexcitable in spasticity, resulting in muscular contractions from stimuli that would not normally trigger a response (Sheean 2001, Stevenson and Marsden 2006).

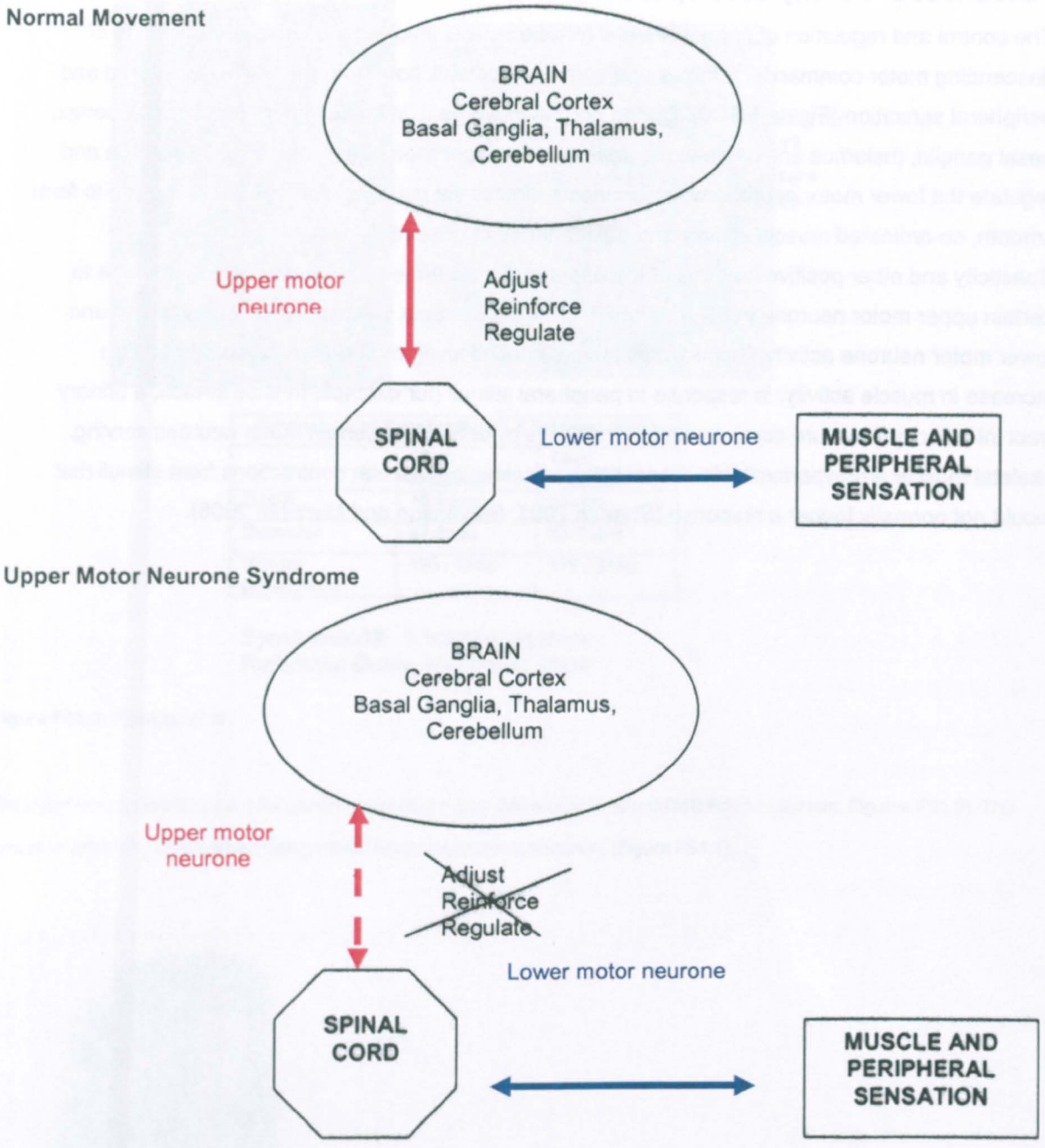


Figure FS4.0: A diagrammatic representation of normal movement and the upper motor neurone syndrome (Jarrett 2004).

Fact sheet 3: The core spasticity team

The core team consists of a consultant neurologist and clinical specialists in physiotherapy and nursing. An outline of their roles (Figure FS3.0) illustrates their unique contributions to the team.

The doctor needs to understand the underlying neurological condition including prognosis, natural history, associated features and possible complications. To identify abnormal features or unexpected changes, that may suggest an alternative cause or second pathology. To be experienced in neurological history taking and examination. Competent in the prescribing and use of pharmacological interventions including oral medication, botulinum toxin and intrathecal drug therapies.
The nurse needs to be skilled in providing education and promoting self-management to the person with spasticity particularly in the area of preventing exacerbating factors and secondary complications. Be able to identify and manage cutaneous and visceral stimuli. Monitor and evaluate the effectiveness of drug regimes. Advise on posture, moving and handling. Manage psychosocial issues. Consider impact on role, employment and social activities. Work with individuals, their families or carers to appreciate the nature of invasive treatments and potential impact on their daily lives. Monitor ongoing accuracy of guidelines and protocols in relation to safe delivery of services particularly with invasive treatments.
Physiotherapists explore the potential for movement patterns and functional ability to be enhanced. They will consider the relative contribution of neural and biomechanical components to spasticity and select treatments to limit soft tissue shortening and loss of function. They will identify underlying muscle weakness and the impact on function. They will be instrumental in treating, advising and teaching the individual or carer how to incorporate effective movement, standing, stretching or positioning into a daily management program.

Figure FS3.0: Brief description of roles in core spasticity team (Stevenson et al 2006)

How the spasticity service has evolved

The service accepts national referrals and has developed through strategic planning and successful business case submission over the last 10 years (Figure FS3.1).

Research and development	Pathway to integration into spasticity service
1. Increasing awareness of ITB therapy through published research. Neurology team explored use of treatment at NHNN	• Clinical governance issues were raised in particular with regard to safety of administering ITB and effective education of patient and ward staff. • A joint business case was produced between neurology and rehabilitation services to develop the infrastructure for running an ITB service. • Role for part time ITB nurse practitioner developed. This post had lead responsibility for the ITB service involving the development of protocols and education tools to ensure a safe and effective service delivery.
2. Research trial of botulinum toxin for spasticity. Involved: consultant neurologist, neurophysiologist, head physiotherapist, medical and physiotherapy research fellows (Richardson et al 2000)	• After research completed focal spasticity management expertise incorporated into neurophysiotherapy acute specialist role. Focal treatment clinics continued within clinical service.
3. Standards were developed for MS services between the	• NHNN did not meet standards, so business case submitted to improve service provided.

	Multiple Sclerosis Society of Great Britain and Northern Ireland and NHNN (MS Society 1997)	• An MS nurse post designed incorporating part time ITB post. This post maintained and developed the protocols and standard of service delivered, developed the advanced nursing role in refilling/ reprogramming pumps and provided education to medical and therapy colleagues on all aspects of the ITB service. • A generalised spasticity assessment clinic developed incorporating both focal and generalised treatment options. Clinicians involved; consultant neurologist, acute neurophysiotherapy specialist and MS nurse specialist. There was additional input from neurophysiologist when required.
4.	Disease modifying drugs for people with MS became more widely available	• Demand on MS service increased at all stages of disease evolution. Difficulty maintaining ITB within the MS service and recognition that the spasticity service needed to reach beyond MS population. A business case was submitted to expand and distinguish between services. • A full time ITB nurse practitioner role was developed. (I came into post)
5.	The ITB service reviewed (Jarrett et al 2001). The referral rate to the spasticity outpatient assessment clinic is increased with a corresponding rise in in-patient work	• The ITB nurse practitioner role expanded to incorporate all spasticity related nursing issues. Post title becomes spasticity management nurse specialist. • A business case developed for a part time physiotherapy specialist dedicated to spasticity management.
6. 7.	The IP (IP) service was reviewed (Jarrett et al 2002). The ITB and IP service continue to expand	• A business case was developed for a second specialist nurse.
8.	Further increase in outpatient assessment referrals, waiting list becomes unmanageable	• A business case submitted to increase neurology, physiotherapy and secretarial input to service.
Current team (January 2007)		
Lead consultant neurologist responsible for overall clinical spasticity service. Including; assessment clinics, ITB and IP in-patient and outpatient services (3 sessions/ week) Consultant neurologist responsible for focal spasticity assessment and treatment clinics (2 sessions/ month) Senior nurse specialist (whole time) responsible for day-to-day running of service. Key clinical areas; spasticity assessment clinics and IP service lead Nurse specialist (whole time): ITB service lead Physio clinical specialist (half time) responsible for assessment clinics, in-patient and outpatient services Senior 1 Physio (full time) responsible for focal spasticity assessment clinics and supporting in-patient and outpatient services Secretarial and admin support (full time)		

(Adapted from Stevenson and Jarrett 2006 pg 110 –111)

Key
ITB = Intrathecal baclofen
IP = Intrathecal phenol
MS = Multiple sclerosis

Figure FS3.1: Development of the spasticity service at the National Hospital for Neurology and Neurosurgery (NHNN) (Stevenson et al 2006).

Factsheet 4: Intrathecal phenol therapy (IP)

Mode of action

Phenol is a neurolytic chemical which when injected peripherally or intrathecally causes coagulation of nervous tissue and denaturing of proteins, which leads to cell damage, axonal degeneration and indiscriminate destruction of motor and sensory nerves (Bonica 1990). Injecting phenol with glycerol limits the dispersal into cerebral spinal fluid and nerve tissue resulting in a relatively neuro-selective effect, which can be further enhanced by specific positioning of the person during and after the intrathecal injection enabling motor nerve roots to be targeted whilst limiting the effect on sensory nerves (Jarrett et al 2002).

History of phenol use

The successful use of IP to reduce pain and spasticity was first reported in the 1950's (Maher 1955, Kelly and Gautier-Smith 1959, Nathan 1959) however due to the inherent destructive nature of the therapy it was never completely accepted into the routine care of people with severe spasticity (Davis 1975) despite further reports of benefit from clinicians over the years (Browne and Catton 1975, Scott et al 1985). As a team we reviewed our service and noted IP can be effective for a relatively small group of patients whose symptoms can no longer be effectively managed with other interventions. If these individuals are carefully assessed and appropriately selected, IP has been found to be a highly effective and well-tolerated treatment in the management of severe spasticity and associated pain (Williams et al 1995, Jarrett et al 2002).

In the earlier studies complications such as bladder and bowel incontinence, limb weakness and painful paresthesia were highlighted, although it was not clear if these complications resolved or persisted (Nathan and Scott 1958, Wood 1978). Another potential problem with IP therapy is the beneficial effects may diminish over time with pain and spasms returning (Lourie and Vanasupa 1963, Hansebout and Cosgrove 1966, Nathan 1969). This is thought to be due to regenerating axons eventually re-innervating the motor endplates of the nerves.

Outcomes of IP treatment

Spasticity, spasms and associated pain can be dramatically reduced or eradicated by IP therapy. This can lead to improved positioning, comfort and ease of carrying out personal care either for the individual or their carer.

Adverse effects of IP therapy

Side effects of IP treatment can be subdivided according to when they occur:

Short-term side effects

These may occur during or soon after the injection procedure and include hypotension, heart rate and rhythm disturbances secondary to sympathetic nerve blockade. Very rarely respiratory depression can occur. Post-procedure the individual may experience a low-pressure headache secondary to cerebral spinal fluid leakage.

Long-term side effects

These include changes in muscle power, sensation, sexual, bowel and bladder function (Figure FS2.0). In addition to sensory impairment causing numbness some people may experience a change in sensation with the appearance of dysaesthetic pain or alteration in the character of pre-existing pain; this is more common with peripheral chemical neurolysis but can occur with intrathecal injections.

- Bladder and or bowel retention or incontinence
- Sexual changes relating to reduced sensation in the perineal area and erectile dysfunction
- Reduced lower limb sensation
- Lower limb weakness within the range of movement available (often this is limited by contractures)
- Deep vein thrombosis (DVT): Spasms can promote vascular flow so some patients may be at risk of DVT if their spasms are significantly reduced
- Neuropathic pain is uncommon with an intrathecal neurolytic block but can be caused by partial destruction of the somatic nerve and subsequent regeneration. It clinically manifests as hyperesthesia and dysesthesia that may be worse than the original pain associated with the spasticity
- Reduced skin integrity secondary to changes in posture in sitting and lying as well as the effects of reduced sensation

Figure FS2.0: Potential long-term side effects of IP

Secondary effects

The impact on a person's spasticity and positioning can be dramatic; if their posture is changed significantly this often will have consequences for their sitting and lying positions. The individual is likely to need a seating review to accommodate the sudden change in posture and to prevent complications such as pressure sores developing. For these reasons it is imperative that IP treatment is only carried out following close liaison with the relevant seating specialists, physiotherapist and, or occupational therapist.

In view of the potential long-term effects of treatment careful patient education and selection is clearly essential before considering IP treatment.

Fact sheet 5: Commonly used oral drugs for spasticity

(Stevenson and Jarrett, 2006, p 62)

Drug	Starting dose	Maximum dose	Side effects
Baclofen	5-10mg daily	120mg daily, usually in 3 or 4 divided doses	Drowsiness, weakness, nausea, vomiting
Tizanidine	2mg daily	36mg daily, usually in 3 or 4 divided doses	Drowsiness, weakness, dry mouth, postural hypotension **Monitor liver function*
Dantrolene	25mg daily	400mg daily, usually in 4 divided doses	Anorexia, nausea, vomiting, drowsiness, weakness, dizziness, parasthesiae **Monitor liver function*
Diazepam	2mg daily	40-60mg daily, usually in 3 or 4 divided doses	Drowsiness, reduced attention, memory impairment **Dependency and withdrawal syndromes*
Clonazepam	0.25-0.5mg, usually at night time	3mg, usually in 3 divided doses	Same as diazepam
Gabapentin	300mg daily (can start at 100mg daily)	2400mg daily, usually in 3 divided doses	Drowsiness, somnolence, dizziness

Cannabinoids

Individuals with multiple sclerosis or spinal cord injuries have used cannabis on the basis of anecdotal evidence and the results of several mostly small studies, which suggest subjective improvement in symptoms. Benefits in self-reported assessments of pain, spasms, sleeping, bladder control and spasticity have been demonstrated. (Wade et al 2003, Metz 2003, Vaney et al 2004, Fox et al 2004). Two large studies have recently been completed (Zajicek et al 2003, Wade et al 2004) they support some symptomatic benefit for cannabinoids but it was not significant for cannabis to be legalised. Cannabis in its natural form is classified as a class C drug in the United Kingdom; possession and supply remain illegal.

Fact Sheet 6: Botulinum toxin

Botulinum toxin (BT) is the most powerful naturally occurring neurotoxin. It is produced by Clostridium botulinum; a gram negative anaerobic bacterium, which if ingested can lead to botulism that can ultimately lead to death. However administered in minute amounts intramuscularly it can cause a temporary weakness of the muscle by blocking nerve transmission at the neuromuscular junction.

In our practice we use it for small muscle groups and tend to refer to it as a focal rather than regional or generalised therapy. We use the time that the injection is active to implement a physiotherapy treatment and stretching program, in the hope that when the injection wears off the spasticity has been alleviated.

Administration

The muscles to be injected are identified by physical examination and then a needle is inserted into the muscle. Sometimes the needle is connected to an EMG (electromyography) machine; this registers the electrical activity of the muscle, over activity would denote spasticity is present and can help guide the correct placement of the injection.

The effect of the injection will start immediately but visual signs of change take between 10-14 days to be evident.

Protocol 1: Assessment

Assessment

Assessment is concerned with gathering and interpreting knowledge of a person in order to ascertain their health needs and plan how best to help meet them. I have led on the development of a spasticity assessment document that has steadily evolved through the experience of team members and audit (Stevenson et al 2006). The overarching purpose is to collate multidisciplinary information in one place pre, during and post the clinic assessment. The document guides the collection of relevant information, reduces duplication by individual disciplines and identifies individuals who may require drug titration prior to the clinic visit. It provides a central record of, phone calls; details of individuals involved in a person's care and agreed plans for treatments.

A summary of headings on spasticity assessment document

Spasticity	Please comment on site and severity of spasticity
Clonus	Please comment whether spontaneous
Spasms	Please comment on which muscles, extensors or flexors, severity, pain, frequency and duration
Pain	Please comment on presence, severity and management. Indicate if pain has been getting worse, better or remains the same
Sleep patterns	Please comment on disturbances, positions and quality
Bed mobility	Please comment on how much, type of mattress used
Bladder	Please comment on current management
Bowel	Please comment on current management
Skin	Please comment on the presence of pressure ulcers and the ability to relieve pressure, change position and sensation and any aids used. Waterlow score =
Mobility	Please comment on outdoor, indoor, mode, aids, speed and distance
Toilet / bath/ shower transfers	Please comment on ability and aids required. Indicate if this has been getting worse, better or remains the same
Transfers	Please comment on car, bed, chair, level of independence and assistance required
Wheelchair	Please comment on posture position, type and make of chair and cushion
Previous therapy and nursing input	Please comment on physiotherapy, OT, seating assessments, and nursing advice. Ensure details of time, date and location of treatment obtained, including names, addresses and contact details.
Options discussed with patient	Make a note of the type of information discussed. For example oral medication, dosage, therapy input, BT, ITB, IP, seating assessments, splinting etc.
Action to be taken: (Please include details of who will implement the action)	

Using the document

Information collected prior to clinic is recorded and reviewed by the team. To initiate the assessment, the person (or if appropriate their carer) is asked to describe the history of their spasticity including when it started to become a problem and how it affects their lives both positively and negatively. The direction of the conversation is led by the person, rather than adhering to the structure of the form. We want to understand the person's lifestyle context and how their spasticity is impacting. An understanding of a person's life context is vital when considering if either of the intrathecal treatments will fit into their lifestyles.

The aim is to qualify points of the emerging story, whilst maintaining the fluidity of conversation. Team members use headings from the form to cue their inquiries. This conservational approach allows an individual to emphasise some issues over others, this provides us with a greater

appreciation of what is important to them. A question and answer technique can restrict such personal perspectives from emerging. As the person speaks details are précised and recorded under the relevant headings.

Protocol 2: Measurement

If a person is admitted for a trial of an intrathecal therapy to supplement the clinic assessment the physiotherapist and I complete a battery of measures. These outcome measures provide a quantifiable judgement pre and post treatment. They contribute a different perspective to the team on the person's spasticity and spasms and form a valuable part of our decision-making when considering whether to proceed with ITB or IP. There is an abundance of literature on measurement scales pertaining to spasticity these have recently been vigorously reviewed by the EU group and fall into three domains; clinical (Platz 2005 et al), biomechanical (Wood 2005 et al) and neurophysiological (Voerman 2005 et al). These reviews establish that there is no one measure that adequately measures spasticity. In practice we routinely use a battery of measures (Figure P2.0) to reflect different aspects of the upper motor neurone syndrome (Figure 1.2). The exact battery is individualised for patients to reflect their particular problems. In an ITB audit from our service (Jarrett et al 2001) we found the most effective tool for assessing the success of ITB was whether a negotiated goal relating to their main problem was achieved or not.

Scale and purpose	Description
Goniometry: to measure passive and active range of movement (Norkin and White 1985)	A long armed hinged protractor is used to measure joint angles
Range of passive hip abduction: To assess ease of maintaining lower half washing and dressing (Hyman et al 2000)	This is simply the maximum distance between the knees measured using a tape measure when the hips are passively abducted with the patient in the supine position
Ashworth scale: To assess stiffness in limbs. This will be influenced by both neural and non-neural changes. (Ashworth 1964)	This is an ordinal scale of tone intensity with five grades from 0 to 4. The scorer passively moves the limb through available range and assesses the level of stiffness
Penn spasm frequency scale: Measures frequency and type of spasms (Penn et al 1989)	This is an ordinal rank scale (0-4) based on self-reporting of lower limb spasm frequency in people with spinal cord related spasticity. It is scored depending on how many spasms are experienced in an average hour.
Numeric rating pain intensity scale (Kremer et al 1981)	A verbal analogue scale to assess a person's perception of pain on a scale of 0-10.
Numeric rating scale for leg stiffness:	A verbal analogue scale to assess the person's perception of stiffness on a scale of 0-10.
Posture in seating score: To assess a person's sitting posture	A self-designed score comprising four simple yes/ no answers which are assigned scores of 1/0 and when summed give an estimate of seating posture (score of 0-4). In addition baseline-sitting tolerance is estimated and scored 1-4 according to tolerance levels of more than 6 hours, reducing to less than 1 hour.
Overall comfort rating: To assess a person's perception of how comfortable they feel. This has been included in addition to the pain VAS following an observation by the team that regularly pre-treatment people recorded no pain, but after treatment stated they felt more comfortable.	The person is asked to rate their level of comfort over the preceding 24-hour period on a scale of 0-10.
Goal setting	The goal agreed will be completely individualised to each person and should focus on what will actually make a difference to his or her life, not to changes visible during a treatment session or stay in hospital.

Figure P2.0: Potential outcome measures we use

Protocol 3: Provision of a safe ITB service

The use of ITB is not without risk of complications; these can be related to baclofen, the infusion system or human error.

Potential side effects of ITB therapy

Signs of acute baclofen overdose:	Depressed respiration, Drowsiness, weakness in lower limbs, Dizziness/ light-headedness, Diplopia, Nausea /vomiting
Other side effects of baclofen:	Muscle hypotonia, Headache,Confusion, hallucinations, mood changes, Seizures, Hypotension , Dysphagia, Dysarthria, Nystagmus, Urinary incontinence or retention, Ileus, constipation or diarrhoea, Sexual dysfunction, Paraesthesia, Bradycardia, Allergic reactions, Peripheral oedema, Deep vein thrombosis
Infusion system:	The catheter can kink, dislodge, split, disconnect,The pump can malfunction or flip over, There is a risk of infection both locally to the pump and catheter sites but also systemically,Titanium allergies
Human error:	This can occur at implant, during the reservoir refills or programming of the pump

The ITB pathway involves selection, education, assessment, trial, implant, ongoing follow-up and pump replacement. (Figure P3.0).

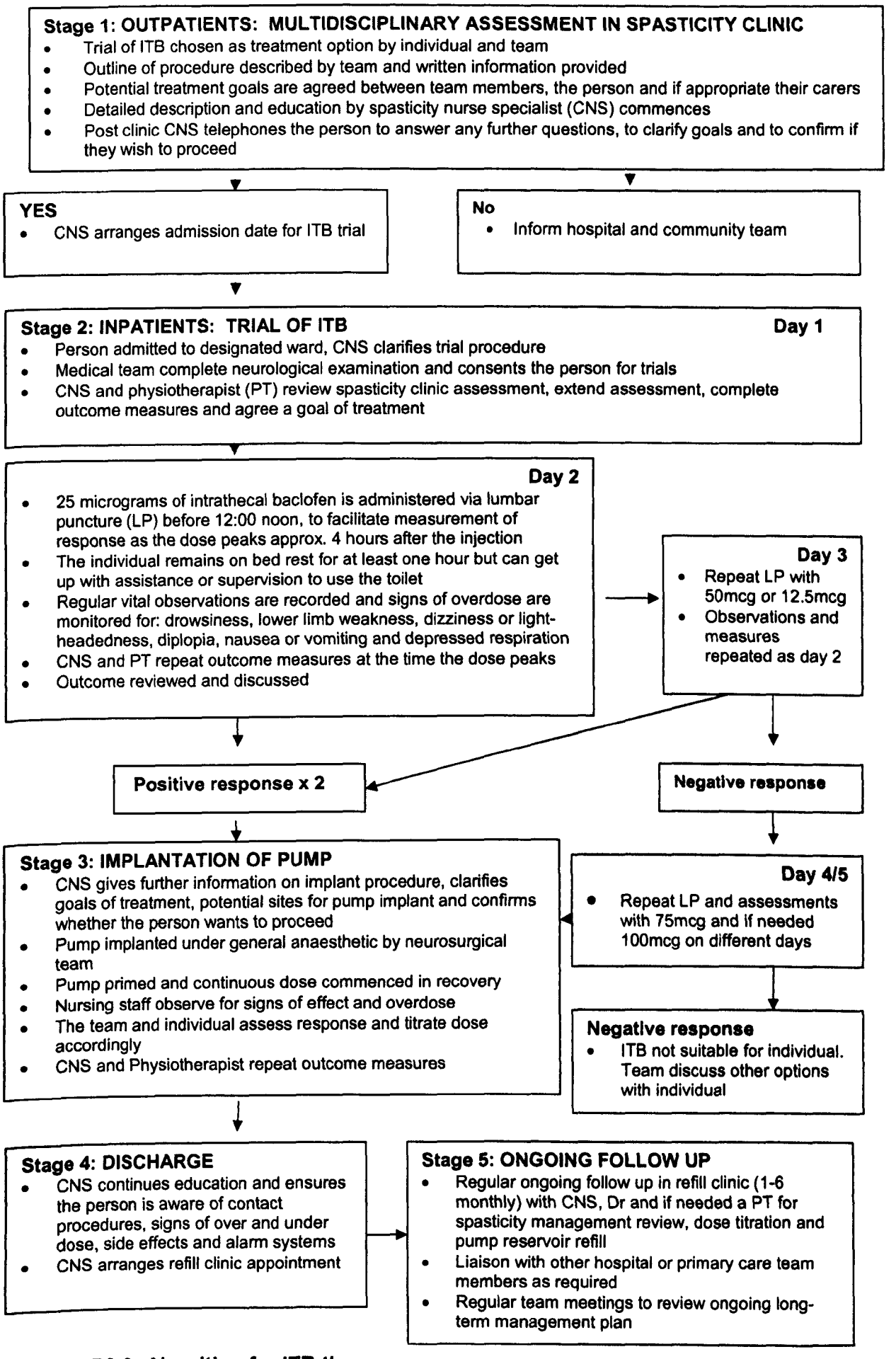


Figure P3.0: Algorithm for ITB therapy

Selection criteria for ITB trial

- Severe lower limb spasticity that impacts on the person's daily life (for example Ashworth grade 2 or above and /or Penn scale 2 or above)
- Physical adjuncts, therapy, nursing, the use of oral medication and, or botulinum toxin no longer adequately managing the person's spasticity
- Individual or their carer participate in discussions about ITB, agree to a trial and demonstrate an awareness of the potential long-term commitment involved with ITB therapy

The ITB trial

The ITB trial is an integral part of the assessment and decision-making process for potential long-term ITB therapy. The trial consists of administering a bolus dose of ITB via lumbar puncture. At least two trials are completed, each on a separate day. The initial dose given is 25mcg with increments being no more than 25mcg at a time. Even if the person has a response at 25mcg the trial is usually repeated with 50mcg to confirm a response and help gauge the potential for goal achievement. This is because in some cases the higher dose produces the same outcome as the lower dose, illustrating the maximal effect of the treatment for that person. This can be useful for the individual to experience as it can guide them to decide whether the impact is significant enough to proceed to implant. On rare occasions if excessive weakness underlying the spasticity is exposed with 25mcg the second dose is halved to 12.5mcg. This occurs predominantly when the aim is to preserve the quality and ability of the individual to walk or transfer whilst minimising some of the negative effects of their spasticity and spasms (Jarrett 2006a).

The trial injection permits a relatively large amount of baclofen to enter the intrathecal space rapidly and the peak effect occurs four hours after injection; therefore there is a risk of overdose or other side effects that necessitates careful monitoring of the individual. The trial doses need to be administered with resuscitation equipment readily available.
To ensure members of the team are available to manage any side effects and to reassess and re-measure the person as the drug peaks after four hours we aim to give the trial injection before midday. A positive result is classed as the person experiencing a positive effect for 6-8 hours post the peak time.

Procedure following trial

The team discuss outcomes from both trials collectively with the individual and their family or carers if appropriate. A decision is made whether the trial had a positive or negative effect, or whether further trial doses are required to clarify the potential usefulness of ITB therapy, doses up to 100mcg.

Protocol 4: Pump implantation

A pump implant is arranged if, the trials are successful, the person meets the pump implant selection criteria (Figure P4.0) and all concerned agree to proceed.

- Severe lower limb spasticity that impacts on the person's daily life (e.g.Ashworth grade 2 or above and /or Penn scale 2 or above)
- Oral medication, physical adjuncts, therapy and nursing no longer adequately managing the person's spasticity
- Individual responds positively to two ITB trials
- Individual or carer agree with the treatment goals, are aware of their role in managing and being responsible for the pump
- If a person has a history of drug abuse or self-harm the future potential risk needs to be considered as minimal by appropriate professionals

Figure P4.0: Criteria for ITB pump implant

The pump is implanted by a neurosurgeon and the therapy commenced once the person is awake in recovery.

Discharge preparation:

The individual's responsibility

At least one person, normally the person with the pump but it can be a family member or carer, needs to take responsibility for the implanted pump system.
This requires:

- Commitment to attend for refills
- Ongoing monitoring of effect on spasticity
- Ongoing observation for signs of overdose and under-dose (Protocol 3)
- Awareness of the alarm systems and ability to take appropriate action to seek medical assistance in both emergency and urgent situations (Figure P4.1)

Emergency
Inform your close family and friends (plus work colleagues if you wish) to contact the emergency services (In the UK: Telephone 999) if you ever show signs of:

- Difficulty breathing
- Being drowsy and are difficult to rouse
- Marked weakness in your legs

Urgent
Contact you specialist nurse or refill centre if:

- You hear an alarm
- There is a gradual or sudden change in your spasticity

Remember to monitor for the emergence of trigger factors, which may aggravate you spasticity such as:

- Bladder and bowel problems
- Skin changes such as blisters, red or broken skin areas
- Any infections
- Tight clothing or splints

Figure P4.1: When to seek emergency or urgent medical assistance for people using ITB therapy

Providing a 24-hour help-line for individuals and teams in the community

The numbers of people who are selected for ITB therapy are significant but remain low in the overall population of any GP or community team's workload. It is therefore essential that adequate support to aid the safe delivery of ITB therapy is available. We provide a 24-hour hospital based contact service, the details of which are given to the person with the pump, any family or carers involved as well as their community teams (Figure P4.2).

- Between 0830-1700 Monday to Friday, the spasticity specialist nurses triage calls
- Between 1700-0830 and at weekends, the nurse in charge of the dedicated ward will triage calls. This involves the nurse taking the following information and then liaising with the Neurologist on call:

1. Name
2. Contact telephone number
3. Reason for calling
4. Has their spasticity improved or deteriorated
5. Date last seen by a member of the spasticity team
6. Have they any other symptoms which may be aggravating their spasticity

e.g. Urinary infection, retention, constipation or broken skin areas

Figure P4.2: 24-hour support service for ITB service

Pump replacement

During the period of my narrative the pumps have been revised from having a 3-5 year battery life to between 5-7 years. After this time an entire pump replacement (the catheter if patent remains in place) is required that necessitates a neurosurgical operation. The electronic pumps have an alarm system that will alert the person if the reservoir volume is low, the battery depleted or the pump malfunctions.

The person's underlying disease process may have deteriorated and their suitability for a general anaesthetic needs to be considered and discussed with the implant team.

Protocol 5: Ongoing refill and follow up

The pump design requires the reservoir to be refilled regularly; this is routinely done in an outpatient setting. At each clinic appointment a spasticity management review is completed, the pump refilled (Figure P5.0), dose adjustments made and any further education with regard to spasticity management discussed. Frequently individuals have other medical issues they want to discuss. Input from other therapists is accessed as necessary.

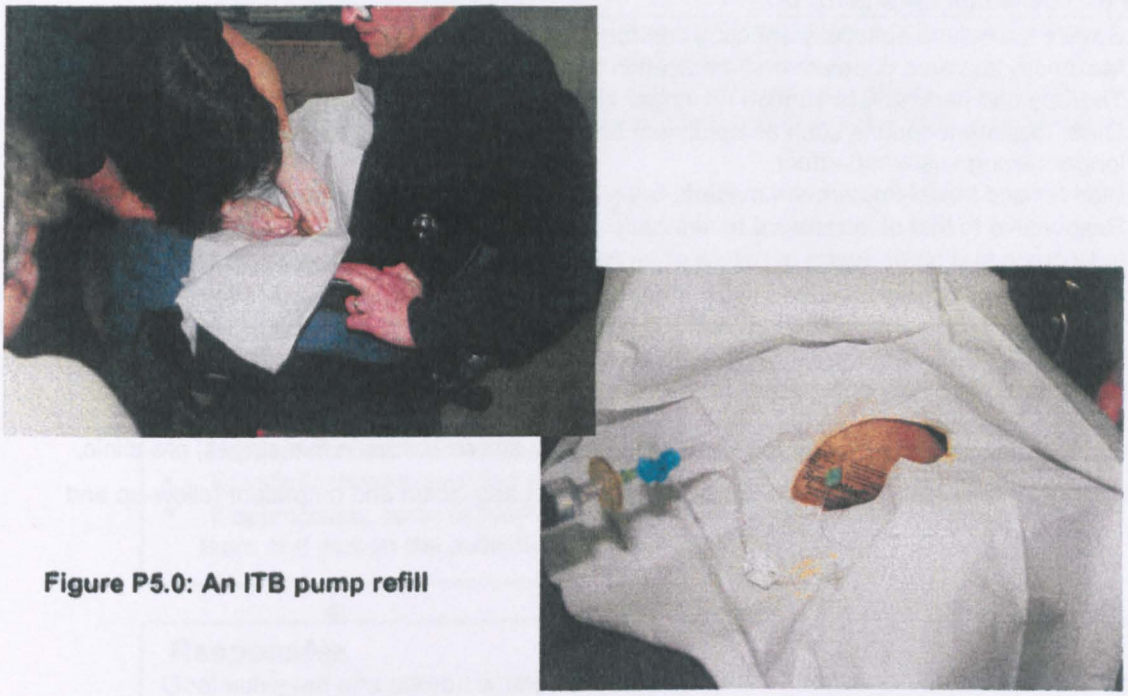


Figure P5.0: An ITB pump refill

Protocol 6: Intrathecal Phenol patient selection

The use of IP should only be considered when other options have been exhausted, bladder and bowel function are already compromised and effective management strategies are in place, and where there is severe pre-existing motor loss and reduced sensation of the lower limbs (Figure P6.0).

Figure P6.0: Selection criteria for IP

- Severe lower limb spasticity affecting comfort, function and/or care
- Maximum tolerated doses of oral medication tried without therapeutic effect
- Therapy and nursing intervention no longer able to sustain effective management
- Other treatment options such as botulinum toxin, ITB considered unsuitable or no longer having sustained effect
- Bladder and bowel impairment evident, but effective management strategies in place
- Responsive to trial of intrathecal anaesthetic
- Individuals and carer aware of nature of treatment, potential short-term effects (for example hypotension) and long-term effects (for example changes to lower limb sensation, sexual, bladder and bowel function)
- Individual, family, carer(s) and the team collaboratively formulate and agree a goal of treatment, which will have a positive effect on the individual's daily life

The overall process as the following algorithm (Figure P6.1) shows occurs in five stages; pre-clinic, spasticity assessment clinic, post-clinic education, in-patient admission and outpatient follow-up and reviews.

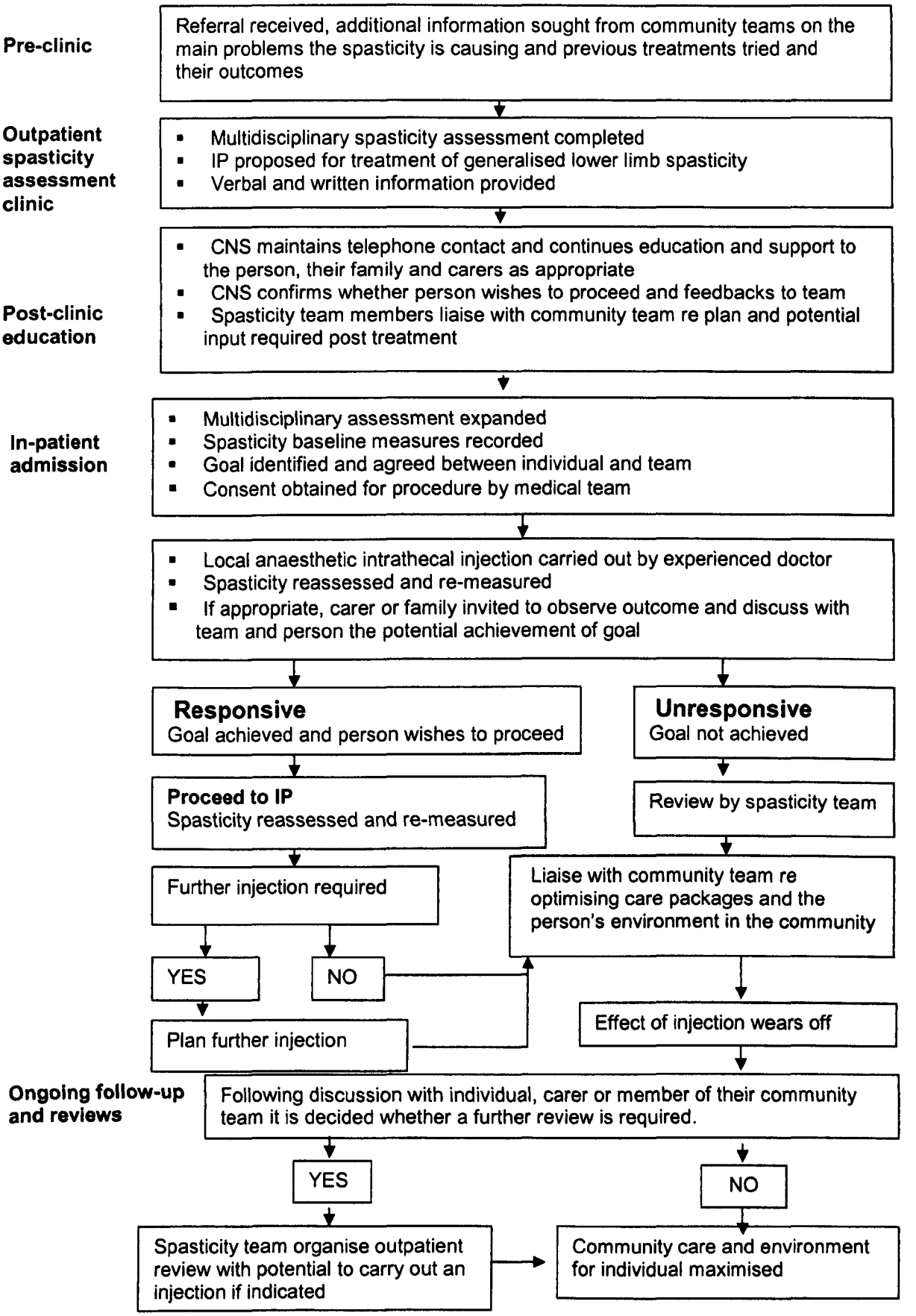


Figure P6.1: IP treatment process

Protocol 7: The IP treatment process

Treatment

There are two distinct phases in the treatment stage, the trial and the phenol injection.

Phase one: The trial

The anaesthetic bupivacaine acts by temporarily blocking nerve transmission by decreasing sodium channel permeability. The trial consists of injecting bupivacaine into the intrathecal space to produce a targeted, short acting anaesthetic to ascertain whether or not the person's spasticity, spasms and/or pain could be managed more effectively with the longer acting phenol injection. This trial allows the patient to temporarily experience the likely effect of having the phenol injection and can assist them in deciding whether to proceed.

Both the local anaesthetic trial and the phenol will only have an affect on the neural component of tone and not on any biomechanical changes intrinsic to the muscles or soft tissues. One of the values of doing a local anaesthetic trial is the opportunity to re-measure and assess if there are any contractures, which may limit the achievement of the goal. This enables the team to predict more clearly what the effects of the phenol may be to the person and their family. It is not uncommon for individuals, their families or carers to hope that the treatment will result in legs that can be straightened; the trial therefore allows them to appreciate the extent of any contractures and avoids any false hopes from the phenol injections.

The trial itself is an important part of the education process for the person, as even the best verbal and written education cannot surpass actually experiencing the injection process, its potential outcome and together with the team predicting how it may positively impact on daily life.

Phase two: The phenol injections

If the trial injection is successful, and the person wishes to go ahead, the process of the phenol injection is much the same as the trial except a larger spinal needle for example 18 gauge maybe required, as the phenol is more viscous (Figure P7.0). Typically patients require both lower limbs targeted and will therefore need two phenol injections, these are performed on separate days, ideally 24 hours apart to minimise any risk of short term side effects such as autonomic dysfunction. The outcome measures are repeated after the final treatment.

- It is advisable that intravenous access is obtained prior to the injection in case intravenous fluids or other drugs are required to maintain perfusion.
- The side and level to be treated is confirmed and the person is positioned in side lying on the targeted side. For example, if the right hip flexors are to be targeted then the person will be positioned on their right side and the injection will be inserted at L2/3.
- It is vital there is communication between the professionals carrying out the assessments and the medical specialist carrying out the injection to ensure the correct area is targeted.
- An expert medical practitioner who has been trained in the giving of intrathecal medication performs a lumbar puncture. A larger gauge needle (for example size 18) will be needed to inject the phenol in glycerol as it is viscous.
- In some situations the use of x-ray guidance to position the spinal needle maybe required.
- The solution is injected and the patients position checked by the injector. Repositioning maybe required at this time to give some pronation such as through the use of a wedge so as to target the motor nerves.
- The person is maintained in this position after the trial injection for 5 minutes and following the phenol injection for 20 minutes.
- The patient's blood pressure is recorded at least every 5 minutes for 30 minutes post procedure and a specialist nurse observes them constantly for at least one hour.

Figure P7.0: The injection guideline

Outpatient follow-up and reviews

The outcomes of the treatment are fed back to the community teams and follow up plans are confirmed. People who undergo IP therapy tend to have complex disabilities and it can be difficult for them to travel to and from hospital on a regular basis. To limit the number of journeys and to minimise disruption to complex care packages, in our service the community team commonly take responsibility for assessing the ongoing effect of the phenol and whether further injections maybe necessary. If further treatment is required, the person or the community team contacts the hospital team and the repeat injections are organised.

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