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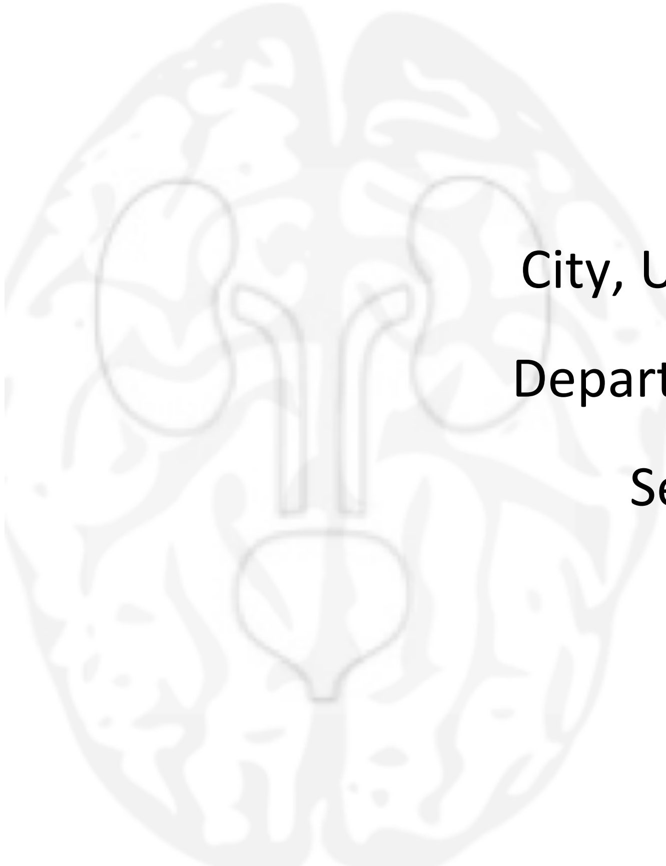
Living with Hidden Conditions

By Adriene Berkeley

A Portfolio Submitted for the Award of Doctorate in Counselling Psychology (DPsych)



City, University of London

Department of Psychology

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Acknowledgements

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Declaration

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Preface: Bringing it all Together

This portfolio includes three distinct parts compiled throughout my doctoral training, the research thesis, a clinical case study and publishable paper. A pertinent thread that runs throughout this portfolio is of the relationship between the physical body and psychological experiences. The preface begins by giving an overview of the three parts of this portfolio. I will move on to explore the overlapping connections that have prompted me to collate these pieces of work before concluding with my reflections on becoming a Counselling Psychologist.

i. Part One: Minding the Bladder: Individuals' Experiences of Adjustment to Chronic Pain Following Successful Sacral Neuromodulation

Acknowledgement of the mind-body connection has encouraged researchers to explore and increase their understanding of the psychological experiences that may impact physical health (Brower, 2006; Littrell, 2008; St. Marie & Talebkhah, 2018). Thus, this section of the portfolio presents a qualitative research study that explores what it is like to live with an implanted medical device that corrects bladder dysfunction and simultaneously causes chronic pain. This study seeks to fill the gap in the literature which has yet to gather understanding on individual's adjustment to persistent pain in the context of having prior bladder symptoms. I intended to bring awareness to these subjective lived experiences and highlight the importance of incorporating psychological care in medical contexts.

Six women participated in semi-structured interviews and attempted to complete diary entries. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) was used to analyse data. Three superordinate themes emerged from the analysis reflecting the shared experiences of adjusting to chronic pain following sacral neuromodulation. The findings highlight the biopsychosocial impact of resolving one chronic condition and living with another.

Each superordinate theme is discussed in relation to the current literature, emphasising new empirical insights. The study concludes by focusing on the clinical implications for the discipline of Counselling Psychology and opportunities for future clinical practice and research.

ii. Part Two: Jumping the Hurdles: The Race to Independence

The second part of this portfolio presents a clinical client study. It draws on my placement experiences as a final year trainee psychologist. I describe my work with a client adjusting to life after sustaining a traumatic brain injury. A model under the pluralistic approach was used to help support the client in understanding what underpins the anxiety and low mood that contributes to his process of adjustment to his injury.

The clinical client study considers the therapeutic approach I used to inform the intervention used in practice and reflects on our therapeutic relationship, the impact of supervision and the unexpected challenges that arose during our work.

I chose to include this case study within this portfolio because of its significant contribution to my personal and professional development as a Counselling Psychologist. This client study is also fitting with the overall mind-body theme of this portfolio.

iii. Part Three: Adjusting to Chronic Pain after Sacral Neuromodulation: An Exploratory Study

The final component of this portfolio is the research article which I intend to submit for publication in the journal of *Psychological Medicine*. This article draws on the above research study presented in Part One. Given the paucity of literature of the phenomenon at hand, the article focuses on providing a concise and insightful account of this exploratory research.

I have chosen to submit to the peer-reviewed journal Psychological Medicine for a myriad of reasons. First, this journal extends across a spectrum of disciplines, including psychology, psychiatry, medicine and basic other sciences. I felt that it was important to choose a journal that shares the commitment to the integration of different fields concerning the care of individuals. This attitude reflects the philosophy of the research study which is to pay more attention to the psychological aspects of medical practice and to make a difference in current practice by amplifying the fact that the mind and physical body are not separate from one another. Furthermore, this journal has a global audience and commendable international reputation, which was an essential factor as I wanted this research to pique the interest of surgeons and allied health practitioners. Finally, the project presented in Part One intends to showcase the diverse role of Counselling Psychologists in health care. Publishing within this journal will support and extend Counselling Psychology's traditional focus on health which I hope will support opportunities for Counselling Psychologists to make meaningful contributions at the interface of psychology and physical health.

iv. Progression of Portfolio

Besides the overlapping connections between Parts One, Two and Three, the evolution of this portfolio is motivated by links in theory, clinical and personal interests. First, all parts of this portfolio share theoretical similarities and align with my position as a practitioner. In practice, I adopt an attitude that all theoretical approaches are equal and useful. This attitude reflects postmodernism, which uses multiple methodologies in attempts to find out about reality (Hansen, 2006). In the research project presented in Part One, I utilised semi-structured interviews and diary entries to understand my participants' experiences. Part Two also demonstrates the use of working with multiple theories in practice. Furthermore, postmodernism has the ontological position that reality is socially constructed and an epistemological position that reality can be accessed through interpretation and enquiry (Safran & Messer,1997). This links with IPA which suggest that lived experience is accessed through interpretation (Smith, Flowers & Larkin, 2009). The theoretical links between the three parts of this portfolio support a biopsychosocial perspective of care which I argue aligns with my style of practice and compliments the integrative nature of Counselling Psychology.

Moreover, my clinical experiences and personal interests motivated the development of this portfolio. Throughout my training, I found myself gravitating toward placements within the medical context or in settings where there was no representation of Counselling Psychologists. I wanted to produce a portfolio that would inform clinical work, stress the connectedness between the mind and body and highlight the abilities of Counselling Psychologists to work in fields typically dominated by other applied psychologists.

My interest in adjustment to unexpected change began from my personal experiences of being hospitalised as a young child. This interest continued when I took on an honorary position in a research capacity at a Uro-Neurology department at a Central London hospital. At the time, I was interested in the factors that influenced the outcomes of successful neuromodulation. However, as I entered my doctoral training, my research focus was inspired by individuals who were having difficulties living with their new devices.

v. Reflections on professional practice and development

My journey to becoming a Counselling Psychologist is at the centre of this portfolio. I had many challenges, including the broad and muddled boundaries for the identity of Counselling Psychology. In addition, my own process of adjustment to the unexpected marks my journey to becoming a Counselling Psychologist. I have often struggled to manage familial difficulties, three placements a week, my academic studies and having to adjust the demands of travelling back and forth between the United Kingdom and my home country.

These experiences have emphasised the need for me to engage in support, which I have struggled to ask for in my past. My willingness to reflect and discuss these difficulties within this portfolio mirrors the experiences of the individuals I have worked with and the importance of being heard and supported.

The three parts of this portfolio have enhanced my desire for working in settings where psychological and physical care can be integrated. Throughout this process, I have also felt that, for me, being a Counselling Psychologist means being an integrative practitioner, who works with clients collaboratively.

This portfolio reflects my personal and professional identity as a Counselling Psychologist and I hope demonstrates my abilities as a reflective practitioner and researcher while paying tribute the to the relationship between psychological experiences and physical health.

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Part One

Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Successful Sacral Neuromodulation

Abstract

The merge of physical and mental health care has emphasised the need to understand the psychological experiences that can impact the mind-body relationship. This study is the first effort to explore individuals who have lived with bladder dysfunction and have undergone sacral neuromodulation that has led to device-related chronic pain. The research aims to illuminate the lived experience of adjusting to chronic pain from a device that is resolving bladder problems. The study employed semi-structured interviews and diary entries to collect data from six women living with device-related chronic pain for at least six months after device implantation. Interpretative Phenomenological Analysis yielded three superordinate themes: “The Trade-off: Chronic Pain for Corrective Bladder Function”, “The Impact of Chronic Pain” and “Living with a hidden disability: The challenge of lack of awareness”. Each superordinate theme is accompanied by subthemes derived from my interpretation of participants’ interpretation of their experiences of persistent pain following sacral neuromodulation. The empirical findings confirm that the mind and body are inextricably linked and provide new insight that highlights that the adjustment to living with pain after bladder dysfunction is a complicated process that is influenced by both individual and societal factors. These exploratory findings are considered in relation to existing literature and implications for clinical practice, training and future research are discussed.

“The mind and body are not separate. What affects one, affects the other”

(Unknown).

1.0. Introduction Chapter

1.1. Introduction

Descartes's (1952) notion of dualism suggests that the mind and body are separate entities. This system of thought has dominated the practice of health (Stewart, 2015). While Descartes philosophical works still influence today's literature, there has been an increase in the recognition of the mind-body relationship (Mehta, 2011). In recent years, political agenda and cross-societal attitudes have changed to favour the integration of physical and mental healthcare. This newfound union has allowed the scientific community to contribute significantly to the understanding of how physical health impacts on mental health and vice versa (Cho, Martin, Margrett, MacDonald & Poon, 2011; Van Eck van der Sluijs, ten Have, Rijnders, van Marwijk, de Graaf & van der Feltz-Cornelis, 2016). A prime example of the mind-body link is pain. The physical sensation of pain affects an individual's emotional and psychological experience which can maintain pain-related disability (Hassed**,** 2013).

Although there is growing recognition of the mind-body relationship, there is limited research exploring individuals' experiences of living with implanted medical devices, despite continuous technological innovations. This absence of literature is particularly evident in the discipline of psychology which has yet to explore the impact of implanted devices for the treatment of bladder dysfunction.
The Office for National Statistics reported that bladder dysfunction affects 8-15% of the population in the United Kingdom (Office for National Statistics, 2016). Notwithstanding the increasing prevalence, bladder dysfunction is still a taboo subject and is seemingly secondary to medical problems affecting other major organs and systems. This can be attributed to feelings of embarrassment which encourage the hesitation to discuss bladder symptoms (NHS England, 2015). Bladder problems can occur as a result of aging, illness, injury or for bladder problems not related to nerve damage or other health conditions, result from the disruption in the communication of the bladder-brain pathway (Dasgupta, Critchley, Dolan & Fowler, 2005; Griffiths, Derbyshire, Stenger & Resnick, 2005; Griffiths & Tadic, 2008). Sacral neuromodulation (SNM) is an electronic mechanism that facilitates corrective communication in the bladder-brain pathway. This implanted device sends electrical impulses to the sacral nerves mediating the interaction between the brain and the renal system. An adverse effect of SNM on physical health is device-related chronic pain (Elneil, 2012). This significant medical complication refers to persistent changes in sensation, described as painful jolting or shocking, which occurs at the implantation site and radiates to the lower parts of the body. The pain can manifest as abnormal sensations, muscles spasms, paralysis and/or paraesthesia (Elneil, 2012; Sukhu, Kennelly & Kurpad, 2016).

To date, little attention has been given to the adjustment to chronic pain following SNM. Perhaps this is the result of a historically fractured approach to healthcare (Naylor, Das, Ross, Honeyman, Thompson & Gilburt, 2016) which prioritised a focus on the physical aspects of an individuals' needs. The medical community acknowledges the need to understand individuals' physical and psychological experiences that can impact bilaterally on the mind-body relationship. Due to the merge of physical and mental health care, it is important to identify whether those with device-related pain following SNM are adjusting to their chronic pain or if they are more vulnerable and require additional more tailored attention.

This chapter begins by reviewing the literature outlining the symptoms of bladder dysfunction and the effects of sacral neuromodulation. There will also be a critical review of the relevant literature that focuses on pain research followed by a review of the phenomenon of psychological adjustment concerning physical and mental health.

1.2. Setting the scene

1.2.1. The Bladder

The bladder is a muscular organ that collects and stores urine that is produced by the kidneys. Dysfunction of the bladder takes many forms including urinary retention (the inability to empty the bladder) and symptoms of overactive bladder including urinary incontinence (involuntary urination) and urgency-frequency. Causes of symptoms include ageing and childbirth, disease and infection such as diabetes, cancer and health conditions such as paralysis. It is recognised that symptoms of bladder problems can negatively impact Quality of Life as they can significantly interfere with daily living, social interactions, intimate and interpersonal relationships and psychological wellbeing (Charalambous & Trantafylidis, 2009; Jackson 1997; Temml, Haidinger, Schmidbauer, Schatzl & Madersbacher, 2000; Tubaro, 2004). Quality of Life has a direct positive relationship with coping and adjusting with long-term conditions. There is also an indirect relationship between Quality of Life and the presence of psychological factors such as depression and anxiety which can sometimes overlap with somatic symptoms. Thus, a review of the literature will follow the impact of bladder dysfunction (specifically urinary retention and overactive bladder) on Quality of Life in this section.

Studies have demonstrated that symptoms of bladder dysfunction disrupt Quality of Life and adversely impact psychological wellbeing (Bartoli, Aguzzi, & Tarricone, 2010; Irwin, Milsom, Kopp, Abrams & Cardozo, 2006; Senra &

Pereira, 2015; Thomas, Oades, Taylor-Hay & Kirby, 2005). Given these findings, research acknowledges that despite bladder dysfunction not being a life-threatening condition, symptoms have a significant and considerable presence in ones' life. For example, Sinclair and Ramsay's (2011) summary of the current literature found urinary incontinence has detrimental effects on individuals' cognitive and physical engagement, emotions, social, familial and romantic relationships, work and self-esteem. Individuals can become emotionally laden experiencing feelings of stigma, fear and anxiety related to being in public; experience a reduction in intimacy and sexual function; and suffer from lack of sleep, concentration and the inability to perform work duties.

For symptoms of overactive bladder, Kinsey, Pretorius, Glover and Alexander (2016) systematic review of its psychological impact revealed consequences of symptoms include feelings of embarrassment and shame, threatened self-image, self-worth, and self-esteem which can manifest into depression, anxiety, and suicidal ideation. As there is limited research that focuses on the psychological impact of overactive bladder, Kinsey et al., (2016) specifically addressed the psychological impact of overactive bladder with strict parameters for selecting and rating existing evidence of thirty-two papers. It is important to note that most of the studies reviewed were predominately quantitative, with only three employing qualitative methodologies and the studies did not provide detailed aspects of Quality of Life. Furthermore, many of the studies in this review used female only samples; thus, the empirical findings are specific to the experiences of women. The dominance of quantitative research and the generalised measure of Quality of Life reflects the need for further psychological research that concentrates on the psychological difficulties associated with symptoms of bladder dysfunction. The overrepresentation of women in the studies reviewed by Kinsey et al., (2016) may link to patterns of help-seeking behaviour seen in women and their willingness to discuss somatic concerns compared to men (McCormick, Fleming & Charlton, 1995). Consistent with previous findings, Lai, Gardner, Vetter and Andriole (2015) also found a positive correlation between stress and overactive bladder symptoms and its impact on Quality of Life. Although these findings confirm that these factors are associated and as such do not prove causation, the authors' use of the psychometric validated Overactive Bladder Questionnaire (OAB-q), a multidimensional tool used to evaluate symptoms of overactive bladder and its impact on Quality of Life (Coyne et al., 2002), attest to the adverse impact overactive bladder has on Quality of Life.

Quality of Life also includes wider aspects of life such as family. The role of the family system has been well documented in a number of long-term conditions (Evans, Hendricks, Haselkorn, Bishop & Baldwin, 1997; Galvin, 2013; Given, Given & Kozachik, 2001; Golics, Basra, Salek & Finlay, 2013; Gunn, Seers, Posner & Coates, 2012;

Keitner et al., 1995; Tsouna-Hadjis, Vemmos, Zakopoulos & Stamatelopoulos, 2000), however, there is limited literature specifically addressing the interplay between bladder dysfunction and family dynamics/relationships. Studies suggest that this results from the embarrassment and shame associated with bladder symptoms (Elenskaia, Haidvogel, Heidinger, Doerfler, Umek & Hanzal, 2011; Elstad, Taubenberger, Botelho & Tennstedt, 2010; Garcia, Crocker & Wyman, 2005; Kinsey et al., 2016; Lagro-Janssen, Smits & Van Weel, 1992).

The few studies that have explored the interchange between family and symptoms of bladder dysfunction found high levels of strain in family relationships due to changes in family roles, limited social activity and the feelings of burden arising from carer responsibilities (Coyne, Matza and Brewster-Jordan, 2009). In addition, research extending beyond the bladder has identified that family members also experience a reduction in their Quality of Life (Nilsson, Lalos & Lalos, 2009; Wittenberg & Prosser, 2013; Wittenberg, Saada & Prosser, 2013) as they often take on active roles in managing their loved one's conditions (Smith, Greenberg & Mallick Seltzer, 2007). As such family members have to negotiate the intricate balance of managing their needs and the needs of the individual living with a condition, which can negatively impact on the family system. A comprehensive understanding of the effects of health disruptions on family relationships has been outlined within the Family Systems Theory, introduced by Bowen (1978). The theory contends that a family is a system of interdependent individuals that form one emotional unit, thus, any changes in one member's life will ultimately influence the thoughts, feelings, and behaviours of the remaining members. In the context of individuals with bladder dysfunction, changes in family dynamics and relationships that arise from the presence of bladder symptoms can negatively impact the Quality of Life in the individual living with symptoms and the other family members.

Some studies have focused on specific facets of Quality of Life relating to a person's ability to participate in intimate relationships (Kinsey et al., 2016). Research notes that bladder symptoms have damaging effects on sexual relationships as sexual desire and intimacy decreases because of feelings of humiliation, negative body image and low self-esteem that develop from the stigmatised nature of bladder dysfunction (Kinsey et al., 2016; Nilsson, Lalos & Lalos, 2009; Nilsson, Lalos, Lindkvist & Lalos, 2011; Proietti, Giannantoni, Sahai, Khan & Dasgupta, 2012; Senra & Pereira, 2015; Salonia et al., 2004). Patel et al., (2006) explored these issues further in a study aimed to describe sexual health in women who had been diagnosed with an overactive bladder. All participants reported symptoms negatively impact on sexual desire, orgasm experience and sexual performance supporting the existence of the relationship between bladder symptoms on Quality of Life.

In terms of occupational function, bladder dysfunction in the workplace is generally viewed as problematic and disruptive (Irwin et al., 2006). The few published studies that explore the relationship between continence issues and employment point out that symptoms often contribute to a lack of concentration, interruption and inability to fulfil work obligations and a reduction in work productivity (Beckett, Elliott, Clemens, Ewing & Berry, 2014; Coyne et al., 2012; Fitzgerald, Palmer, Berry & Hart, 2000; Fitzgerald, Palmer, Kirkland & Robinson, 2002; Irwin, 2006; Sexton, Coyne, Vats, Kopp, Irwin & Wagner, 2009). Furthermore, research with participants who experienced either bladder or bowel problems or both found that individuals' ability to work was exacerbated by dysfunction resulting in increased sick-leave and isolation (Evans, 2007). Additional factors that contributed to the challenge of maintaining work with symptoms concerned lack of awareness from others, the role of stigma and having to change job role.

Overall, these findings reveal the psychological impact of bladder dysfunction and its impact on ones' life. It is evident that symptoms should not be underestimated nor ignored. Although the impact of dysfunction is significant yet variable, the evidence nevertheless demonstrates the adverse effect that bladder difficulties impose on Quality of Life.

1.2.2 Sacral Neuromodulation

Sacral neuromodulation (SNM) is the indicated uro-neurological treatment option for individuals who have not been successful or cannot tolerate other conventional bladder control therapies (Hubsher, Jansen, Riggs, Jackson & Zaslau, 2012; Kohli & Patterson, 2009). In normal functioning, the brain controls the bladder by sending electrical signals via the spinal cord to the sacral area located near the tailbone. These sacral nerves command the bladder and pelvic floor muscles that manage urinary control and relay information regarding bladder sensations such as fullness. In bladder dysfunction, messages sent between the bladder and brain are either inappropriate, unwelcomed or erroneous. SNM helps restore bladder control by generating pulses that are delivered through a wire lead, implanted under the skin to correct the communicative relationship between the two systems.

The installation of the nerve stimulator occurs under general anaesthetic over two stages. Stage 1, the test phase, inserts a temporary wire in the lower back that connects to an external stimulation device. This stage examines individuals' responses in controlling bladder symptoms for a maximum period of 8 weeks. Following the success of stage 1, stage 2 involves the implantation of the permanent device.

Several studies attest to the efficacy of SNM in alleviating voiding symptoms (Cardarelli et al., 2012; van Kerrebroeck et al., 2007; Siegel et al. 2016; 2018; Sukhu, Kennelly & Kurpad, 2016; Tahseen, 2018). The literature also shows that SNM improves Quality of Life (Banakhar, Al-Shaiji & Hassouna, 2012; Das, Carlson & Hull, 2004). Despite its advantages, the current literature identifies pain as a common source of dissatisfaction with SNM (Foster, Anoia, Webster & Amundsen, 2007; Janknegt et al., 2001; van Kerrebroeck et al., 2007; Liberman & Valiquette, 2011; Tahseen, 2018). Pain often leads individuals to make the decision of surgical revision or having to endure their new pain to avoid the return of bladder symptoms. Although this modern treatment has slowly gained popularity, there have only been few attempts that highlight SNM long-term outcomes (Ismail, Chartier-Kastler, Perrouin-Verbe, Rose-Dite-Modestine, Denys & Phé, 2017; Peeters, Sahai, De Ridder & Van Der Aa, 2013; Siegel et al. 2018; 2017). There is also an absence of literature concerning an individual's adjustment to SNM device-related pain. Exploring this phenomenon is an important consideration given that not all individuals who undergo SNM are satisfied.

1.2.3 Symptom Perception

Literature exploring the impact of the body on the mind highlights that ill physical health is a risk factor for psychological difficulties as physical symptoms are associated with emotional distress. An example of this relationship is evidenced by several researchers exploring the effects of ill health on depression and anxiety (Dwight, Kowdley, Russo, Ciechanowski, Larson & Katon, 2000; NICE Guidelines, 2009; Ohrnberger, Fichera & Sutton, 2017; Osborn, 2001; Scott et al., 2007).

When investigating the relationship of the mind on the body, physical symptoms are in part determined by continuous psychological and environmental factors such as coping style and emotional processing (Ongaro & Kaptchuk, 2018). When living with physical symptoms individuals become more aware of their bodily dysfunction and begin the process of symptom perception which refers to how individuals actively acknowledge and interpret their physical symptoms. While it is known that dysfunction in bodily systems can impact the mind, symptom perception highlights the psychological representation of bodily symptoms as symptoms can emerge from the somatisation of the negative emotions arising from this process (Phillips, Cornell, Raczynski & Gillil, 1999). In this respect, emotional and cognitive processes including an individual’s illness beliefs and personality mediates symptom perception and the resulting emotional impact from this contributes to the experience of physical symptoms.

It is this framework that allows us to appreciate the prominent role of the mind in chronic pain. In this context the experience of pain is intensified as one will selectively attend to their painful bodily sensations and depending on their internal beliefs and external environmental cues this will magnify their pain experience (Skevington, 2004; Walentynowicz, Witthöft, Raes, Diest & den Bergh, 2018).

1.3.3 Pain

1.3.3.1 Defining pain

The International Association for the Study of Pain (1994) defines pain as: *"An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."* This definition acknowledges that pain is a complex system involving sensation and affect. As a sensory experience, pain has a primitive role of protecting the body by signalling illness or injury through touch. As an emotional experience, affect and mood influences the perception of pain (Gonzales, Martelli, & Baker, 2000). While the mechanisms of pain are still poorly understood, Melzack and Wall's (1965) Gate Control Theory of Pain is one of the first modern theories that provide a scientific explanation underlying the psychological perception of pain. The authors intertwine both sensation and affect by proposing thoughts and emotions influence pain experience. That is, how one thinks and feels influences pain disability as these psychological factors play a key role in furthering the sensation of pain. The theory holds that pain is a function of information travelling into the spinal cord through different nerve fibres and the interplay among these nerves determines where and when painful information will relay to the brain. The understanding of gate control and the influence of psychological factors points to pain being an experience of perception and not just sensation, thus, pain extends beyond the physical. The scientific community supports the mind-body link in pain by attesting that an individual's personality and their experiences of psychological factors contribute to the continuous interpretation and assessment of pain-related stimuli, adding to the physical sensation of pain (Hansen & Streltzer, 2005; Miró & Raich, 1992; Nielsen, Staud & Price, 2009; Shivarathre, Howard, Krishna, Cowan & Platt, 2014).

1.3.3.2 Chronic Pain

Chronic Pain is defined as pain that persists beyond the standard healing time of three to six months that can last indefinitely (Gatchel, Peng, Peters, Fuchs & Turk, 2007). Chronic pain is a global phenomenon, that affects approximately 28 million adults in the United Kingdom (Fayaz, Croft, Langford, Donaldson & Jones, 2016) and in recent years has become a prevalent health concern as its contributed significant costs to the healthcare system

(Philips, 2009). There is growing recognition that individuals with chronic pain present with adverse problems such as anxiety and depression in addition to problems with their broader system such as social role loss and relationship difficulties (Bair, Robinson, Katon & Kroenke, 2003; Kawai, Kawai, Wollan & Yawn, 2017; Breivik, Collett, Venrafridda, Cohen & Gallacher, 2006; McWilliams, Cox, & Enns, 2003).

1.3.3.3 Psychological factors of pain

Psychological factors are central to the experience of pain (Innes, 2005; Zanini, Voltolii, Gragnano, Fumagalli & Pagnini, 2018), thus, the following section explores the factors of emotional distress, psychological processes and personality and how they reinforce the experience of persistent pain.

1.3.3.3.a Emotional Distress

Psychological distress can manifest emotionally causing a sense of discomfort and uneasiness that interferes with daily living (Arvidsdotter, Marklund, Kyle, Taft & Ekman, 2016; Tedstone Doherty, Moran & Kartalova-O'Doherty, 2008). This disruptive feature of chronic pain can be experienced as feelings of anger, fear, frustration, depression and anxiety.

Anger

When individuals internalise feelings of anger, it causes them to become self-critical. When anger becomes intolerable, individuals tend to externalise their feelings by acting out inappropriately toward themselves and others. Although anger is a naturally occurring reaction to chronic pain, research has identified externalised and internalised anger as a well-known contributor to the increased experience of persistent pain (Okifuji, Turk, & Curran, 1999). This is because anger triggers the fight-or-flight response which causes the senses in the body to heighten. Kerns, Rosenberg and Jacob (1994) considered the effects of anger on pain using multiple regression analyses. The authors' findings based on one hundred and forty-seven individuals revealed that internalised anger influences pain intensity and experience. Their position suggests that internalised anger may increase sensitivity to pain by dampening pain moderating opioids in the brain which in turn further contributes to increased feelings of anger. These findings are supported when exploring anger expression and suppression in women with fibromyalgia (Middendorp, Lumley, Moerbeek, Jacobs, Bijlsma & Geenen, 2010). The authors noted that both forms of anger were associated with increased experience in pain intensity, identifying suppressed, internalised anger as costlier in pain perception.

Fear

Fear, related to the chronic pain experience, may result from the pain itself or the fear of undergoing various activities or movement that may, or is expected to, bring on further pain (Wideman et al., 2013). Research suggests that fear can isolate chronic pain sufferers, increase avoidance behaviour and influence the perception of pain factors, which together intensifies pain experiences (Breivik et al., 2006; Gatchel & Neblett, Kishino, Ray, 2016). Fear and anger have similar responses as both activate the fight-or-flight system. The fear-avoidance model of chronic pain postulates that when an individual perceives pain as threatening this can increase pain and disability as fear encourages avoidance behaviours, which can lead to frustration, anger and depression (Cook, Brawer & Vowles, 2006; Leeuw, Goossens, Linton, Crombez, Boersma & Vlaeyen, 2007; Simons & Kaczynski, 2012). Furthermore, evidence-based psychological interventions targeting fear in pain management demonstrate that a reduction in fear and avoidance is associated with a reduction of severity in pain experience (Coakley & Wihak, 2017; Keefe, Porter, Somers, Shelby & Wren, 2013; Lee, Mcauley, Hübscher, Kamper & Traeger ,2016; Moseley, 2004; Simons & Kaczynski, 2012; Wicksell, Melin, Lekander & Olsson, 2009).

Frustration

Dow, Roche and Ziebland (2012) qualitative analysis of forty-six interviews attempted to understand sources of frustration in individuals experiencing chronic pain. The authors revealed that thirty participants verbalised their frustration resulted from the unpredictability and the invisible aspects of their chronic pain (Masoudi Alavi, 2013). The effects of frustration can impede on everyday activity, interrupt future goals and fuel feelings of anger and depression (Linton, Flink & Vlaeyen, 2018; Wade, Price, Hamer, Schwartz & Hart, 1990). Additionally, this emotional state is associated with increased pain severity and the maintenance of persistent pain (Linton & Shaw, 2011; Lumley et al., 2011). The given results are not surprising as individuals may feel that they are compromising their Quality of Life living with chronic pain. Neuroscience and psychosocial research confirm that negative emotions such as frustration can further develop and amplify pain experience (Meagher, Arnau, & Rhudy, 2001; Wiech & Tracey, 2009). Informed by the constant information from our senses, negative emotions modulate pain intensity by changing the neural mechanisms that underlie pain perception and pain-related behaviour (Baliki et al., 2006; Tan, Jensen, Thornby & Sloan, 2008; Wiech & Tracey, 2009).

Depression

The current literature widely recognises the relationship between chronic pain and depression (Fishbain, Cutler, Rosomoff & Rosomoff, 1997; Haley, Turner & Romano, 1985; Okifuji & Turk, 2016; Romano & Turner, 1985; Zis, Daskalaki, Bountouni, Sykioti, Varrassi & Paladini, 2017). Recent advances in neuroimaging highlight the reciprocity between the two constructs, that is, depression influences chronic pain and chronic pain prolongs depression (Ezzati, Katz, Lipton & Lipton, 2017; Sheng, Liu, Wang, Cui & Zhang, 2017). The Diathesis-Stress Model proposed by Banks and Kerns (1996) provides an account of the development of depression in chronic pain. The model suggests that it is the psychological experience of living with persistent pain that leads to the development of depression rather than the isolated physical experience of chronic pain. Thus, premorbid vulnerabilities such as how individuals assess their pain experiences, how they behave when experiencing pain and their interactions with healthcare professionals, exacerbated by the stressor of chronic pain, leads to the genesis of depression in chronic pain and vice versa.

Anxiety

Anxiety is commonly seen in individuals with chronic pain (Krishnan, France, Pelton, McCann, Davidson & Urban, 1985). While some individuals are easily able to adapt to their pain, coping with the physical changes and daily demands that chronic pain presents can generate anxiety related to a person's abilities, identity, safety, employment and sexual intimacy (McWilliams, Cox & Enns, 2003). Anxiety contributes to the increased experience of chronic pain in the same fashion as fear as this emotional state activates the flight-or-fight response when something threatening is pending and could occur. In the case of chronic pain, this signals that there is something wrong in the body and requires attention, thus, the warning signal of persistent pain naturally activates the flight-or-fight response. Anxiety can have emotional, physical, cognitive and behavioural manifestations in addition to the increased engagement of avoidance behaviours that may be perceived to bring about or increase chronic pain (Ahmad & Zakaria, 2015). These manifestations and avoidance behaviours become chronic themselves which in turn leads to more pain as pain stresses the body and stress causes the body to experience pain by increasing pain sensitivity and reactivity.

1.3.3.3.b Psychological Processes

The meaning individuals attribute to their chronic pain can influence their pain-related experience. Cognitive models of therapeutic treatment have helped identify that interpretations, appraisals and beliefs about individuals' unique pain experience coupled with their coping resources can increase pain and disability (Burns, Nielson, Jensen, Heapy, Czlapinski & Kerns, 2015; Ehde, Dillworth & Turner, 2014; Gatchel et al., 2007; Moreno, Garcia & Pareja, 1999; Peters, 2015; Pincus & Morley, 2001; Santos, Ribeiro & Teixeira, 2015; Thorn, 2017; Turner & Chapman, 1982; Wiech, 2016). Thus, this section explores the role of the psychological processes mental defeat, perceived injustice, catastrophizing and attention in the chronic pain experience.

Mental Defeat

In a paper by Tang, Salkovskis and Hanna (2007), individuals with chronic pain referred to a sense of defeat as a reaction to their experience. Individuals acknowledged that persistent pain "belittled them as a person" and led to feelings of "not being a human being". The psychological literature identifies this as mental defeat. A distinct cognitive construct, mental defeat in individuals that experience chronic pain creates feelings of loss of control, autonomy and identity (Tang, Salkovskis, Hodges, Soong, Hanna & Hester, 2009). This sense of self-processing disrupts life as it increases experiences of chronic pain by being a key indicator of heightened suicide risk, depression, anxiety and posttraumatic stress disorder (Ehlers, Clark, Dunmore, Jaycox, Meadows & Foa, 1998; Tang, Beckwith & Ashworth, 2016). These findings are not unexpected as a recent linear multiple regression analysis by Hazeldine-Baker, Salkovskis & Osborn (2018) revealed that mental defeat strongly connects with a lowered belief in the ability to achieve goals and encourages affective disturbances in pain which influences pain perception.

Perceived injustice

A growing body of scientific literature links perceived injustice with chronic pain (Carriere, Sturgeon, Yakobov, Kao, Mackey & Darnall, 2018; DeGood & Kiernan, 1996; Margiotta, Hannigan, Imran & Harmon, 2017; McParland, Hezseltine, Serpell, Eccleston & Stenner, 2011; Scott, Trost, Bernier & Sullivan, 2013; Sullivan, Adams, Horan, Maher, Boland & Gross, 2008). Cognitions of perceived injustice refers to evaluations of fairness, loss and blame experienced by those with chronic pain. Loss can relate to the loss of mobility, ability to work and socialise; blame can be internal or about healthcare professionals failing to provide adequate care and perceived injustice of fairness can relate to the invisibility and stigma associated with chronic pain.

According to emerging literature, perceived injustice is a risk factor for adverse outcomes associated with chronic pain (Browning, Penn, Overstreet, France, Richardson & Trost, 2017; McParland & Eccleston, 2013; Sullivan, Davidson, Garfinkel, Siriapaipant & Scott, 2009; Sullivan, Scott & Trost, 2012). In a review article by Miller, Scott, Trost and Hirsh (2016) the researchers indicate that individuals who perceived greater injustice toward their pain had increased severity of pain and were more likely to show symptoms of mood disorders and posttraumatic stress. The review also highlighted that individuals that perceived greater injustice were less accepting of their chronic pain. Martel, Dionne and Scott (2017) cross-sectional study echoed these findings. Using a qualitative procedure in a sample of four hundred and seventy-five chronic pain individuals the researchers note that acceptance of pain links with increased pain disability and that individuals experiencing perceived injustice were more likely to have increased pain intensity, disability and distress.

Catastrophizing

Catastrophizing is frequently referred to in the chronic pain literature as an exaggerated, negative cognitive response to actual or anticipated pain (Vowles, McCracken & Eccleston, 2008). When an individual experiences chronic pain, catastrophizing may take the form of rumination and magnification that can lead to feelings of helplessness, anxiety and depression (Beck, Rush, Shaw & Emery, 1979; Leung, 2012; Miró, Castarlenas, de la Vega, Galán, Sánchez-Rodríguez, Jensen & Cane, 2018; Quartana, Campbell & Edwards, 2009; Turner & Aaron, 2001). Pain catastrophizing directly influences the development and trajectory of chronic pain by worsening psychological risk factors, impacting an individual's behaviours, functionality and wellbeing (Burns, Ritvo, Ferguson, Clarke, Seltzer & Katz ,2015; Elvery, Jensen, Ehde & Day, 2017; Leung, 2012; Margiotta et al., 2017). Severeijns, Vlaeyen, van den Hout and Weber (2001) found catastrophizing to be a significant predictor of pain intensity and disability and increases the risk of developing psychological distress in people with chronic pain. This constant pattern of negative thinking which can develop cognitive distortions concerning how much the pain hurts, lead to worries and fears related to pain and cause thoughts associated with not being able to reduce the intensity of the pain, is often the primary target of cognitive-behavioural treatment of chronic pain (Miró, Castarlenas, de la Vega, Galán, Sánchez-Rodríguez, Jensen & Cane, 2018). Improvements in chronic pain-related disability and pain experience associated with cognitive-behavioural based treatment supports the validity of catastrophizing increasing the risk of further pain and disability.

Attention

Pain is known to naturally draw on attentional processes (Seminowicz & Davis, 2007; Van Damme, Crombez & Lorenz, 2007). For those with chronic pain, this cognitive hypervigilance can increase pain intensity by interrupting attentional performance and reducing ones' ability to deal with their pain and disability (McCracken, 1997; Moore, Eccleston & Keogh, 2017; Moore, Keogh & Eccleston, 2012; Veldhuijzen, Kenemans, de Bruin, Olivier & Volkerts, 2006). The Cognitive Load Theory (Sweller, 1988) is a theoretical framework used to understand this the relationship between pain and attention. The model posits that working memory becomes burdened when an individual performs a task, this is known as the cognitive load. For individual's experiencing chronic pain, pain-related information overwhelms the working memory, diverting attention and reducing ones' ability to process crucial information subsequently increasing pain severity (Smith & Ayres, 2014). Functional imaging studies of the prefrontal cortex involving individuals with chronic pain reflect the attentional burden of chronic pain on brain function (Apkarian, Bushnell, Treede & Zubieta, 2005; Bantick, Wise, Ploghaus, Clare, Smith & Tracey, 2002; Bushnell, Čeko & Low, 2013; Farmer, Baliki & Apkarian, 2012; Martucci & Mackey, 2016; 2018; Martucci, Ng & Mackey, 2014). Although recent neuroscientific evidence has yet to confirm causality, i.e. whether chronic pain results in changes in brain activity or whether brain activity was different prior to symptoms of chronic pain, the evidence gives clear indication that attention is associated with chronic pain and can contribute to pains severity.

1.3.3.3.c Personality

The biopsychosocial approach has highlighted the relationship between personality and chronic pain. In psychology, there are two main avenues of thought concerning this relationship. The first concentrates on how personality factors affect experiences of, and adaptation to, chronic pain while the second focuses on how individuals with particular compositions of personality predispose individuals to manifest chronic pain (Gatchel, 1999; Krok & Baker, 2014; Pulvers & Hood, 2013). Despite the growing interest of this relationship, it has been difficult to empirically support personality-driven approaches of chronic pain, however, research has endeavoured to understand how personality interacts with pain. For example, the literature reveals that personality traits can impact cognitive processes such as catastrophizing (Ellis & D'Eon, 2009; Goubert, Crombez & Van Damme, 2004; Lackner, Quigley & Blanchard, 2004; Sinclair, 2001). This section focuses on how the personality attributes self-efficacy, locus of control and sense of self further influence pain experiences.

Self-efficacy

According to Bandura (1997), self-efficacy refers to an individual's belief or confidence in their capacity to successfully perform activities. Within the chronic pain literature, this refers to the capacity to execute performance attainments despite the presence of pain. The literature suggests that self-efficacy plays a critical role in one's motivation, behaviour, feelings and thoughts as low self-efficacy links with the impediment of motivation, helplessness, depression and anxiety (Ehrenberg, Cox & Koopman, 1991; Maddux & Meier, 1995; Muris, 2002; Tahmassian & Jalali Moghadam, 2011). Thus, research implicates low self-efficacy in having adverse effects on the perception of pain, control and adjustment to pain as well as pain severity and disability (Costal, Maherl, McAuleyl, Hancockl & Smeetsl, 2011; Cummings, van Schalkwyk, Grunschel, Snyder & Davidson, 2017; Jackson, Wang, Wang, Fan, 2014). As self-efficacy is a mediator of pain perception in chronic pain due to its association with chronic pain-related emotional distress (Arnsetin, 2000; Burns, Kubilus, Bruehl, Harden & Lofland, 2003; Jensen, Turner & Romano, 2001; Lackner & Carosella, 1999), individuals with lower levels of self-efficacy in their personality are more likely to have their chronic pain maintained (Denison, Asenlöf & Lindberg, 2004).

Locus of Control

In the context of chronic pain, locus of control refers to how much an individual believes they have control over their persistent pain. Individuals are thought to either have an internal or external locus of control. People with an internal locus of control believe that their chronic pain is contingent upon their actions, emphasising a sense of personal agency over their behaviour (Rotter, 1966). With an external locus of control, one believes that their chronic pain is contingent upon chance, fate or the environment, suggesting they have little perceived control (Rotter, 1966).

An individual's locus of control can play an essential role in how they experience living with chronic pain. People with chronic pain that have an external locus of control are more likely to report pain of higher intensity and disability (Crisson & Keefe, 1988). Research suggests that this differs from those with an internal locus of control who are more likely to adopt adaptive coping strategies and experience less pain-related disability and psychological distress (Buckelew, Shutty, Hewett, Landon, Morrow, & Frank, 1990; Härkäpää, Järvikoski, Mellin, Hurri, & Luoma, 1991). Given the findings, it appears that an external locus of control encourages the adoption of maladaptive strategies such as negative emotional and cognitive processes that significantly maintains their chronic pain as individuals have fatalistic views on their pain (Coughlin, Badura, Fleischer & Guck, 2000; Keedy, 2009; Seville &Robinson, 2000; Wong & Anitescu, 2017).

Sense of self

An individual's sense of self is not a unitary concept but is composed of many facets such as one's beliefs, attitudes, behaviour, personality, knowledge, roles and abilities. As contemporary research emphasises the disruptive impact chronic pain has on behavioural, cognitive and psychological performance, it is unsurprising that pain that persists impinges on one's sense of self, particularly in their relationship with their physical bodies (Osborn & Smith, 2006). This interruption to an individual's sense of self begins in the early stages of chronic pain. For example, when people with persistent pain seek help for early troubling pain symptoms and are discredited by the medical community, leaving the individual feeling unsupported, unheard and feeling that there is no answer to their pain. Additionally, as the pain becomes chronic, the sense of self is interrupted when individuals feel that their bodies are no longer “theirs” which can lead to worries about burdening others due to their impairments and a sense of uncertainty for the future due to the unpredictability and restrictions of their chronic pain. Furthermore, the loss of socioeconomic roles built around one's sense of self is also compromised.

The all-consuming focus of individuals trying to prove their pain as they face the challenge of the invisibility of pain and gaining credibility from others also contributes to the damage of ones’ sense of self (Osborn & Smith, 2006; Tang, Goodchild, Hester, & Salkovskis, 2010). In Smith and Osborn's (2007) in depth, interpretative phenomenological analysis the authors identify how chronic pain can have a debilitating impact on an individual’s sense of self. Smith and Osborn (2007) also note that the erosion of the sense of self has broader negative implications on one’s functioning, emotional and psychological impact. Self-perceived burden, shame, embarrassment, guilt, lack of acceptance and loss of social roles are some commonly reported interpersonal experiences in individuals with longstanding pain that compounds and amplifies the pain experience (Kowal, Wilson, McWilliams, Péloquin & Duong, 2012; Morley, 2010; Roy, 2004).

1.3.3.4 Treatment Approaches to Chronic Pain

Traditionally, pharmacological treatments of pain aim to reduce or avoid pain sensations (Blondell, Azadfard & Wisniewski, 2013; Zeller, Burke & Glass, 2008). This approach is more suited for acute pain where there is usually a presence of physical pathology. Treatment for chronic pain, as a subjective experience that is highly vulnerable to psychosocial factors, is conceptualised within a biopsychosocial model (British Pain Society, 2010; Roditi & Robinson, 2011; Wade & Halligan, 2017). This perspective entails biological, psychological, affective, behavioural, cognitive and social components of pain thus, treatment’s focus can extend beyond the physical body and include consequences such as psychological distress and socioeconomic disadvantages.

As highlighted earlier in this chapter, moving beyond a purely biological conceptualisation of pain has led to growing empirical literature of how psychological, cognitive, behavioural and socialisation factors contribute to the development and perpetuation of chronic pain and pain-related disability. This growing recognition has encouraged the central role of psychologists in the development and implementation of assessment tools and methods for monitoring and treating chronic pain (Eccleston, Morley & Williams, 2013). In fact, psychological and behavioural interventions are now viewed as an essential component to the interdisciplinary biopsychosocial approach of managing chronic pain (Sturgeon, 2014). This is supported by the growing systematic and meta-analytic literature attesting to the efficacy, and cost-effective benefit psychological interventions provide (Hoffman, Papas, Chatkoff & Kerns, 2007).

The therapeutic interventions that focus on regulating arousal associated with chronic pain are self-regulatory approaches. This approach includes relaxation training, mindfulness, biofeedback and hypnosis. As previously discussed, chronic pain can elicit physiological and emotional responses which can contribute to the further maintenance and exacerbation of the pain experience. Self-regulatory approaches endeavour to increase an individual's control over these instinctive responses using the mind-body connection (Grossman, Niemann, Schmidt & Walach, 2004). For example, mindfulness interventions can target attentional components that impact cognitive load and distorted perceptions of chronic pain, reducing pain intensity and pain-related disability (Chiesa & Serretti, 2011; Hilton et al., 2017; Majeed, Ali & Sudak, 2018; Reiner, Tibi & Lipsitz, 2013; Zeidan & Vago, 2016).

The premise for the use of behavioural interventions in chronic pain is that pain behaviours support the presence and experience of chronic pain. Pain behaviours include fear avoidance, catastrophizing, emotional responses and observed physical behaviour such as facial grimacing, altered posture, reduced movement, verbalising pain experience and health-seeking behaviours. These behaviours are influenced by an individual's context, their understanding of their pain, personality style, cultural patterns, familial experiences and social experiences (Fordyce, 1982). Research delineates that behavioural management of chronic pain such as operant behavioural therapy and fear avoidance interventions attempt to reduce pain behaviours and its reinforcing effect on the pain experience by encouraging the use of healthy behaviours which has shown to lessen pain-related disability and improve Quality of Life (Morley, Eccleston, Williams, 1999; Smeets, 2009; Van Tulder, Ostelo, Vlaeyen, Linton, Morley & Assendelft, 2000; Woods & Asmundson, 2008).

As individuals with chronic pain can develop cognitive appraisals which subsequently influences their behaviour, the model of choice is cognitive-behavioural therapy (CBT). The CBT perspective is heavily supported empirically with individuals with persistent pain (Bradley,1996; Ehde, Dillworth & Turner, 2014; Majeed & Sudak, 2017; Morley, Eccleston, Williams, 1999; Morley & Keefe, 2007; Turk, Swanson & Tunks, 2008). This method of pain management is a goal-oriented, systematic procedure that helps people identify and develop skills to change their negative thoughts and behaviours related to their chronic pain. The CBT approach utilises many techniques to accomplish this. For example, techniques that help individuals produce a relaxation response to physiological responses, cognitive appraisal and restructuring maladaptive thoughts techniques, behavioural activation and emotional awareness and learned coping skills techniques. CBT has also been proven to improve chronic pain symptoms as it changes the way the brain responds to pain by reducing the arousal associated with pain control chemical such as norepinephrine and serotonin (Yoshino, Okamoto, Okada & Takamura, 2018). Because CBT has evolved to include cognitive and behavioural interventions, acknowledging that pain is inclusive of an individual's cognition, behavior, affect and cultural and socioeconomic status, it has been subsumed by the biopsychosocial conceptualisation of chronic pain management (Ehde, Dillworth & Turner, 2014; Gatchel et al., 2007; Turk, Swanson & Tunks, 2008).

Another psychological intervention is acceptance and commitment therapy (ACT). The premise of ACT as applied to chronic pain is that aside from the actual unpleasant physical sensation of pain, it is individual's struggle with their pain that causes their suffering (Burch, 2008; Dahl & Lundgren; 2006). Like other perspectives, ACT is a third wave CBT approach that proposes that chronic pain is an experience that is influenced by individuals' emotions, beliefs, attitudes and past experiences (Hayes, Strosahl, & Wilson, 2003). ACT has shown promising results for aiming to restore adaptive functioning within the context of continuing chronic pain (Dahl & Lundgren; 2006; Hayes et al., 2003; McCracken, 1998; Robinson, Wicksell & Olsson, 2004; Wetherell et al., 2011). However, unlike CBT which focuses on reducing pain severity through teaching, ACT promotes psychological flexibility. Rather than trying to change thoughts and feelings ACT encourages behaving in a way that is consistent with one's goals and values. The model proposes that reducing the suffering associated with chronic pain starts by increasing awareness and non-judgemental acceptance of the pain experience, which will lead to improvements in functioning, wellbeing and decrease pain-related disability (Kerns, Sellinger & Goodin, 2011).

1.3.4 Adjustment

The current literature is not consistent in defining adjustment. The discrepancy lies in researchers using the term differently based on their theoretical frameworks or research outcomes. Typically, quantitative research views adjustment as an outcome measure (Lazarus,1969). The term is considered as an endpoint, evaluating whether or not an individual has achieved adjustment. In contrast, qualitative studies, such as those routed in psychology, refer to adjustment as a process. The focus is to denote positive mental health and wellbeing by understanding how individuals healthily rebalance and adapt to their new circumstances (de Ridder, Geenen, Kuijer & van Middendorp, 2008). Considering adjustment in this way focuses on how individuals adapt, including the circumstances that influence adjustment and the consequences that may arise. In the context of health, adjustment incorporates the continuous changes made in an individual's life when living with a chronic illness (Sharpe & Curran, 2006). As such, the dynamic process of adjustment would begin at symptom presentation and continue throughout the progression of the illness, considering the changes in between. It is evident that ongoing stressors such as chronic pain have psychological and social consequences that require psychological adjustment

(Dekker & de Groot, 2018; Moss-Morris, 2013; Stanton, Revenson & Tennen, 2007). Thus, going forward adjustment will refer to the physiological, emotional, behavioural, cognitive and sociocultural aspects of living with a chronic condition.

1.3.4.1 Theoretical approaches to adjustment

Several theoretical frameworks attempt to explain how individuals adjust to changes in their physical health. The biomedical model supports a disease-orientated approach to adjustment as it proposes that individuals are made up of a complex set of interrelated body systems. Focusing on disease and disability, mainly in which pathophysiology is present, the biomedical model assumes a direct relationship between illness and adjusting to physical symptoms (Walker, Jackson & Littlejohn, 2004). The difficulty with this theoretical approach of adjustment is that it is reductionist in form as it fails to acknowledge how psychological and social processes can influence the experiences of individual's living with changes in their health (Larsen, 2016). Also, the privilege of the disease model does not consider conditions without apparent pathophysiology such as chronic pain as the model implies a direct relationship between pathophysiology and disability, thus adjustment to these conditions is omitted.

In contrast, psychological approaches to adjustment concern the wellbeing and coping processes that support it. de Ridder, Geenen, Kuijer and van Middendorp (2008) highlighted five elements necessary for successful adjustment to chronic illness: the ability to successfully perform adaptive tasks, an absence of psychological disorders, high positive affect and low adverse effect, the ability to maintain functional status such as maintaining employment, and satisfactory wellbeing and Quality of Life. As emotional, cognitive and personality factors can influence the physical experiences of conditions, it is unsurprising that these factors can also influence adjustment to chronic illness (Stanton & Revenson, 2012).

The meeting point between biomedical and psychological approaches to adjustment is the biopsychosocial approach. We know that living with chronic conditions incorporates both biomedical, psychological and social factors. For example, cognitive, emotional, behavioural and personality processes which are influenced by cultural and social norms can maintain and increase chronic intensity and disability. Thus, it is essential to consider the dynamic, reciprocal interactions between the biological, psychological and socio-cultural process that contribute to the adjustment of health conditions. The biopsychosocial model supports higher outcomes of adjustment as it embraces the various multifaceted aspects of adjustment such as the role of the medical community and how this interferes with biological, psychological, behavioural and social mechanisms.

1.3.4.2 Adjustment to Chronic Pain

Despite the commonality of chronic pain, the adjustment to it is not extensively studied. That is because there are differences in adjustment seen in individuals with chronic pain, as some can adaptively function while others may not (Gatchel et al., 2007). The answer to this discrepancy can be explained by the many psychological variables that influence whether individuals with chronic pain can adjust and restore functioning. Research that has attempted to explore adjustment to chronic pain recognise that this concept involves the ability for individuals to learn how to resume 'normal' functioning including participating in physical and psychosocial activities which is influenced by psychosocial factors (Geisser, Robinson & Riley III; 1999; Jensen, Moore, Bockow, Ehde & Engel, 2011; Jensen, Turner, Romano, & Karoly, 1991).

Esteve, Ramírez-Maestre and López-Martínez (2007) quantitative study found that the psychological variables acceptance, rather a lack thereof, and pain-related cognitions were influential factors in the adjustment to persistent pain and pain-related disability. Similarly, Smith, Lumley and Longo (1999) consider cognitive and emotional variables to be vital in adjustment to chronic pain. The authors found that individuals' emotional and cognitive coping and the personality variable self-efficacy were essential predictors of adjusting to chronic pain and the reduction of physical pain, psychological distress and disability. Findings by Chan, Hadjistavropoulos, Carleton and Hadjistavropoulos (2012) also support the complex relationship between psychosocial factors and adjustment to chronic pain. Chan et al., (2012) regression analyses found that psychosocial variables such as self-efficacy, emotional and behavioural coping strategies influenced the maladjustment to chronic pain and disability.

1.4. A Gap in the Literature: The story thus far

Previous studies have shown how bladder dysfunction can have a broad and significant impact on ones' life. Research also provides insights into how day-to-day living is affected by chronic pain. Despite the worldwide prevelance of bladder difficulties and chronic pain, the literature reaches a standstill, particularly for qualitative studies offering richer insights in to the impact of these two conditions (Goldberg & McGee, 2011; van Hecke, Torrance & Smith, 2013; Irwin, Kopp, Agatep, Milsom & Abrams, 2011; Jackson, Stabile & McQueen, 2014; Minassian, Drutz & Al-Badr, 2003). Perhaps this reflects the lack of, or minimal, multidisciplinary way of working with uro-neurological conditions despite evidence of psychosocial consequences. Literature concerning sacral neuromodulation also appears to omit the exploration of living with the device and research tends to focus on documenting its efficacy in the restoration and facilitation of bladder function. This could be explained by the relatively new practice of sacral neuromodulation within the last few decades. The literature has not explored chronic pain in the context of prior bladder difficulties.

Ongoing research that conceptualises the adjustment to pain highlights that the experience of chronic pain is very complicated due to the influence of factors such as thoughts, feelings, behaviours and experiences. We know that living with chronic pain necessitates adjustment in various life domains (Jensen & Karoly, 1992) and we know that psychosocial factors are important in predicting adjustment to chronic pain (Jensen, Moore, Bockow, Ehde & Engel, 2011; Molton et al., 2009). However, there is still a lack of in-depth data about how individuals adjust to chronic pain as research tends to examine the subjective nature of adjustment to persistent pain through objective measures such as questionnaires and regression analyses. Furthermore, chronic conditions are usually seen as negative as it is typically evidenced by psychological, physical and emotional distress. However, adjustment to conditions should be inclusive of both positive and negative aspects. If there is a positive dimension in the adjustment to chronic pain, it has yet to surface in the literature.

More specifically research has yet to explore individuals experience of adjustment to chronic pain following successful sacral neuromodulation and what it means to individuals who have arguably “traded-in” a set of symptoms for another.

1.5. Introduction to the Current Study

1.5.1. Rationale

While the concepts of bladder dysfunction, chronic pain and adjustment have been explored previously, in the body of literature there is an absence of understanding the implications of chronic pain-related adjustment after sacral neuromodulation for bladder problems. As mental and physical healthcare begins to merge into one practice, exploratory studies shedding light on the adjustment to chronic conditions, which integrates the biological, psychological and sociocultural levels, is necessary to identify potential risk and protective factors that will encourage adaptive chronic-related adjustment. Exploration is also necessary to assess whether the introduction of psychological input such as therapeutic interventions should be added to the treatment of this population and what kind of input would be most helpful.

As this is an exploratory study, this research can guide the development of psychosocial interventions targeting this potentially vulnerable group and others within the medical community; create insight into the processes of adjustment and encourage a multidisciplinary way of working within healthcare. By using a qualitative methodology to allow an open-ended expression of individuals' experiences, the current study can explore both individual and contextual factors of adjustment to chronic pain following sacral neuromodulation which researchers can build upon with more extensive, longitudinal studies and inform current treatment options within uro-neurology.

1.5.2. Aims and Research Questions

This study will attempt to fill the current gap in the literature regarding the chronic pain-related adjustment process, positive or negative, in the uro-neurological population. Thus, using phenomenological methods, this study aims to understand the adjustment to chronic pain following the implantation of a device that corrects bladder dysfunction.

Following the review of the current body of empirical literature and my clinical experience within uro-neurology the objectives of this study are guided by the questions:

1. What is the physical, psychological, and social impact of chronic device-related pain?
2. What are the participants' perceptions and expectations towards their sacral nerve stimulator?

and

3. What are the participants' perceptions of adjustment?

This thesis seeks to address the aims and objectives within the following research question: What are individuals' experiences of chronic pain following successful sacral neuromodulation?

1.5.3. Relevance to Counselling Psychology

The current study has the potential to be beneficial to a broad audience within psychology and healthcare; however specific attention is given to the field of Counselling Psychology.

The practice of Counselling Psychology aims to promote personal and interpersonal growth (British Psychological Society, 2015) by using either brief or long-term interventions that can focus on prevention, development and adjustment across one's life. Counselling Psychologists are guided by a philosophy that values wellbeing and personal development rather than disease and sickness, mental health opposed to mental illness and views individuals’ strengths as positive assets that can assist in their growth (Kasket, 2012; Woolfe, Dryden & Strawbridge, 2003).

Although in recent years, the philosophical and historical differences between Counselling Psychology and other professional fields of psychology appear to be diminishing as there is growing avocation for one, merged applied discipline of psychology (Goodyear, Murdock, Lichtenberg, McPherson, Koetting & Petren, 2008; Ogunfowora & Drapeau, 2008), Counselling Psychology is committed to its humanistic roots (Strawbridge & Woolfe, 2010). It seems that this historical and philosophical uniqueness relating to Counselling Psychology’s identity has been detrimental rather than helpful when compared to our Clinical Psychology counterparts (Brady-Amoon & Keefe-Cooperman, 2017; Gazzola, De Stefano, Audet & Theriault, 2011).

There are more and more psychology posts arising within health specialities, attesting to the importance of psychology. Rather than using our distinctiveness as a divisive tool, it is essential that this research endeavours to show how our individuality supports the role for Counselling Psychologists to work within fields traditionally dominated by other specialities.

In the context of the current study, the implications for Counselling Psychology relates to our ability to assess and facilitate the treatment of psychological and behavioural problems resulting from, or related to mental and physical health (Wahass, 2005). Knowledge from the current study can play a role in the prevention, promotion of adaptive behaviours and improve Quality of Life of the study’s population by revising current treatment strategies. For example, NICE guidelines concerning adjustment suggest cognitive-behavioural strategies of treatment in improving pain experience (Hoffman, Papas, Chatkoff & Kerns, 2007; Roditi & Robinson, 2011). Perhaps Counselling Psychology’s pluralistic nature, which aligns with the biopsychosocial perspective (Melchert, 2010) can assist in putting forward interventions that facilitate chronic pain adjustment and possibly prevent long-term problems.

1.5.4. Final Note

The literature and my personal experience within uro-neurology guide the motivation to conduct this research. As a result, I have chosen to write this research in the first person. Evidenced in earlier parts of this chapter, this is a common practice in qualitative research (Zhou & Hall, 2016). I believe writing in the first person helps to represent my ideas, captures my reflective nuances and invites readers to become more engaged with my research.

2.0. Methodology Chapter

2.1. Introduction

This chapter endeavours to provide a description and explanation of how I attempted to answer the research question: What are individuals' experiences of adjustment to chronic pain following successful sacral neuromodulation. The study aims to offer insight into participants' inner world. The focus here will be on the psychological aspects of individuals' adjustment to chronic pain such as the emotional, psychological and personality factors that may be involved. The study will also attempt to illuminate Counselling Psychology's contribution to practice in areas traditionally dominated by other clinical counterparts. The chapter divides into four sections: the methodological overview, methods, analytic procedures and the consideration of reflexivity.

2.2. Part one: Methodological Overview

2.2.1. Theoretical Framework

2.2.1.1. Qualitative vs Quantitative Approach

Several considerations guided the decision of whether the current study would follow a quantitative or qualitative approach, with a specific focus on the research aims and question, anticipated outcomes and the acceptability of the methodology in Counselling Psychology. Primarily, the current study aimed to provide a detailed description of the lived experiences of individuals experiencing chronic pain following sacral neuromodulation. The intention is to provide a level of detail that can inform and highlight the need for psychological support. In addition, the field of Counselling Psychology points towards using a qualitative approach to capture a detailed description of complex phenomena (McLeod, 2011; Wertz, 2005). With this in mind, the current study accepted the use of a qualitative methodology as this approach pledges to explore and understand individuals' inner world offering in-depth insight into the complexities of individuals experiences rather than quantifying data at the group level.

Qualitative research not only refers to the study's design but also to the way in which researchers apply qualitative methods. It provides an overarching paradigm for conducting research and as such is viewed as a theoretical research approach and a methodology. According to Kuhn (1962), the research paradigm is "the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed" (p. 45). Ontology, epistemology and methodology characterise these sets of beliefs. Ontology refers to assumptions of reality; it is concerned with what is “out there” to know and the construction of reality. Epistemology is how we can know about that reality, which focuses on the acquisition of knowledge and the relationship between the researcher and participant (Ponterotto, 2005). It is crucial to consider these assumptions as it determines the methodology, the ways of finding out about that reality, including what kind of knowledge the researchers want to produce, the research questions, data collection and analysis (Willig, 2012).

One fundamental aspect of a qualitative paradigm is that it does not assume that there is a single, correct version of reality or truth. Instead, it argues that there are multiple versions related to an individual’s context or subjective experience. Interpretive in nature, this paradigm points toward knowledge being internally constructed and entirely subjective, as well as being influenced by the researcher's prior insight of the research context and beliefs while capturing and making sense of an individual’s reality (Ashworth, 2003).

This perspective differs from the quantitative paradigm at the opposing end of the spectrum that we see in research. Grounded in positivism, the beliefs and assumptions of the quantitative position are that there is one version of reality to a research phenomenon, that is objective and independent of subjective experience and the researcher’s perspective or beliefs (Barker, Pistrang & Elliott, 2016; Ponterotto, 2005). As the positivist paradigm rests on different assumptions about the nature of reality, it creates context-free generalisations with quantitative modes of inquiry. Here, the researchers remain detached from participants to find causal explanations about the research phenomenon.

2.2.1.2. Epistemological Position

Clarifying my epistemological position was a challenging task. Qualitative researchers can adopt from several different epistemological perspectives on a realism–relativism continuum first depending on their research question and the kind of knowledge the research aims to create. At one end of the spectrum, a realist stance subscribes to the view that there is an objective, single reality where researchers are not central to the research process. The data collected provides accurate, pure information about the world instead of constructed findings. By contrast, a relativist stance bares the assumption that there is no single reality and that research needs to explore variations of these truths to construct findings. A position that lies mid-way between the two, critical realism, embraces a form of epistemic relativism and ontological realism (McEvoy & Richards, 2006). This perspective accepts that reality cannot be directly accessed therefore to truly understand subjective reality will always require interpretation (Bhaskar, 2008; Houston, 2001).

Three questions posed by Willig (2012) were used to help identify my epistemological roots: What kind of knowledge do I aim to create? What are the beliefs and assumptions I hold about the world I am exploring? What is the relationship between myself and the knowledge I hope to produce? My initial response was that I am interested in exploring my participants' unique inner world by capturing their descriptions of the subjective experience of adjustment to chronic pain following sacral neuromodulation. While I acknowledge that there is a reality, I also acknowledge that each participant will experience that reality differently depending on how they make sense of their experiences (Willig, 2008). That is, I recognise that there will be commonalities among my participants' experiences; however, they will experience adjustment to pain in different ways. Furthermore, because I intend to gain a better understanding of what my participants' experiences are, I acknowledge that the data I gather may not offer direct access to this reality, and therefore is subject to interpretation. Therefore, researcher reflexivity is necessary when considering the impact of the researcher-participant dynamic on the research process and findings.

Neither a sole realist nor a relativist position can be accepted given my response to the above questions. Instead, I adopt a critical realist approach as I understand that there is an underlying reality, but there are multiple perspectives related to this and that the knowledge is communicatively constructed (Harper, 2011). This position also reflects my clinical practice as an integrative counselling psychology trainee. In practice, I align with a postmodernist attitude which is founded on using multiple methodologies to find out about reality. Thus, because of the pluralistic nature of postmodernism, I believe that no single psychological intervention is suitable for all clients. Instead, I view each client as unique and distinctive, each with their own form of mental distress, attesting the inappropriateness of one approach to fit all. The critical realist position also allies with literature that highlights that the experience of chronic pain is highly subjective and individualised (Turk & Melzack, 2001), hence, individuals identify their own level of discomfort. Since the perception of pain is experienced within a social and cultural context (Vallath, Salins, & Kumar, (2013), it can be difficult to communicate the intricacies of this experiences, for example, the psychological process, and as such it may require interpretation from another person such as a psychological or medical practitioner.

2.2.2. Interpretive Phenomenological Analysis

The critical realist framework is compatible with interpretive phenomenological analysis (IPA). Developed by Jonathan Smith (1996), IPA is a type of qualitative methodology that is concerned with understanding how individuals make sense of lived experience (Finlay, 2011; Smith, Flowers & Larkin, 2009). Its compatibility with critical realism stems from IPA's view that individuals' experiences are shaped by how they make sense of them using their thoughts, beliefs, judgements and expectations (Smith et al., 2009). Thus, individuals are experts of their experiences who share their knowledge through their own stories, in their own words (Reid, Flowers & Larkin, 2005). This links to the tenet of IPA that acknowledges that direct access to participants lived experience is not possible; calling for the researcher's conceptions to make sense of the participant's personal world through interpretation. Smith et al., (2009) suggests adopting a central position along the continuum of Ricoeur's (1970) hermeneutics of 'empathy' and the hermeneutics of 'suspicion'. Hermeneutics of empathy attempts to reconstruct the original experience in its terms and the hermeneutics of suspicion uses psychological knowledge and theory to shed light on the phenomenon. The hermeneutics of empathy allows researchers to have an unquestioned acceptance of participants understanding of their experiences. Hermeneutics of suspicion allows the researcher to occupy an expert role using outside theory and knowledge to generate underlying meaning of participants' experiences (Willig, 2013). Thus, adopting a central ground position on this spectrum means that the process of interpretation is grounded in participants experiences but also considers the context of these experiences which allows for a richer, more in-depth interpretations of analysis.

This commitment to the double hermeneutic, which refers to participants attempting to make sense of their inner world and the researcher attempting to make sense of the participant trying to make sense of their inner world, further illuminates IPA's compatibility with a critical realist underpinning. It allows researchers to produce a description of participants lived experiences while also developing an interpretive analysis based on a theoretical and sociocultural context (Smith et al., 2009). This dynamic interpretation leads researchers to understand the data by thinking about any given part to understand the whole and vice versa. As this requires researchers to draw on their psychological knowledge, theory and personal experience to interpret the described inner world of participants, it calls for the necessity of the researcher's reflexivity to fully explore their ideas about the investigated phenomenon (Chan, Fung & Chien, 2013; Langdridge, 2007).

IPA, founded on the phenomenological philosophy developed by Husserl, posits that there is an existence of multiple realities depending on subjective experience (Hermberg, 2006). It is also idiographic and interpretative as it aims to gain an understanding of lived experiences from a particular group of individuals within a specific context, requiring researcher interpretations to explain what it is like to be that person in their environment. As a result, a common criticism of IPA is that it is more experiential than phenomenological as IPA brings together phenomenological and hermeneutic philosophies (Chamberlain, 2011; Pringle, Drummond, McLafferty & Hendry, 2011). However, IPA is in keeping with phenomenology as it positions itself as an evolving approach that encourages researchers to engage with its underpinnings, so that the data stays close to the explored phenomena.

2.2.2.1. Rejection of other analytic methods

Alternative analytic methods were thoroughly considered and rejected for this research.

When researchers fail to provide interpretation beyond description, it questions why other analytic methods such as grounded theory (GT) and thematic analysis (TA) were not employed instead (Brocki & Wearden, 2006). Although GT and IPA share similar strategies for data analysis and both can align with critical realism (Oliver, 2012), a fundamental difference to reject GT for the current study is an epistemological one. Lomborg and Kirkevold (2003) position classic GT as having a realist orientation as it assumes that there is an objective reality that can be observed and documented by the researcher. The researcher acts as a witness rather than bringing their preconceptions and interpretations into the research process. As such, the researcher's role is to produce the kind of knowledge that describes a clear account of the social reality through repeated analysis (Charmaz, 2008). The current study is not attempting to generalise to broader social phenomena or to create general laws of behaviour at a population level, therefore, I felt IPA was more appropriate as the study endeavours to have an idiographic focus on participants' subjective experience of chronic pain following sacral neuromodulation.

Similar to the analytic methods mentioned above, TA is used to identify, analyse and report patterns within data (Braun &Clarke, 2006). However, Braun and Clarke (2006) highlight that TA differs from other methods as it does not derive from a theoretical underpinning. This flexibility allows researchers to employ TA with any theory they choose to align themselves with, creating a detail-rich description of data.

TA would also be an appropriate method for the current study in light of the aim to pursue an exploratory, data-driven approach to adjustment to chronic pain as opposed to taking a top-down approach driven by theoretical interests. TA provides an opportunity to achieve this via latent or interpretive analysis, which examines the ideas, concepts and assumptions that shape the semantic content of the data, creating a theoretically driven, detailed analysis (Braun & Clarke, 2006). However, despite the suitability of TA for the current study, the decision to reject this analytic method stems from the philosophical underpinnings and beliefs I hold. I was attracted to the phenomenological and hermeneutic roots that underlie IPA which I feel are essential for understanding participants lived experience of adjusting to chronic pain following sacral neuromodulation. Even though there is recognition of the role of the researcher in TA, it places less emphasis on the double hermeneutic interaction

(Smith et al., 2009), which conflicts with my position as a researcher as I value making sense of participants attempts to make sense of their experiences.

2.3. Part two: Methods

2.3.1. Research Design

Described earlier, the current study will employ a qualitative approach to answer the research question. While many areas of research in chronic pain and adjustment typically attempt to predict outcomes (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006; Lazarus, 1969), this study considers the process of individual adjustment to chronic pain. To explore these experiences in depth I conducted six one-to-one semi-structured interviews with individuals who were experiencing self-identified chronic pain for at least six months' post-device implant. The interviews were conducted either online or in person and lasted between 40-75 minutes to allow participants to tell their stories about living with pain after receiving a corrective bladder device. As part of the multimethod design of this study, diary entries were used to facilitate the understanding of participants lived experiences (Larkin & Thompson, 2012). All of the data, except the diary entries, was digitally recorded, transcribed and analysed using IPA.

2.3.2. Data Collection

2.3.2.1. Rationale for a Multimethod Approach

The phenomenon explored in the current study is complex and demands more than one data collection method to enhance understanding of these complexities. Therefore, the rationale for developing a qualitative study with a multimethod approach to data collection was to increase the possibility of creating rich, detailed findings. The idea stemmed from my theoretical position and choice to utilise IPA, both of which focus on adopting a participant-centred viewpoint rather than a witness-centred one (Collier & Elman, 2008). Also, the philosophical stance that underlies my practice as a practitioner further encouraged the use of a multimethod approach to data collection. When working with clients, I believe that one theoretical orientation is not better than another, that is, all theories are useful, context-driven and can be in tension with one another. Likewise, in research I find value in employing different data collection methods and believe that no research method is inherently superior to any other. This methodological pluralism is supported by critical realism which infers that research can select and employ various methods of data collection (Barker, Pistrang & Elliott, 2002). By combining interviews and diary entries, these interpretative tools aim to discover in-depth insights into participants experiences from their perspective.

A common criticism of interviews is that they can seem intrusive to participants and may be susceptible to interview bias (Iida, Shrout, Laurenceau & Bolger, 2012). The use of diary methods offers a solution to this as they allow participants to respond without the element of intrusion or the immediate influence of the researcher. Diaries are also beneficial as it provides the opportunity for participants to write about their lived experiences of an event at the time they occur. However, as diaries require long-term motivation and participation from participants, they have been criticised for being less informative than other collection methods (Symon, 2004). The use of interviews can combat this specific issue as they allow participants to provide in-the-moment insight and context when describing their experiences.

The strengths of each tool complement each other and cancel out their disadvantages, giving insight into the parallel of living with a device that has been successful yet causes consistent pain. By triangulating data collected in this way, a comprehensive picture of participants experiences emerges, illustrated by themes that provide insight into participants' inner world (Morse, 2003; Palakshappa & Gordon, 2006). Thus, the detailed level of knowledge produced is appropriate for applied research (Way, 2011) and is consistent with the objectives of the current study.

2.3.2.2. Semi-structured interviews

To the researcher's knowledge, little to no research explores the phenomenon under investigation in the current study. Semi-structured interviews are a popular data collection method used in exploratory studies that hope to form the foundation for more conclusive future research (Singh, 2007). Semi-structured interviews are the exemplary method for IPA as it fits with the ethos of qualitative research (Smith et al., 2009). Given the idiographic, data-driven nature and theoretical underpinnings of IPA, semi-structured interviews facilitate the understanding of individual's inner-world based on the interviewee's dialogue of their own experiences and subjective perceptions. Therefore, this tool acquires a detailed account of individual's personal world through guided discussion, offering the participant the opportunity to be the 'expert' in communicating their experience. Unlike structured interviews, which minimise the researcher-interviewee interaction favouring a more positivist paradigm, semi-structured interviews allow researchers to address their agendas while being open to the exploration of other areas that may emerge during the interview process.

The development of the interview schedule required several stages. I found it helpful to write down exactly what I wanted to find out from this study, i.e. what it is like to live with pain after SNM. It was also beneficial to note down my prior knowledge of the topic area based on my work experiences. I then consulted the literature on SNM, chronic pain and adjustment and found that there was paucity of research which employed semi-structured interviews. Next, I conducted a pilot interview with an individual living with consistent pain after cosmetic surgery to determine whether the interview schedule reflected the research question effectively. Although the participant in the pilot study was not part of the specialist population within the current study, the process proved vital in revealing a number of insights. For example, the original schedule focused on a lot of information that was not relevant to my research question. Also, some parts of the interview schedule were not free of my preconceptions, as noted in the question "What is it like to have this identity (diagnosis)?" I noticed that I had imposed my idea about what diagnosis means to participants when in this context participants may not experience their diagnosis related to their identity at all.

The interview schedule was revised following several discussions with both my clinical and research supervisors culminating in the decision to include prompts, descriptive, evaluative and comparative questions. The final step was to liaise with colleagues on my doctoral cohort to ensure the interview schedule was open-ended, free of ambiguity and easily understood (See Appendix A for full interview schedule). I structured the interview schedule order so that it began with participants' bladder symptom history and gradually explored their current experiences of living with pain. I set out the questions in this chronological way because I believed it was necessary to contextualise their bladder symptom experience in order to fully understand their decision to have the nerve stimulator implanted and how this then impacted on their current experience of pain.

Semi-structured interviews are typically conducted in person as they rely on the direct interaction between the researcher and participant, however, online interviews can also serve as a viable alternative. The current study employed both face-to-face and online meetings, i.e. FaceTime. The rationale for an electronic interview option derives from the present study's target population. Uro-neurology is a medical domain that is highly specialist and governed in central London, which created the challenge of geographical limitations as most potential participants lived in areas well beyond London borders. Online alternatives were meant to alleviate participants' distress from the challenges of having to travel great distances.

I considered how choosing FaceTime as the online data collection alternative to in-person interviews would affect the current study. First, I argue that I could still draw on qualities of a qualitative researcher that is essential when conducting interviews. That is, I would still be able to demonstrate empathy, create participant-researcher trust through reflective listening, thoughtful questioning and sensitive probing (Bauman, 2015). I also reflected on my theoretical position as a researcher. It is arguable that online methods may hinder observing the body in the interviewing process, essential for embodiment (Finlay, 2011; Salmons, 2015). Following a critical realist approach and using IPA, having a physical connection is desirable as it can add to the interview experiences. However, I argue that the ability of researchers to observe and make a note of nonverbal signals and changes in verbal expression is not only limited to in-person contact. In my opinion the use of an online alternative does not negate my ability as a researcher to engage in embodied reflexivity. I also argue that the use of online options also speaks to the context-specific nature of this study as it highlights some of the challenges participants face having to adjust to chronic pain such as being able to participate in face-to-face interviews.

The primary tenet of critical realism is for the researcher to grasp whether participants understand their experiences, through dialogue and combine this with the researcher's prior knowledge. Therefore, it is crucial that in the interview participants gain awareness to what may be affecting their adjustment to chronic pain by reflecting on their experiences (Edwards, O'Mahoney & Vincent, 2014), again, I argue that this is still possible via online interviewing. Foreseeable practical challenges were considered by ensuring a secure connection to prevent loss of data, obtaining signed consent forms and being in a private University room for confidentiality, further supported the choice to online interviews.

2.3.2.3. Diary Entries

Diary methods, the complementary source of data collection, provide rich, first-person observations of individuals' experiences over time (Iida, Shrout, Laurenceau, & Bolger, 2012). Diaries can be formatted based on time or event. Time-based formats are highly structured requiring respondents to complete sections of the diary at regular intervals, whereas event-based diaries follow an open format in which individuals can record their experiences of an event in their own words (Gonzalez & Lengacher, 2007). The choice for the current study to use event-based diaries was to allow participants to capture their thoughts, feelings and behaviours when triggered by a chronic pain event. For example, an event may be a participant experiencing a "jolt" of pain during a social gathering. The provision of this format aligns with the aim and theoretical underpinnings of the current research and makes it suitable for IPA.

The use of diaries in research is often labelled as laborious (Marelli, 2007), thus, the development of the diary entry template required in-depth consideration. Several efforts were made to overcome monotony to ensure that the diary entries in the current study complemented the semi-structured interviews. Efforts included providing comprehensive written guidance on diary usage, giving an example of a finished diary entry and providing participants with the opportunity to use electronic versions based on individual preferences. Additionally, diaries were kept for a maximum of 14 days as research has demonstrated that the commitment to complete tasks such as diaries decreases over time (Smith et al., 2009; Symon, 2004). Please see Appendix B for the study's diary template.

2.3.3. Sample

2.3.3.1. Sample size

Contrasting with what we typically see in psychological research, studies utilising IPA are conducted on small sample sizes (Smith et al., 2009). IPA encourages and supports reduced participant numbers due to the practicalities of having to transcribe and analyse each case for the creation of in-depth knowledge of a phenomenon. While IPA can be used with larger sample sizes, Smith and Osborn (2007) highlight that that novice IPA researchers like myself may become overwhelmed with the vast amount of data created with a large participant group, which can lead to an insufficient level of analysis.

Despite the general trend of smaller sample sizes in IPA, there is no single rule regarding participant numbers. Instead, there are several factors unique to each study which influence sample size; including the depth of analysis; the richness of knowledge from individual cases; how the researcher wants to explore similarities and differences across cases, and the constraints the researcher is operating under, including time restrictions and access to participants (Pietkiewicz & Smith, 2014). In light of the paucity of research in the exploration of adjustment to chronic pain following SNM I wanted to have a sample that gives me the opportunity to compare participants' experiences. A sample size of six created the opportunity for me to develop an in-depth understanding of each participant and consider connections between other accounts of experiences without getting overwhelmed by the amount of qualitative data. Determining sample size was also influenced by potential participants being a part of a specialist population with only a small percentage of those who have undergone SNM reporting chronic pain. Other pragmatic constraints included the time constraints of my doctoral research and geographical accessibility. As novice qualitative researcher, having had more experience in quantitative studies, I initially felt uncomfortable with a sample size that felt comparatively small. However, as IPA focuses on depth, not breadth, a sample size of six fits in with its recommendation of a sample size of between six-eight participants (Smith et al., 2009). A participant group of six also fits in with the rationale of an exploratory study. The purpose of research exploration is to gain further insight into a phenomenon that has not been studied in-depth to identify potential issues that could inform future research (Singh, 2007), rather than offer an interpretation of generalised findings which would be helpful from a larger sample size.

A characteristic of an IPA sample is homogeneity (Smith et al., 2009). In agreement with the theoretical underpinnings of IPA, participants are purposively selected to create a homogenous participant group that is meaningful to the research question. Employing purposeful sampling depends on participants sharing essential variables (Smith et al., 2009). For the current study, all six participants chose to undergo SNM following bladder dysfunction due to central nervous system abnormalities and now live with the consequence of chronic pain. Although the participant group is homogenous in the sense that the sample all experienced self-identified chronic pain for at least six months after device implantation, participants varied in demographic information, experience and their descriptions of pain (i.e. “jolts” or “shocks”). As this procedure is part of a specialist area within uro-neurology, I felt that these criteria were sufficient in producing a homogenous group for the research aim and objectives, capturing psychological variability in participants’ experiences without over homogenising the sample.

2.3.3.2. Participant Selection and Invitation

Once ethical approval was sought and confirmed by City, University of London ethics committee and the National Health Service ethics committee (see Appendix C and D), the process of recruiting participants commenced. Following the principle of homogeneity, participants were identified using six inclusion criteria. The first criteria was the experience of chronic pain with participants reporting self-identified persistent pain for at least six months after device implantation. This time frame eliminates post-surgical pain which typically lasts for days or weeks and allows time for the process of adjustment. The next criteria stated that participants must have no other stimulation device or causes of chronic pain such as multiple sclerosis, dementia, chronic fatigue or fibromyalgia, with the latter two occurring before the device implant. For pragmatic reasons, the next three criteria focused on the stimulation device time frame, age, gender and language. Participants were selected on the basis that they did not have an implanted device for a period not exceeding 15 years as this aligned with the study’s aim, to explore the process of adjustment. The nature of qualitative research relies heavily on language, thus participants must be English speaking as this is the researcher's native tongue. Participation was open to males and females, however, as SNM is commonly used more in women, they are more likely to dominate the participant sample. Finally, participants needed to be aged between 20-55 years as this target range coincides with SNM being common in women of childbearing age. The exclusion of participants was deemed necessary for those who failed to meet this criterion, such as those who had a neuro-stimulation device for other reasons outside of bladder dysfunction. Participants were identified by those who reported the experience of persistent pain following the device's successful control of bladder symptoms. Before the start of data collection, there were hopes of identifying participants solely from a database provided by a consultant in the uro-neurology department of the National Hospital for Neurology and Neurosurgery. However, due to time constraints and challenges, this was later changed to include online advertisement in patient support groups which have posting forum (See Appendix E). Participants could identify themselves through the short description of the study and the above criteria. The consultant database led to the recruitment of one participant with the remaining five participants being recruited from the support groups. An electronic copy of the consent form and participant information sheet was provided for participants to further consider their participation (See Appendix F and G). Upon receiving the scanned or posted signed consent forms, arrangements proceeded for the in person or online semi-structured interviews.

2.3.3.3. Participants

As expected, women dominated the makeup of the sample group. Participants ranged between twenty-three and forty-six years of age and all but one participant identified as White British. Below is an introduction of each participant with the purpose of highlighting their experiences of bladder dysfunction before SNM. I argue that this is helpful as participants will find significance in their adjustment to chronic pain by making meaning through their lenses of prior experiences, memory and identity (Salmons, 2015). Pseudonyms are assigned to participants to protect identities.

“Mira”

Mira is a forty-year-old registered nurse whose bladder dysfunction began after the natural birth of her first child. Her choice to undergo sacral neuromodulation stemmed from unsuccessful attempts to restore bladder function using other medical techniques. Mira is distressed about the possibility of having to remove the device due to discomfort from pain. She told me that removal of the stimulator would lead to the use of a suprapubic catheter. In removing the device, Mira feels that she will no longer be able to work in her desired field and told me that it would lower her confidence regarding body image and self-esteem.

“Lynn”

Lynn is a senior social worker who is currently only able to work from home. At forty-six years old she describes having overactive bladder dysfunction throughout her life, which significantly worsened after a fall in her mid-thirties. Lynn previously found living with bladder symptoms challenging in that she was not able to “do” or accomplish much. Her consultants suggested SNM as a ‘last effort attempt’ to resolve her bladder dysfunction. Lynn feels that she did not have a choice but had to undergo the SNM procedure.

“Jennifer”

Jennifer is a thirty-one-year-old part-time sales assistant. Her choice to undergo sacral neuromodulation stemmed from difficulties with bladder control since childhood. She described anger towards the medical community for not coming up with a solution from bladder dysfunction much sooner as she feels she has had “tremendous challenges” in life due to bladder dysfunction. Jennifer chose the stimulation device to “turn my life around”.

“Hannah”

Hannah is a twenty-three-year-old who identifies as a receptionist when she can take on work. She describes struggling with bladder dysfunction since her early teens, with no known cause. Hannah told me that she has not been able to engage in a “normal life” due to her bladder dysfunction. For example, being able to go to university, secure full-time employment or maintain romantic relationships. Hannah recently underwent SNM to restore normal bladder function.

“Emma”

Emma, forty-three, is a white American that has lived in the United Kingdom for over twenty years. With no medical cause for her bladder dysfunction, she has suffered from symptoms since childhood. Currently unable to work, Emma expressed her frustration with the medical community and members of society for not understanding or recognising the impact of bladder dysfunction. She expressed her bladder symptoms as “a negative way to live life”. Emma said to me that she was recently introduced to SNM and did not receive any information about the impact of living with the device.

“Izzie”

Izzie is a thirty-two-year-old teacher who suffered from bladder symptoms since early adulthood. She decided to have the stimulation device as other treatment options were not suitable. She told me that her problems affected her social and romantic relationships as well as being able to seek out and maintain employment. Izzie’s consultant referred her to a specialist hospital outside of her area to undergo SNM.

Pseudonym	**Gender**	**Age**	**Occupation**	**Ethnicity**
“Mira”	Female	40	Registered Nurse	White British
“Lynn”	Female	46	Social Worker	White British

“Jennifer”	Female	31	Part-time Sales Assistant	White British
“Hannah”	Female	23	Receptionist	White British
“Emma”	Female	43	Unemployed	White American
“Izzie”	Female	32	Teacher	White British

Table 1: Demographic Information of Participants.

2.3.4. Procedure

2.3.4.1. Interview Procedure

Each participant experienced the adjustment to chronic pain in a unique way. Semi-structured interviews give the opportunity for researchers to understand complex phenomena by allowing participants to express their thoughts, feelings, reflections, responses and views of their inner world (Salmons, 2015). The following interview procedure was replicated regardless of whether interviews were carried out in person at the Uro-Neurology department at the National Hospital for Neurology or Neurosurgery or online in a private research room at City, University of London. Two interviews were conducted face-to-face with the remaining four carried out via FaceTime.

Before the start of each interview, I noted my feelings and expectations. I found this reflexive exercise to be therapeutic in giving me a sense of relief from my anxiety associated with being a novice qualitative researcher. The interviews began by reintroducing myself as the primary researcher, my status as a final year trainee counselling psychologist and clinical research fellow at the NHNN. I gave the opportunity for participants to confirm their identity and age as a way to draw on the context-dependent nature of qualitative research, which emphasises that context is vital for participants to generate meanings (Willig, 2012). Using my experience as a trainee psychologist, I found disclosing my trainee status and giving a summary of my relationship with uro-neurology was influential in creating the participant-researcher trust emphasised by Bauman (2015). In therapeutic practice, this would be like building a ‘safe space’ in the first therapist-client encounter. Participants were reminded that the purpose of the study was to mutually explore their experiences of adjustment to chronic pain following SNM. A review of the study’s aims and objectives, information sheet and informed consent form was included. I did not choose to include a demographics section on the consent form due to my personal preference. Reflecting on this, I noticed that this information arose spontaneously from the interview process, supporting my decision. Attention to the option of the researcher informing the participant's GP of their participation in the consent form was highlighted. A copy of this letter can be found in Appendix H. Next, I adhered to a suggestion from Smith et al., (2009) to give a brief description of how the interview is likely to proceed, explaining that at times the interview can feel like a one-sided conversation. It was at this point that I clarified confidentiality. Participants were reminded that their interviews were audio recorded for transcription. I highlighted this point by showing participants the recorder to reduce ambiguity. I directed participants to the confidentiality procedures in the information sheet. At this time, I gave participants the opportunity to ask any questions or clarify any concerns or queries that might have arisen.

The recording was initiated and the interview began with the question "To begin with, could you give me a brief history of your bladder problem from when it started to opting for SNM treatment." The first question aimed to contextualise participants' experiences before having the stimulator device. The following items took on a funnelling approach to become more relevant in exploring the specific research question more directly. While the intention was to a have a chronological guide of how to capture answers to the research question, the interview schedule was not followed prescriptively but instead followed the direction of the respondent. The decision to allow for flexible responses ensured that I remained close to the purpose of semi-structured interviews. That is, to use the predetermined questions on the interview schedule as a guide to cover all relevant areas traced out by the aim of the research while simultaneously allowing for in-depth probing and expansion of what the participant perceives what is most important (Alshenqeeti, 2014).

The majority of participants could openly discuss their inner-world spontaneously, requiring little probing from myself. This inner-world included their feelings, thoughts and behaviours related to their experience of chronic pain. On occasion, some participants found it difficult to explore their experience due to the nature of the research topic. During these interviews, I became more active in the interview process as it was helpful to use the interview schedule as an exploratory prompt.

The final two questions were "If you were the interviewer, is there anything you would have asked or would have liked to know more about?" and "What was it like being interviewed?". These questions created the chance to summarise and clarify what participants had expressed while also giving the opportunity to reflect on the interview process. Ending the recordings here, the total length of interviews lasted between forty and seventy-five minutes. At the end of each meeting, notes were taken in relation to my feelings and reflections on the interview.

I also included observations, key phrases and descriptions which stood out for me during the interview which was used to inform data analysis.

Time was reserved at the end of each interview to give a thorough verbal debrief, once again outlining the study's purpose and aims. The NHS Ethics committee supported the decision to omit a written debrief deciding that a verbal debrief was sufficient. Options for dissemination were also discussed at this time, allowing participants to determine if they would like to be informed of the findings of the study when the research is complete. Dissemination would take the form of one electronic version of an A4 letter briefly describing the purpose, aims, findings and implications of the study.

2.3.4.2. Diary Procedure

The participants whom I found to be more able to discuss their experiences during the interview openly had the option of also completing diary entries. As the diary entries were complementary methods of data collection, I argue that this selection based on researcher's clinical appraisal of participants' engagement was appropriate. The chosen participants were provided with an introduction to the purpose of using diaries as a form of data collection before the discussion on dissemination. I gave a thorough explanation on how to fill in the diary template when experiencing a triggering event, accompanied by a completed example. I explained that diaries would be kept for fourteen days post-interview, mentioning that participants had the flexibility to fill in as much or as little as they see fit. The choice to set out the diaries in this way was to mimic the properties of a semi-structured interview, being that there were prompts available to help participants deeply engaged in their present experience. Participants understood that they could fill out the diaries online or by hand and diaries could return them the same fashion. Once participants were able to reach an understanding, an opportunity was given to ask any further questions which may have come up during the diary briefing. Seven days post-interview, a reminder email was sent to participants about the remaining time for diary entries. The collection of diary entries took place on the fourteenth-day post-interview.

2.3.5. Ethical Considerations:

2.3.5.1. Permission from Appropriate Sources

Gaining appropriate ethical approval is in accordance with the British Psychological Society Code of Ethics and Conduct (2009). City, University of London Psychology Department Research Ethics Committee granted full ethical permission for this study (PSYETH (P/L) 16/17 127)**.** During the planning stages of the research, the application had a narrow age range, did not have the use of online interviews and had the exclusion criteria that participants that have the device for two years or more were not able to take part. At that time, I was not fully aware of participants' geographical challenges. Additionally, I felt that I was too rigid with my criteria that participants could only have the device for two years or less. I decided to extend this to fifteen years based on homogeneity. I felt that my potential participants will already be homogeneous in the sense that they have all undergone surgery for bladder dysfunction and will have the device, will most likely be female and have experiences of pain. Thus, the criteria for only having then device for two years or less and keeping the age range rigid was too constraining and excluded others. I recognised the importance to show variability between my participants' experiences in the current research.

I was also required to gain ethical permission from the National Health Service Health Research Authority and approval from the University College London Hospitals Research and Development team. Acquiring authorisation was due to my professional ties within the Uro-Neurology department at the National Hospital of Neurology and Neurosurgery; the target research population, and the original participant identification process which solely relied on a consultant's database. As a novice to this procedure, I found it difficult to navigate alone. After I submitted my application in January 2017, I continued corresponding with the Camden and Kings Cross Research Ethics Committee until the study was approved in April 2017. The committee granted permission based on the high-level consideration of the research design and method. For the exchange between the ethics committee and I regarding minor amendments refer to Appendix I.

Ethical guidelines also governed my interactions with participants throughout the research process. I held two ethical frameworks in mind during the development and implementation of the current study: the values of Counselling Psychology (Kasket, 2012) and the British Psychological Society Code of Ethics and Conduct (2009).

2.3.5.2. Applying Ethics

With each participant, I endeavoured to be transparent about the purpose, aims and objectives of the research. I ensured that both written and informed consent was obtained before the start of each interview, highlighting that participants have the option to cease participation at any time during the interview and their right to withdraw provided data. I also reiterated the use of recording, illuminating that verbatim extracts may be included in the final version of the research.

2.3.5.3. Confidentially

During the recruitment phase of the research process, I was aware of the low security of unencrypted e-mails. In case of the unlikely event of inadvertent disclosure of email content, I ensured confidentially by omitting personal and sensitive material between emailed participant-researcher contact.

Confidentiality and its limits were thoroughly expressed in written form and reinforced through verbal communication. In keeping with the Data Protection Act (1998), I kept all signed material gathered from participants in a securely locked cabinet in the researcher's home for those who completed online interviews and within the uro-neurology department for those who had face-to-face interviews. The researcher had sole access to these files. Participants were made aware that the destruction of these items will take place when the research is complete. For transcription, I informed participants that protection of their identities would take place using pseudonyms and anonymising data that would prevent identification. Furthermore, only one password protected file of each audio-recorded interview was kept and stored anomalously on the researcher's home computer. These files were destroyed immediately after transcription.

2.3.5.4. Potential risk or distress for participants

Participants' reactions to the current research topic will be highly individualised, however, we know chronic pain is often associated with emotional difficulties (Shuchang et al., 2011). Therefore, it was likely that participants would experience strong emotions during the interview. I had to consider this as literature highlights that managing this can be a conflict for those that hold a dual professional identity, that is, as a researcher and as a trainee psychologist (Hoeyer, Dahlager & Lynöe, 2005). Initial precautions that were set to minimise harm was ensuring anonymity, confidentiality and being transparent by acknowledging the possibility that intense emotions can arise during the interview. In the case that participants become vulnerable during the research process, my experiences as a doctoral trainee will aide me in the identification of such issues. Without assuming a clinical role, mitigation of these issues included signposting to appropriate support, having trained personnel who could respond to emergencies on the premises regardless of the interview setting, contacting participants' care team and making research and clinical supervisors aware of each research interview.

2.3.5.5. Potential risk or distress for researcher

Researchers who are exploring sensitive topics regularly require emotional support to minimise potential risk or emotional difficulties (Melville & Hincks, 2016). Although researchers expect the likelihood of the expression of intense emotions; they will not be aware of their emotional responses to these emotions, thus requiring further support. The tools I used to mitigate my own potential risk or distress was reflection and debriefing. I kept a reflection journal to note my feelings before each interview, writing down my thoughts and expectations. After each researcher-participant meeting, this journal was used to make sense of participant's experiences relating to my own experiences and express any feelings that may have personally arisen. Using the reflective diary was useful in eschewing emotional distress. However, there were moments where I felt I needed further support in alleviating my stronger reactions and feelings of isolation as a novice researcher. Debriefing, or rather emotional debriefing, took the form of scheduling regular meetings with my supervisors and personal therapist during the research process. As anxiety and distress are common reactions for researchers (Sherry, 2013), the purpose of emotional debriefing was to ensure that I felt supported rather than looking for formal assistance. Further consideration regarding reflection and debrief occurs in Part 4.

2.4. Part three: Analytic Procedure

Larkin and Thompson (2012) state that organising a detailed, plausible and transparent account of the meaning of data is the purpose of interpreting qualitative data. IPA sets out a flexible menu of steps that can assist in identifying what matters to participants when exploring their adjustment to chronic pain following sacral neuromodulation and the subsequent illumination of their meaning to participants. This menu describes the process of transcription, coding and theme development for each interview.

2.4.1. Transcription

Verbatim transcription is the first stage of the analytic process. Following the suggestions by Smith et al., (2009) and those of my research supervisor, transcription aimed to take place within one week of each interview in efforts of keeping myself immersed in the data. As I was aware of the type of analysis to be conducted, I deemed it unnecessary to be too specific with transcription. For example, if a participant stuttered the word “I” seven times, this was not reflected in the transcript. IPA is concerned with what participants have said, and is not about quantity as in content analysis, rather it is focused on meaning, not description (Biggerstaff & Thompson, 2008; Gill, 2015). However, I did choose to include dynamics of speech which I found notable or audible, for example, pauses and vocalised non-lexical utterances such as grunts and “hmm”. Punctuation was kept to a minimum to reduce inadvertently changing the meaning of what was said unless it was evidently clear that participants had reached the end of a remark.

Completed transcriptions led to the initial reading of data along with the audio recording to ensure accuracy. The process of rereading the text at least twice after the transcription was completed was designed to make me more familiar with the participants’ account of their experiences, in addition to detecting new insights with each read.

2.4.2. Initial Noting

Initial noting of the entire transcript took the form of noting anything that I could recall from the interview in the margins of the transcript. Notes included my emotional reactions to participants’ responses, my preconceptions, psychological concepts and connections that come to mind forming preliminary interpretations.

I then took on a more systematic approach using analytic tools outlined by Smith et al., (2009). For each transcript, I used three different coloured pencils to target descriptive, linguistic and conceptual comments (See Appendix J). Line by line the colour red focused on the content of what the participant has said by noting face value descriptions direct from the text. These descriptions included any emotional responses, descriptions, explanations or phrases expressed by participants. Descriptive comments identify what matters most to participants and can later be used to further develop the understanding of their inner world (Smith et al., 2009).

At the next level, I used the colour green to guide my attention to each participant's use of language including metaphors, pronoun use, laughter, repetition of phrases and how participants expressed language through tone and emotion. I took the perspective that descriptive comments are used to help me understand "what" participants' experiences are and linguistic comments help me to understand the meaning behind the words by considering "how" participants have said them.

Conceptual comments were captured using the colour brown. With each line, I asked myself the question "what does this mean for her?" in efforts of stepping back from the direct text and taking the approach of viewing the data more broadly. My understanding of conceptual comments took the form of a personal visual metaphor Single Race vs Human Race (Figure 1). This metaphor developed from preference to use visual strategies to assist my understanding of ideas and my personal interests in culture and society.

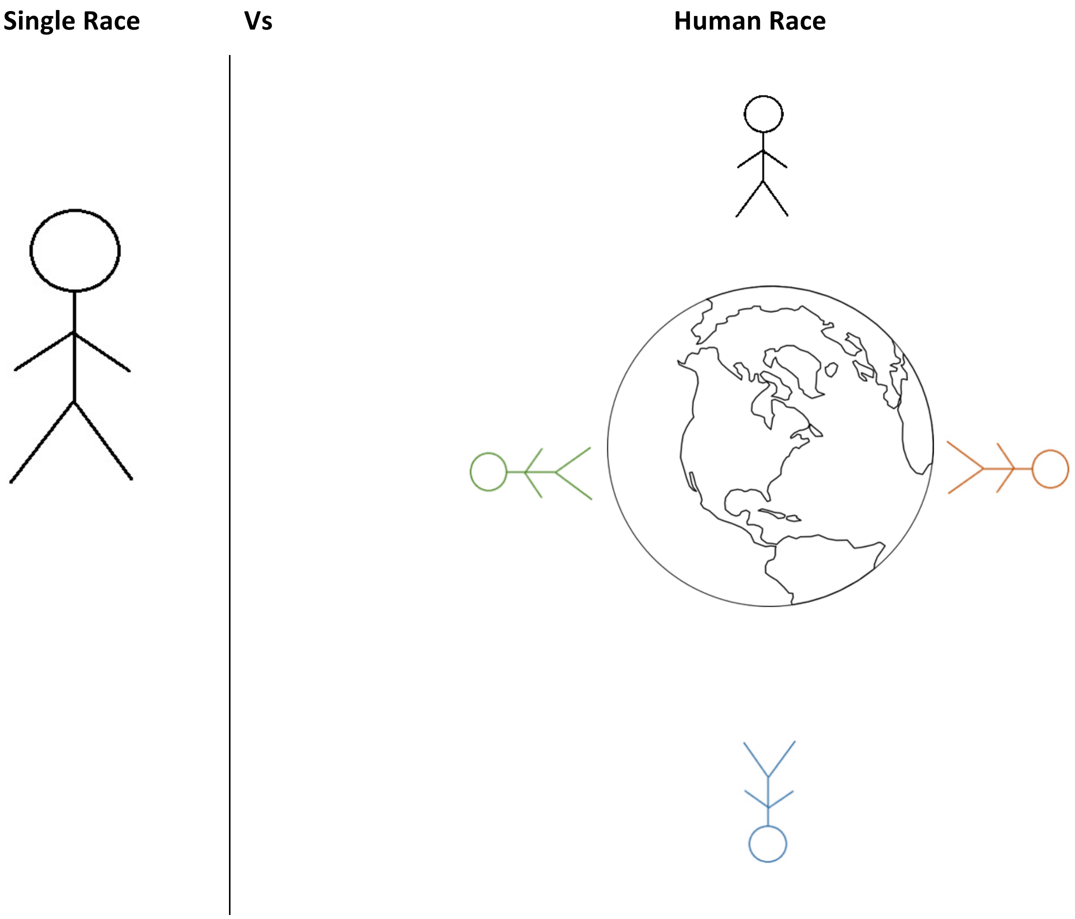

Figure 1: Race vs Human Race metaphor that best reflects my understanding of conceptual comments.

Instead of just looking at one race, this would be each line of the transcript; I needed to look towards a global view that looks at humans as one. This perspective follows the circular interpretation nature of IPA which encourages researchers to think about given parts of the data to understand the whole and in reverse. At this stage, conceptual comments are used to develop insight into participants' understanding of adjusting to chronic pain following SNM. Near the end of the initial noting stage, I found it helpful to talk through examples in supervision before continuing further.

2.4.3. Emerging Themes

Following the steps of initial noting, fundamental concepts began to emerge from the data. I split the development of emergent themes into two parts; original emergent themes and conceptual emergent themes. Original emergent themes capture essential qualities such as patterns that were mentioned several times and my interaction with the commentary from each section of the transcript. The stage of conceptual emerging themes reflects asking myself for each original emergent theme the question “what does this mean for that person?”. The purpose was to move away from being descriptive and move towards interpretation by creating themes based on the feelings, thoughts and behaviours of each participant. For example, an original theme of “catheter bag” emerged from the text where the participant described having a catheter bag that was visible to others. Through conceptualising this theme, I considered whether this meant that the participant was embarrassed. By questioning what it means to be experiencing an original theme or what it means for that participant, I ensured I could develop themes in line with the principles of IPA while also ensuring that themes were the direct result of questions (Smith et al., 2009).

Following this process, for each transcript, I typed out a list of emergent themes with supporting text extracts. I felt that this secured the themes and that the excerpts tell me about the experience of the participant. As both a visual and creative learner, it was at this stage that I decided to write out the list of emerging themes on paper to look for common connections. Each participant was assigned to a different colour of paper. I cut out each item and laid them out on a blank surface to begin creating clusters of themes that I felt shared common features (See Appendix K). This process was laborious and required constant shifting and fitting like pieces of a jigsaw puzzle. From here, a clear image of subthemes and superordinate themes developed. I referred to my hand-taken notes taken during University research modules during the development of subthemes and superordinate themes. I thought about the development of themes in IPA regarding visualising a basket of sweets; emergent themes would be the individual pieces, packaged by subthemes which are placed into the sweet basket (See Appendix L). It was a conscious choice to name themes using participants' own words as I was wary of creating themes that were too factual or reflected too closely to psychological concepts. Based on its roots in phenomenology, IPA reports it is concerned about participants' experience and not what's "out there". Therefore, I felt that using participants' own words for theme names would better reflect their thoughts, feelings and behaviours.

Upon organising all emergent themes, subthemes and superordinate themes (See Appendix M), I had to reflect on the aim of my research. As IPA is ideographic, it is the identification of the themes that are essential, thus, exclusion of subthemes and emergent themes occurred if they arose from one participant. Additionally, the exclusion of subthemes and emergent themes began for items that I felt were not directly relevant to the research question. The Analysis chapter will further consider the elimination of themes in more detail. The above stages of analysis refer to data collected during interviews. Replication of the above analytic steps occurred for diary entries omitting the need for transcription.

2.4.4. Triple Hermeneutic

The triple hermeneutic refers to the reader's interpretation of the researcher's understanding of participants' experience. Although this is typically not considered as an analytic procedure of IPA, I do believe this triple hermeneutic is part of my menu of analytic processes as your interpretation contributes to the development of your knowledge of participants adjusting to chronic pain following SNM. Hence, the understanding of the current phenomenon all comes down to interpretation, which I argue involves the reader.

2.4.5. Evaluating Analysis

A profound argument against qualitative research regards the ability to establish reliability; the replicability of procedure and results, validity and the appropriateness of tools (Roberts & Priest, 2006; Rolfe, 2006). In contrast to quantitative studies which utilise statistical methods for determining validity and reliability, qualitative research excludes the need to apply reliability. Validity criteria seen in quantitative studies as IPA is a non-prescriptive, creative process that aims to make sense of and develop a meaningful understanding of phenomena (Smith et al., 2009).

However, typical issues that arise in IPA studies regard the lack of methodological clarity and insufficient analysis

(Smith, 2011). Smith, Flowers & Larkin (2009) recommend applying Yardley's (2000, 2008) four principles to assess the quality of qualitative work. The criteria are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

1. Sensitivity to context considers relevant literature, the socio-cultural context and the researcher-participant relationship from which data emerged (Smith, Flowers & Larking, 2009; Yardley, 2000). By conducting a review on the limited literature, I demonstrated consideration to relevant literature as the study arose from a gap in the current literature. The acceptance of pertinent literature minimised the risk of "reinventing the wheel" and aimed to extend understanding beyond existing research. Additionally, relevant literature guided the choice to accept a critical realist orientation and employ IPA. In all aspects of the current study, relevant literature directly influenced the decisions behind the research. Furthermore, utilising my therapeutic skills as a trainee counselling psychologist, i.e. empathy, during the data collection process, encouraged sensitivity to context. Using these skills ensured that I was able to remain sensitive to the experiences of the individual participants given the sensitivity of the topic being investigated. Reflexive awareness supported my appreciation for socio-cultural context by examining the participant-research dynamic. I endeavoured to remain aware of socio-cultural factors such as the perceived status and role of being a researcher, that may be present and influencing the relationship between myself and the participants.

2. Yardley's (2000) recommendations for enhancing validity suggest that research should demonstrate commitment and rigour. Commitment refers to the in-depth engagement the researcher has with the topic whereas rigour refers to thorough data collection and analysis. The application of IPA through competency and skill attest to my commitment and rigour. Although I am new to qualitative research and IPA methodology, I developed a solid foundation by immersing myself in the literature. In addition, the role-plays and practical skills within my doctoral training further developed my competency skills. Also, supervisory review from academic supervisors highly competent in qualitative research and a specialist uro-neurology consultant allowed for thorough topic engagement and in-depth analysis. Furthermore, the real-world application of this research also demonstrates a commitment to validity. This study attempts to understand a phenomenon by obtaining a real-life, representative sample where the greater implications of this research can be applied in a real-life setting.

3. Transparency and coherence reflect the researcher’s ability to provide sufficient detail of the methods and analysis used. This step assists in establishing research outcomes that genuinely represent the data collection and analysis. I aimed to maintain coherence by explicitly stating the aims of the study and how I collected and analysed the data to answer the research question. In addition, coherence was achieved by discussing ontology, epistemology and methodology and their compatibility with the theory and methods used in this study. Furthermore, a reflexive element was also added to enhance the study’s transparency, focussing on how sensitivity to context may have influenced the study’s findings. Reflexivity included the thoughts, feelings, expectations and predictions I held before engaging with this research and my attempts to be explicit about my contributions to the research.

4. Research that delivers meaningful, new information ensures the credibility of the findings. Thus, Yardley’s (2000) suggestion of impact and importance was borne out by exploring the possible mechanisms that mediate the adjustment process to chronic pain following sacral neuromodulation. It is hoped that this research will highlight the important factors that will help in the adaptive adjustment to individuals by improving the quality of care. The provision of detailed information from this study can be used to inform future treatment options and be published in journals relating to psychology and medicine. The implications for Counselling Psychology are fully examined in the Discussion chapter.

2.5. Part four: Reflexive Engagement

2.5.1. Epistemological and Methodological Reflexivity

Reflexivity requires the ability and willingness to accept that researchers contribute to the research process (Yardley, 2000). As a trainee counselling psychologist, I did not find this to be a foreign concept. During my training, the skill of reflection has been shown to be an essential component of therapeutic practice. Reflective practice best defines "looking back" and continuously thinking about what has happened between and during the therapeutic process. Reflection requires reflexive thinking which involves a more critical, immediate and continuous self-awareness without self-adulation (Dallos & Stedmon, 2009; Etherington, 2017; Martin, 2011). These concepts have become automatic in my clinical practice, ensuring ethical practice. Therefore, I appreciate the purpose of reflexivity within research.

Kasket (2012) reminds us that when engaging in qualitative research, it is necessary to focus on epistemological and methodological reflexivity. Epistemological reflexivity refers to the acknowledgement that the study's findings could have been different following an alternative theoretical underpinning and approach. Methodological reflexivity involves being aware of my behaviour during the process of the interview. Alternative theoretical foundations and methodologies were considered and excluded and were fully discussed in earlier sections. While IPA does not position itself as a superior choice of method in qualitative research, I found this approach to be the most suitable for my research question. In line with upholding reflectiveness and transparency, we can concede that this study's analytic procedure and design 'constructed' the findings. That is, the methods of data collection based on the research question were constructed in such a way to elicit understanding. Moreover, the superordinate and subthemes were formed based on my interpretations of meaning constructed by participants. However, other approaches would have given rise to a different understanding of adjustment to chronic pain after sacral neuromodulation. For example, discourse analysis is concerned with how reality is manufactured in conversation and grounded theory is designed to identify and contextualise social processes (Willig, 2008). These methods contrast with IPA which focuses on the production of knowledge of how inviduals see the world, revealing one's private thoughts and feelings (Smith et al., 2009).

Moreover, I found the researcher-participant power rapport to be vital when considering epistemological and methodological reflexivity as ontological, epistemological and methodological choices may influence power and answers to the research question. Power dynamics in research are inevitable and can manifest across gender, age, education and knowledge of experience (Karnieli-Miller, Strier & Pessach, 2009). All power differentials between participants and researchers during the research process cannot be controlled. However, it was important that I recognised that the knowledge brought forth by the participants were presented by 'experts'. That is, participants are the most knowledgeable in conveying their realities, and I must position myself to refrain from holding a definitive perception of their experience. As IPA literature suggests reflexive strategies to uphold both epistemological and methodological reflexivity (Smith, 2004), I regularly sought academic and clinical supervision, in addition to completing my reflexive journal detailing the research process (Smith et al., 2009). There were some questions illuminated in my research notes that governed my reflexive journaling such as: what did I notice, what did I connect or feel disconnected to, was I too leading, what were my emotional responses to what happened and how is my own experience relevant to the interview outcomes?

2.5.2. Personal Reflexivity

Engaging in reflexivity is also about identifying and considering the influence of my preconceptions developed through current literature and previous clinical work experience. Although I endeavoured to bracket my approach and experiences to new material in this study, I could not completely 'seal' them off. I was aware that the purpose of reflexivity was to reveal my own biases in efforts of minimising their impact on the research process and that the priority was to be open-minded throughout the life of this research.

Qualitative research recognises that researchers and participants are not neutral, both influence the research process (Fletcher, 2017; Smith, 2004). Thus, my own experiences may unintentionally shape the research (Horsburgh, 2003). As I must be clear about the beliefs and assumptions I hold, I have decided to note these in the following reflexive testament:

I am a 25-year-old Trainee Counselling Psychologist. My initial motivation to research the adjustment to chronic pain following sacral neuromodulation developed from my experiences as a Clinical Research Fellow at the Uro-Neurology clinic before and during my professional training. During this time, I observed first-hand pre-surgical meetings with consultants at each stage of sacral neuromodulation and attended postoperative meetings with the ward's clinical nurse specialist. During this experience, I spent a lot of my time advocating potential pathways for Psychological support within this specific clinic. I believe that individuals can benefit from having Psychologists as part of their care team during and after the sacral neuromodulation procedure. Furthermore, as a child I was hospitalised for a surgical procedure after a breach in my mastoid bone caused reoccurring bacterial meningitis. I remember having to adjust to the pain that accompanied the surgical treatment. I can recall wanting to be supported adjusting to my new reality. I also believe that adjustment is a significant theme in other areas of my *life. Born and raised in Bermuda, at 17 I decided to move to the United Kingdom to pursue higher education. I spend most of the academic year in England and the rest of the year back home. This change is a constant adjustment in itself, which is something I've struggled with over the years.*

Albeit the above statement provides insight into why I've decided to explore this topic, it also illuminates the potential for my past to influence the research process. My experiences have led to the beliefs that individuals who have undergone sacral neuromodulation need psychological support. Furthermore, my younger experiences have created the assumption that individuals may have difficulties adjusting to pain, as I did, and would require psychological support. I've also assumed that adjustment is problematic based on my struggles. This study aims to explore individuals' experiences of adjustment not to identify if there are any consequences of this process. Despite what I have seen during my involvements, it is important that I make reflexivity a constant process to avoid purposely looking at this experience through a 'negative lens' to suit my objectives. That is, I want this research to reflect the authentic experiences of participants, instead of only emphasising what I perceive to be essential factors to highlight.

2.5.3. Reflecting on the Method Process

There were many challenges I encountered during this phase of the research. Given the purpose of reflexivity, I wanted to give the reader insight into the difficulties I faced, particularly with participant recruitment and data collection.

I initially planned to recruit participants solely from a consultant's database, however, after many failed attempts to secure participants, I decided to reach out to support groups. Contacting potential participants in this way led to several responses from interested individuals. I finally began to feel a sense of relief and accomplishment; however, this was short lived. Most of the potential participants did not respond back to emails, despite my many attempts and prompts to reach out which led to feelings of frustration, panic and anger. Consequently, I began to question why I would choose to explore an extremely specialist population. For those individuals that I could maintain contact with, the next stage of the research process was data collection. I can remember being excited to start this process although this too was a challenging phase. Some participants would cancel within five minutes before the agreed interview time; other participants did not attend their interviews, and some participants would reschedule their interviews at least 2-4 times. I began to place blame on participants, often expressing that they are "not *helping me and I am trying to help them". Additionally, having a multimethod approach to data collection also presented challenges. For the five participants that expressed interest in filling out diary entries, two were returned. The first was overdue by two months and filled out incorrectly and the second diary was completed within the specified timeframe but did not elicit enough detail.*

I became less engaged with my research due to the anger and frustration I experienced from the recruitment and data collection process; however, the use of supervision significantly shifted my perspective. In these meetings, my supervisor encouraged me to put myself in participant shoes like I would with my clients in clinical practice. I was struck by a comment said to me: "the participants are not directly helping themselves, they are helping others". That is, despite participants experiences of chronic pain, they were still willing to participate in this research which will not have direct results for them but implications for others. After supervision, I began to reflect on my experiences with participants and their experiences with persistent pain. The rescheduling, cancellations, lack of responses and engagement with diary entries all fit into the context of how difficult it can be for individuals to navigate their lives with newfound chronic pain. Instead of feeling that I was intentionally being let down by participants, I placed myself in their world which developed empathy, appreciation and understanding for my participants.

2.6. Summary

I am interested in gaining a better understanding of how individuals experience the adjustment to chronic pain following successful sacral neuromodulation. In the hopes of providing a context for future research to develop, the current study employed a qualitative design, utilising a multimethod approach to data collection. The chosen method and analytic strategy to explore participants' inner world is Interpretative Phenomenological Analysis because of its roots in phenomenological epistemology which focuses on how participants experience a phenomenon (Willig, 2008).

3.0. Analysis Chapter

3.1. Introduction

In this chapter, I present three superordinate themes and their related subthemes derived from the interpretive phenomenological analysis. The themes are contextualised by participants quotes that were communicated during data collection to provide an account of individuals' experiences of adjustment to chronic pain following sacral neuromodulation.

As mentioned in the Methodology Chapter, the discovery of themes in IPA forms from the researcher's engagement in the double hermeneutic process (Smith, Flowers & Larkin, 2009). The interpretation of themes is made at a descriptive level which offers a detailed account of participants experiences and at an interrogative level where the researcher offers an interpretation of these experiences (Smith, Flowers & Larkin, 2009). As the analysis is a co-construction of "giving voice" and "making sense" of lived experiences (Larkin, Watts & Clifton, 2006), my interpretations may differ from another researcher.

It was a priority that my interpretations were grounded in participants' reflections. Therefore, it was a conscious choice to use participants own words or expressions as subtheme titles as I believe this evokes their embodied and lived experiences. I argue that by using participants' words for subtheme titles is more indicative of the experiences of adjustment to chronic pain for all participants. I recognise that this approach of titling themes may differ from other IPA researchers. However, as the focus of IPA is to understand the first-person perspective from the third-person position (Larkin, Watts & Clifton, 2006), I wanted to ensure that I stay as close as possible to participant's experiences during interpretation, which researchers can miss if titles become too conceptual. Finally, the choice to use participants' words for theme titles emerged from IPA's appreciation to understand participants lived experiences (Smith, 2004). Having roots in phenomenology, IPA is concerned with the direct experience of participants by encouraging their stories to be told in their own words (Langdridge, 2007; Smith, Flowers & Larkin 2009). Thus, by constantly thinking about how participants' may view subtheme titles, this helped to ensure that I retained the voice of their inner-world. This perspective also assists in my analysis as it reflects IPA's hermeneutic concerns regarding researcher's interpretations which endeavour to find meaning beyond the direct claims expressed (Eatough & Smith, 2008; Smith, Flowers & Larkin, 2009).

The subthemes generated do not cover every aspect of participants experiences but were chosen based on their relevance to the research question. Table 2 provides a summary of the superordinate and subthemes presented in this analysis following my interpretation of individuals' interpretation of their own lived experience. I endeavoured to illustrate subthemes with at least three quotes as recommended by Smith (2011). Quotations are followed by the participants' pseudonyms and the corresponding page and line number from transcription.

	Superordinate Themes		
	The Trade-off: Chronic Pain for Corrective Bladder Function	**The Impact of Chronic Pain**	**Living with a hidden disability: The challenge of lack of awareness**
Sub-Themes	"It works, but there's pain!"	"It's very emotional"	"Believe me"
	"New normal"	"Gritted Teeth"	"Bionic Lady"
		"It affects my whole life"	"Take it seriously"

Table 2: Table of Superordinate and Subthemes

3.2. Superordinate Theme 1:

The Trade-off: Chronic Pain for Corrective Bladder Function

This superordinate theme aims to capture the lived experiences of the women living with chronic pain from a device that is designed to restore their bladder function. The "Trade-off" refers to the unexpected compromise participants describe of having to exchange a life of bladder difficulties for life with persistent pain. The two subthemes have been labelled "It works but there's pain!" and "New normal".

3.2.1. "It works but there's pain!"

All participants described an enduring journey of life with bladder symptoms characterised by the lack of hope for a cure, endless hospitalisations, painful medical tests and failed treatments for their unexplained bladder dysfunction. Participants view the restoration of bladder function provided by the nerve stimulator as a positive change for themselves and their relationships. However, participants are aware that their source of positivity is the cause of another life-long difficulty.

Emma provides an illustration of this subtheme when she talks about her experiences with the nerve stimulator:

> ***"After I got home from the surgery, almost immediately, maybe an hour after it was like I was cured! It was like I didn't have bladder dysfunction at all. I couldn't believe it! I couldn't believe it! But I did have a lot of pain, especially where the leads are. But I was told that the scar tissue just has to finish healing and it will go away, you know. But now, you know, it's always hurting me. It's always nagging me. It's like a burning feeling. It never goes away. It never stops. It works but there's pain!"*** **Emma, 1/10**

For Emma, it seems that her disbelief over the positive effects of the nerve stimulator derives from her lack of hope for a cure for her bladder dysfunction. The repetition of the phrase "I could not believe it!" emphasises this disbelief. Emma's excited tone of voice suddenly shifts when she begins discussing her pain which may indicate her current struggle of having sudden persistent pain. Her use of short, abrupt sentences toward the end of her comment seems to emphasise her realisation that her chronic pain is unlikely to improve with the SNM device. Emma's next comment further mirrors this "Trade-off":

> ***"It should not be a trade-off, you should not have to get better to get sick. You know it is not fair. Especially when you go in not knowing and you think you're gonna' be cured and you come out and you feel lousy."*** **Emma, 4/114**

The "Trade-off" is also highlighted by Hannah when she describes the positive impact of the nerve stimulator:

> ***"But yea, I've been out and about more. I lost my confidence before, dealing with a lot of infections day in and out, trying to see my friends and work, I lost my confidence. It was hard doing things with my partner, booking things, seeing my family. I would have to tell you on the day really. So [laughs] in that aspect, yea. Because I can now say well I'm going to come do this with you or I want to do that with you, so. That's helped me in that aspect. So now I'm infection free but not pain free"*** **Hannah 1/26**

Jennifer echoes a similar narrative:

> ***"Yea definitely, its improved my symptoms. Erm, like if I had a choice of either catheterising for life or having this procedure, I'd rather have this permanently rather than have to, erm, have to catheterise all***

> ***the time. Because I find that I'm not getting any infections like I did when I was catheterising all the time, you know. So, it has improved my quality of life, in that point of view. Erm, but pain wise, you're conscious that it's there. The pain is so difficult. But, erm, a lot of bladder problems have reduced, it's improved my infections. Erm, before I couldn't be out and about with friends and couldn't be quite social when I was younger."*** **Jennifer 2/35**

Hannah's and Jennifer's description of life with the sacral nerve stimulator draws attention to their experience of unexpectedly exchanging their symptoms of bladder dysfunction for chronic pain. When both women reflect on their experiences with bladder dysfunction, their words seem to emphasise the idea that their device gives them a sense of freedom. I can remember taking note of Hannah's use of laughter during the interview. During these moments of laughter, Hannah's facial expressions and body language would be excited and then her behaviour would immediately become sullen. Hannah would look at the floor, lower her voice and display facial expressions of sadness. To me, it gave the impression that once she verbalised her experiences, she became more aware of her bladder dysfunction-chronic pain barter.

Mira, Izzie and Lynn further illuminate a sense of freedom offered by the device. Mira remarks:

> ***"It worked…It was brilliant! I was back to normal. It was like being a proper person again!"*** **Mira, 3/36**

Izzie comments:

> ***"Dealing with this is nothing compared to what I went through before the device. You know I am able to get out of the house, I feel, mentally I feel better, because I am able to do things. You know, you still have your bad days with the pain and you think "ah I can't do this" but it is definitely, definitely, the best, in the last five years this has made life liveable."*** **Izzie, 1/14**

> ***"So, it's massively, it's massively improved my symptoms and then I suppose with my mental health as well. Because I am able to get out now which was a massive thing. So, erm, yea. Emotionally, yea definitely, I am not feeling nowhere near what I was feeling when I had the catheters. And I feel like it's improved my relationship with my husband and my son because I can go out with them more, I'm not bed bound."*** **Izzie, 1/27**

Finally, Lynn states:

> ***"Erm, I, I get up once a night, to have a wee, I manage to, you know, erm, without wetting. I don't wet myself anymore. Erm, I because what was happening is before. In between the wetting I was going to the loo, erm, and it would be something like up to 30 plus times a day. Erm, and I was getting up about five times a night, but as well as wetting. And now during the day, I've got it, it's, the most I've got it down to is fourteen times a day. Erm, which is incredible! Erm, but with regards to pain, that's another story."*** **Lynn 8 /114**

These three extracts convey freedom in the sense that the device allows the women to return to their sense of self, engage in social activities and repair their relationships. Reflecting on the tone with which Mira, Izzie and Lynn spoke in, their speech was energetic and dynamic when they spoke about the positive changes of their devices. However, their excitement would trail off in a way that I believe communicates frustration and disappointment, for example, in the interview with Lynn there was a recognisable change in voice tone and body language between "Erm, which is incredible!" and "Erm, but with regards to pain, that is another story." Lynn broke eye contact, looked down at the floor and spoke softly, for me, this non-verbal communication encapsulates the "Trade-off" experience. The see-saw in participants positive and negative responses illustrates the nerve stimulators beneficial and adverse effects on the women and how they have to manage this awareness.

The consolidated statements in this subtheme imply a sense of newfound freedom from bladder dysfunction while acknowledging that it comes with a cost. As the participants recognise the benefits of the working nerve stimulator, it has significant implications for participants' present chronic pain experience as it helps to illustrate the benefit for participants to adjust to a long-term, painful effect. The metaphor that comes to mind analysing this subtheme is "can't have your cake and eat it too." Although it may not fully encapsulate participants pain experience, for me, the trade-off exemplifies this metaphor as participants are giving up their bladder dysfunction, *finally a piece of cake*, but now face the consequence of chronic pain, *can't eat it*.

3.2.2. "New normal"

This subtheme is closely related to *"It works but there's pain!"*. Participants discussed how they are managing the expectations of living without bladder dysfunction and their reality of experiencing chronic pain. The "new normal" brings attention to how pain is altering participants' everyday life in a significant way.

Emma introduced this the metaphor in her comment:

> ***"Erm, I just want to live a normal life. Like when I first got the surgery I was thinking "oh this is just post-surgery pain, then after a few months I realised "oh gosh this the rest of my life pain!" It's not, it's not ever gonna go away. I am still trying to get used to the fact that this is my new life. This is my new normal."*** **Emma 3/86**

Some participants take a spirited approach to their "new normal" by adopting a silver-lining attitude. Izzie rises to the challenge of her chronic pain by comparing her life before the sacral nerve stimulator, she comments:

> ***"Erm, there are times you are in agony with the device and you need to adjust your life to deal with that. The device has made such a difference that I just have to cope with the pain, you have to cope with it."*** **Izzie, 3/69**
>
> ***"But then again, you have to deal with it or you don't deal with it. It's kind of like you have to get up and go, you can let the pain win but then what's the point of having my device in? Don't get me wrong you have to take a dose of pain killers to do it but if that's what it takes then that's what it takes. At least at the end of the day I'm not having bladder problems because that was the worst."*** **Izzie, 3/73**
>
> ***"You have to learn to love the device for what it does, you have to accept the pain*."** **Izzie, 5/121**

Izzie uses repetitive, succinct language here which emphasises her position against chronic pain becoming a disruptive factor in her daily living. Her comments seem to suggest that although chronic pain is a now a regular part of her life, she is willing to push through it. However, I do wonder whether this "I just have to cope with the pain" attitude is connected to her acceptance of her persistent pain or to the acceptance of her limitations resulting from her persistent pain. The use of "you can let the pain win but then what's the point of having my device in?" suggest that Izzie is willing to live with pain if it means having normal bladder function, however, I wonder if this attitude concedes defeat. Is Izzie accepting her pain or accepting the fact that there is nothing she can do to stop the pain? Alternatively, Izzie's comments could reflect resilience rather than acceptance. It may be that Izzie is not accepting of her chronic pain but can appropriately adapt to the stress of persistent pain. Izzie's comments of having to "cope" with her pain and not letting the pain "win" may demonstrate her attempt to rise above her difficult experiences. In other words, Izzie may be using the process of resilience to counteract her chronic pain experience. Her positive emotionality toward her device can demonstrate this. Conceivably, Izzie's comments could reflect her strength of being able to adapt to the stressors of chronic pain and accept its presence rather than the experience. Izzie's comments may show how she manages adversity in order to move on with her life and how her perceptions of strength and weakness and what it means to face the ups and downs of life may encourage this resilience.

The same question of acceptance comes to mind with Jennifer who states:

> ***"The pain is a sacrifice to improve my health."*** **Jennifer, 3/66**

> ***"Erm, I don't see what more I can do. I have to accept it. It's taking me quite a long time to accept this because the pain is a constant reminder of not being able to do what I want. You know, why me? Why do I have this? First my bladder and now this."*** **Jennifer, 5/126**

Like Izzie, Mira also expands on the need to take a positive perspective regarding her chronic pain:

> ***"Pain affects everybody, but, like I said I'm just more determined to not allow it to. There's a lot of people that, and I'm in no means slating other people or anything, erm, a lot of… I'm, I don't let it affect me emotionally. Some people do and they can't help it because that's just the type of person they are. And I think, I think that, as tough as this sounds, adds to their pain. I do. And I think having the positive attitude towards the device, I think that helps. Because I don't let it get to me. And I kind of push the pain to the back of my mind. But it is there because it's always there. Believe me I know about it when I sit down. Or lay down. Or roll over onto my left side when I'm asleep. My husband knows about it too when I go [screams]."*** **Mira, 11/161**

In this comment, Mira's determination reiterates Izzie's attitude of persevering with chronic pain. Her remarks suggest that holding negativity towards the device and highlighting its faults contribute to the chronic pain experience. Therefore, having an appreciation towards the nerve stimulator helps her to adapt to her "new normal". While Mira advocates for not letting pain affect her emotionally, I think it is important to draw attention to the use of her statement "I push the pain to the back of my mind". I reflected whether this means to ignore and distract herself from pain, which helps Mira to manage her expectations of bladder function and the reality of chronic pain that is before her. Perhaps for Mira, if she did not push her pain to the back of her mind, her pain experience would be too much of a challenge to face. If this is the case, I query whether Mira is inadvertently contributing to her experiences of chronic pain if she pushes her emotions aside and doesn't confront what she is feeling. While this strategy for Mira could provide immediate emotional relief and a sense of gained power over her chronic pain, the shutting off or avoidance of her emotions may function to further the physical and distressing psychological effects of pain. Suppressing her experience of pain may be beneficial temporarily but can hinder her ability to adjust in the long-term. This illuminates the role of physical, emotional and perpetual elements in the chronic pain experience. We know that chronic pain extends far beyond sensation and the affective and evaluative components of pain can individually produce and maintain the physical element of chronic pain. Therefore, Mira's combination of expectations, beliefs and ways of coping to her "new normal" influences her illness perceptions and emotional experiences which together may contribute the physical experience of her pain and her difficulties with adjustment.

In contrast to Izzy and Mira, Emma describes her acceptance of her "new normal" as difficult:

> ***"It varies day to day, it's difficult to adjust because part of me say I should accept this as my life but part of me says I shouldn't have to live like this. I am a human being, why should I have to live with this! So, some days I am better at accepting the pain and some days I am really angry about it and I want answers and I don't deserve to be in pain!"*** **Emma, 4/101**

This comment departs from the other participants' descriptions of their attitudes toward their sudden chronic pain. The other women express a determination to live life despite their conditions in a way that aligns with the concept of acceptance. For Emma however, it appears that she often rejects having to live with chronic pain. Her comment "I am a human being, why should I have to live with this!" seems to highlight a sense of unfairness which may link to her views and rights as a person. Her expectations for the nerve stimulator may shape Emma's sense of injustice and unfairness. Possibly Emma feels that she should not have to adapt to a life with chronic pain as this consequence was an unwanted problem, and she intended to have a life free of any chronic symptoms with the device. Moreover, her previous experiences with bladder dysfunction could support feelings of unfairness and injustice. As Emma also felt that her bladder problems were unfair, the similarities between her bladder symptoms and chronic pain symptoms may function to remind Emma that her “new normal” will be of little change to her life before the device.

Participants also spoke about what it means to adjust to their “new normal”. Collectively, participants have different views on adjustment but agree that their “new normal” requires awareness and planning.
Izzie communicates:

> ***“Yea, I do think I am adjusting. I am not bothered by the pain as I used to be and I think that’s an adjustment. Because you to learn to love the device for what it does, you have to accept the pain. So, I think I have adjusted to the pain of the device because I am learning my limits and what I can and can’t do.”*** **Izzie, 5/120**

In agreement with earlier comments, Izzie acknowledges that she forgives the device-related pain because of its benefits to her wellbeing. For Izzie, she explains that adjustment to her “new normal” requires this attitude. Izzie’s comment also highlights her insight into understanding the boundaries her pain imposes. Her statement “I am learning my limits and what I can and can’t do” reflects this awareness. Izzie’s positive portrayal of her device and chronic pain reflects the intricate process of adjustment. Like other participants, Izzie acknowledges the chronic pain that is caused by the device that corrects her bladder problems, however, this awareness seems to be less emotionally laden for Izzie than the other women. Her reduction of psychological distress shows in her comment that she is “not bothered by the pain as I used to be and I think that's an adjustment.” Izzie gives the impression that her compassion towards her device is responsible. Her reference to forgiveness seems to show her ability to accept that her device causes her sudden chronic pain, letting go of her prior expectations for the stimulator. This forgiveness allows Izzie to reduce the emotional distress she experiences ultimately encouraging the process of adjustment to her persistent pain.

In contrast, Mira holds a different opinion to adjustment:

> ***“I think there’s a fine line between adjusting and coping. Ah, I think I’m just learning to cope rather than to adjust. I think for me adjustment would mean I can do things normally. Coping means I’m managing to do what I need to do. Erm, like I said I was a dancer, I can’t dance now. It’s too painful. And if I was adjusting, I’d be able to dance. Erm, so yea, I think I’m just coping right now.”*** **Mira, 21/ 302**

Unlike Izzie, Mira does not agree that she is adjusting to her “new normal” but is rather contending with her persistent pain. While Izzie seemingly takes on an attitude of acceptance regarding her limits resulting from her chronic pain, Mira seems to be still struggling with aspects of her “new normal”. It is essential to note Mira’s tone while verbalising this comment. As Mira spoke her tone progressively got softer, and her body language shifted in a way indicative of disappointment, that is, Mira turned her head down, took an expelled breath and rounded her shoulders forward. It seemed that as Mira reflected on what it meant to adjust, she became more aware of the difficulties her chronic pain imposes and how this has caused daily changes.

Hannah shares a similar view to Mira on adjustment to her “new normal”:

> ***“I haven’t yet. I mean, you adjust to the pain but just as you adjust to it, it gives you a new pain. You have to adjust with the pain rather than adjust to it. I mean I’ve been in a lot more pain before but…overall, it’s a good thing, I mean compared to what my life was like before to now, it’s a good thing a very good thing. But the pain will never disappear, so that, that really saddens me. Adjustment to me means adjusting to the situation you’re in when you’re in it. Like, in order to adjust properly you need to be prepared for every situation. So, making sure you’ve got all you need to help you to keep going. And as long as you do that, you adjust to different situations. You know, that’s making sure you have all your pain killers, your device, your batteries, purse, wallet and proper support. Once you know you’ve got them, it is fine, you know you can conquer anything.”*** **Hannah, 7/184**

Hannah’s notion of planning is further supported by Jennifer:

> ***“I think it’s just assessing what you can and can’t do and planning. Planning ahead when you wake up and see what you can manage that day, you know.”*** **Jennifer 5/131**

Both Hannah and Jennifer describe the use of planning and implementing strategies to adapt to their chronic pain. Like Mira, it seems that both women struggle with living with their persistent pain, however, they identify tools that help with the management of their “new normal”.

This subtheme validates that chronic pain is a significant factor in these women's lives. Each participant has their perspective toward their new life with pain and how they modify and make changes that encourage them to manage their prevailing chronic pain experiences.

In summary, this superordinate theme sought to illuminate the lived experiences of women no longer living with bladder dysfunction but now enduring a life with chronic pain. The two interrelated subthemes bring attention to participants' bladder dysfunction-chronic pain "trade-off" while also highlighting participants' views and management of living with an unanticipated consequence that has emerged and altered their daily lives.

3.3. Superordinate Theme 2:

The Impact of Chronic Pain

This theme explores the experiential impact of pain on the emotional, cognitive and psychological experiences of individuals adjusting to chronic pain following sacral neuromodulation. Subthemes include "It's very emotional", "Gritted teeth" and "It affects my whole life".

3.3.1. "It's very emotional"

Despite the variation in participants' responses, all participants spoke about the mental and emotional strain related to their device-related pain. Hannah chronicles her emotional experience with the nerve stimulator:

> ***"You know, and now pain makes me cry a lot. It sounds very wimpish to be honest, but it makes me cry a lot. Erm, yea. Nobody else gets what it's all about. It's very emotional. You look at other people, and you go "how come their body does that, what's wrong with mine?" You know [laughs]. It's very emotional. Some days I wake up, and I'm fine, other days I wake up, and I have to get reassurance, after reassurance, after reassurance that I'll be ok and then I get myself in a bit of a mess."*** **Hannah, 5/124**

As Hannah provides her account of the emotional impact resulting from chronic pain, it seems as if she sensitive to how others perceive her. Inferring, the word "wimpish" may hint to her experiences with others who may have negatively commented on her crying behaviour in the past. Thus, Hannah gives a disclaimer of being "wimpish" before her admission that pain causes her to cry. This self-perception may also explain Hannah's conflictual use of laughter in her comments. She begins to laugh immediately after she questions her differences in bodily function to others. For me, this reflects a sense of self-blame and responsibility for the chronic pain Hannah is experiencing. The colloquial phrase that comes to mind while reading her remarks is “there is pain in laughter”. Perhaps Hannah uses humour to mask this self-blame to minimise or hide her emotional experience. Her comments on reassurance and getting herself into “a bit of a mess” seems to reflect this idea. I am reminded of Hannah’s use of laughter in the subtheme “It works, but there’s pain!”. Hannah used humour in a moment that was distressing, the same way she has here. Hannah’s use of laughter seems to reflect her attempts to lower the level of stress and anxiety caused by her chronic pain. The use of humour as a means of communication may help with realising the psychological tension she experiences, for example, during her interview her laughter appears to relieve her emotional pain and reduce the adverse effects caused by her current situation.

The sense of self-blame within Hannah’s comment is also highlighted by Mira:

> ***“Erm, and I think yes, I suppose emotionally I do sometimes say “it’s my stupid body, why can’t my body work, why can’t I be normal?” But I think I’m more questioning rather than getting, I don’t get upset about it. It’s more the questions as to “why me?”. You know, “what, what did I do wrong? Did I cause this myself?” But all I did was have baby and I have, you know, lots of people have babies and it doesn’t happen to everybody. So, is there, is there, you know, something to do with my body?”*** **Mira, 9/134**

In this comment, Mira implicates her body as the responsible factor for her chronic pain which is highlighted in her mentioning of normality and bodily failures. Moreover, Mira’s self-blame also factors in her experiences of bladder dysfunction. She refers to having giving birth to her first child, which initiated the start of her bladder dysfunction. This comparison of self-questioning emphasises how Mira attributes the occurrence of her chronic pain to herself. My attention is also drawn to her statement “But I think I’m more questioning rather than getting, I don’t get upset about it.” Although I am careful not to label her experience as false or denial, I do wonder whether Mira is aware that her self-blame does seemingly upset her. While making this comment during the interview, Mira made changes in her body language, facial expression and voice tone which aligned with perceptions of sadness and difficulty. She spoke with a flat tone, and closed posture with her head down and pointed the side and her mouth appeared slightly turned own. It would be interesting to note what Mira would think of this interpretation.

Naturally, participants spoke about low mood as an emotional consequence of their chronic pain.
Hannah describes:

> ***"It does…sometimes it can affect me bad. It can keep me down for a little while."*** **Hannah, 2/43**

The presence of low mood is further expanded on by Lynn:

> ***"Erm, yea it, it gets you down because it's like, on one hand you've got this amazing gadget that you're now not wetting yourself, but then on the other hand it's like, it, it sort of does a similar thing to how, when I was totally incontinent and having all the problems with urine infections, and with the catheter and with the changing of the catheter which was absolutely horrendous. Erm, so it's, like you're exchanging one problem for another problem."*** **Lynn, 15/233**

Lynn's statement closely links with the aforementioned superordinate theme "The Trade-Off". In addition to Lynn's current experiences of chronic pain, the comparison of her life before the nerve stimulator provides the context for Lynn's current low mood. It seems that her similar physical health experiences significantly contribute to her low mood, reflected in her remark "like you're exchanging one problem for another problem".

Jennifer also speaks about the challenges she faces living with chronic pain which is the source of her low mood:

> ***"Pain, pain does get you down, you know. Especially like psychologically. If you're like, it's a really good day and you know, people invite you to shopping you can't because it's really hard to get mobile. So, you can't really walk around, so sometimes you just have to take it a bit easy and not do as much. It can be frustrating. It can be really, really frustrating. It is what it is, you know. You just try to get on with it and carry on as best as you can, really. It's really frustrating because you know that you can do more and you kind of…you know you want to do more but you know that your pain just won't allow you to do more. And you're thinking "oh well I just wish I could do what all those other people are doing around me". You know. And it's like, I'm so young and I've obviously still got goals I want to meet and stuff and it's just like you can't, you have to reschedule all your goals...because I'm not like everyone else and I can only do what I can physically do."*** **Jennifer, 3/77**

Jennifer recounts how her chronic pain affects her ability to participate in activities, engage socially and has created obstacles for her life plans. This sense of loss and low mood was common among the participants as they

often compared the similarities of their old life and new life, which was heightened by their expectations of having a life free of bladder symptoms.
Jennifer goes on to say:

> ***"I never know one day to the next. There's no script you can go by. So, I feel quite uncertain. There's never any guarantee to anything, anything with me. I never know what's going to happen or if I could be okay or not be okay. You just don't know how the pain will be day to day. And I find that it really has a knock-on effect on my mood system. It brings it totally down, you know. It's hard, it's hard being so uncertain."*** **Jennifer, 4/116**

In addition to low mood, the above comment denotes a sense of anxiety for Jennifer that is caused by her chronic pain. When making this comment during her interview, Jennifer had a varying speech tone and took quick breaths. I can remember Jennifer patting her hand on her chest in what looked like an effort to self-soothe, followed by taking a drink of water. Again, Jennifer's comments here align with her statements made in the subtheme the "new normal", that is, having to assess what she can do daily rather than planning and being able to do what she would like serves as a continuous reminder of how uncertain the consequences of her pain is. Jennifer then attributes her difficulties with this uncertainty as a contributing factor to her low mood, which often presents as feelings of hopelessness.

Other participants shared Jennifer's awareness of how chronic pain has a "knock-on effect" on their mood.
Mira states:

> ***"Oh, I get really grumpy. When I'm tired I get grumpy, when I'm poorly I get really emotional. Things that wouldn't normally affect me, affect me. Erm, I just get upset over stupid things. Really emotional and I don't know why. I don't know why the pain affects me."*** **Mira, 15/ 212**

I am drawn instantly to Mira's comment "I don't know why the pain affects me". In earlier sections of this subtheme and the prior superordinate theme, Mira takes the position that she does not let her pain affect her emotionally, there is a general sense that she is in control of her chronic pain experiences. Here, however, it is as if her chronic pain takes control of her causing changes to her mood that she is not able to have power over. This speaks to the nature of chronic pain and how the cognitive and emotional toll of pain affects one's life and experiences of mood. Emma continues to discuss the impact of pain on her mood:

> ***"Oh, anything throughout the day can make me mad. You know, any tiny stresses which shouldn't cause so much stress sends me off. You know, I am so much more sensitive to stressors because of my pain. You know so when something little happens I just flip off the handle bars, you know with the littlest bit of stress*."** **Emma, 2/56**

Like Mira, Emma reflects on how her chronic pain has changed her ability to handle stressors. For Emma, she recognises that her lowered stress threshold develops into anger. The use of "flip off the handlebars" brings me back to my thoughts on how overwhelming the experience of chronic pain can be for these women. Emma's comment highlights the emotion-pain connection as she brings attention to how her chronic pain and feelings of anger, frustration, stress and despair are intertwined.

In addition to low mood and anxiety, participants also talked about their conflicting feelings of guilt and disappointment arising from their experiences of chronic pain.
Izzie makes the statement:

> ***"Erm, I think, like, I don't think anyone quite understood that you would still be in pain. It is not the miracle that was promised. I didn't think the pain would be as severe as it is from the device."*** **Izzie, 3/89**

Jennifer says:

> ***"But I feel guilty because I know I'm suffering but I should just try to be grateful because there are people worse off than me. And that's what I keep thinking. So, I'm trying to be positive, be lucky for who I've got, who I am and what I can do even though it's not as much as I would like."*** **Jennifer, 5/121**

The comments made by Izzie and Jennifer were typical among the participants. Each of the women describe the emotional conflict of feeling guilty for not having an appreciation toward the device correcting their bladder symptoms despite its consequence of pain. Izzie's remark "it is not the miracle that was promised" provides insight into participants' disappointment with their device which develops into feelings of guilt. As Jennifer refers to other people, who either have bladder dysfunction or who are generally "worse off", it may be that this guilt relates to the specialist nature of bladder dysfunction and the device. This may make Jennifer feel that she should not be critical of the nerve stimulator and its consequence of pain as there are others who have not been giving the opportunity to have the device implanted.

Furthermore, there seems to be a link between participants' self-blame, low mood, conflictual feelings towards their device-related pain and thought patterns. The women describe repetitively focusing upon the pain of the device and what this means for their future. Mira introduces this style of thinking:

> ***"Erm, but yea I mean it's very [pause]. I get, it upsets me to think that, that it's not working and the possibility of what's going to happen next upsets me."*** **Mira, 9/120**
>
> ***"Erm, I think, that's, that, I'm thinking too far ahead but you do. You start thinking about the future and what, "what next, what if it doesn't work? What next?"*** **Mira, 10/146**

Lynn talks about a similar thought process to Mira:

> ***"Because you're constantly, you know, it's either that or that, you know? Erm, it's horrible. It's, erm, yea. But I don't want it out. But I want the pain to go away. In my head this is what I keep thinking."*** **Lynn, 17/244**

It appears that Mira and Lynn's constant thinking stems from their recognition of "The Trade-off". The women continuously question whether they should remove the nerve stimulator because of their chronic pain. As the device is the last treatment option for bladder dysfunction, the choice of either living with bladder dysfunction or having to endure chronic pain contributes to their regular overthinking of their bladder function-chronic pain dilemma, unsurprisingly impacting their mood.

Jennifer comments on the relationship between her thinking and mood:

> ***"Because now I'm in my head all the time, just like I was before the device. I can't, I don't want to be out and about, I can't do certain things…it's just like how it was with my bladder except now it's because of***

> ***pain. You know I'm gutted that I still can't do things I enjoy because of the pain when I finally got relief from the bladder symptoms! I feel a bit gutted that I'm going to miss out on this and that. I do feel disappointed."*** **Jennifer, 3/67**

Jennifer's reference to being "in my head all the time" stems from the similarities she has identified from her life with bladder dysfunction and her current experiences of device-related chronic pain. Jennifer recognises that her chronic pain symptoms cause the same mental distress as her bladder dysfunction did. It seems that the similarities such as withdrawal, social isolation and not having the ability to participate in things she desires are constant reminders of how life before the nerve stimulator. During the time of bladder dysfunction, Jennifer did not have the freedom to participate in every activity she desired. It may be that the overthinking experienced by Jennifer is the product of her worry or even the confirmation that despite resolving her bladder dysfunction, she still has the same restrictions imposed with her device.

This comparison is also described by Hannah:

> ***"I talked very negatively before, low confidence and I worry it will be the same because of the pain. So, I keep thinking about that."*** **Hannah, 3/78**

It seems that the women's constant thoughts either focus on the future or their observations of past bladder dysfunction and current pain occurrence. I am struck by Jennifer and Hannah's awareness of their engagement with their experiences of continuous thinking. It feels as if they can recognise its effect on their mood, however, as the women have made an unexpected "Trade-off", their current expectations and uncertainty of the impact of the stimulator and newfound reality significantly contribute to this pattern of constant thinking.

The extracts conveyed within this subtheme bring attention to the personal psychological consequences of living with chronic pain following successful sacral neuromodulation. Participants describe negative feelings such as self-blame, low mood and anxiety. This subtheme also revealed what appears to be rumination over past, present and future concerns. This thinking pattern appears to signify a collective sense of helplessness experienced by the women as they are now living with persistent pain from a device that is paradoxically managing their bladder function effectively.

3.3.2. "Gritted teeth"

Every participant discussed the attempts to manage their pain around others. This theme reflects participants' determination to summon up their strength during their experiences of pain in efforts of not letting others know how they honestly feel. It speaks to the nature of participants unwillingly having to accept their pain experience around others. Mira offers a description of this subtheme when discussing her interactions with others while experiencing pain:

> ***"And I always try and put a brave face on. I always try and be happy, I always try and be the one, you know? Somebody walks past me at work and I'll smile at them. "Morning! Alright?" That's me. That's who I am. I try and make things pleasant for other people even if It's unpleasant for myself. Even if, through gritted teeth, I'm saying morning. Whether that may be because I'm in pain or I just don't want to say good morning to that person, I do, I do it. Because that's, that's me."*** **Mira, 16/226**

I interpret Mira's repetitive use of the word "always" at the beginning of the excerpt as the testament of her longstanding effort to combat her chronic pain. This is not the first-time Mira has shown determination to minimise her pain experiences. In previous sections of this analysis, Mira has pitted herself as an opponent endlessly fighting against her pain.

Mira's words here also illuminate her self-concept as she mentions the beliefs that she holds about herself as "the one", a positive, happy individual. Comments such as "That's me. That's who I am" and "Because that's, that's me" appear to suggest her awareness of how the pain she experiences can produce changes within her. My understanding of what is expressed by Mira is that she appears to be competing with herself in the sense that she does not want to lose who she is because of her pain. Thus, by using determination Mira regularly counters against her pain causing changes or disruptions in her self-perception.

Lynn also describes an account of minimising her pain experiences with others:

> ***"You can't continue telling people the shit that you're going through. Excuse my French. It's, it's just, it's embarrassing."*** **Lynn, 10/148**

Lynn 's firm voice tone while expressing this comment denoted similarities to Mira in that she avoids telling others about her pain-related experiences. This sense of having to endure pain in efforts of "saving face" highlights Lynn's personal experience. Unlike Mira, the comment "it's embarrassing" suggests prior experiences of judgment either from herself or from others. Paired with the use of the word "continue" which gives the impression of no change, I interpret a sense of frustration that has developed from Lynn previously telling others about her bladder difficulties and now having to say that since receiving the implanted device it has fixed those problems but now results in chronic pain. Lynn continues to reflect on her choice to not tell others about her experiences that stem from the tension caused by her "Trade-off":

> ***"Erm, so it's, like your exchanging one problem for another problem."*** **Lynn, 16/236**

From Lynn's account, it seems that her embarrassment results from her continuous physical health difficulties and the judgment that accompanies these experiences. While I acknowledge that many women typically experience embarrassment when it comes to discussing their bodies, whether functioning normally or abnormally, it appears that both Mira and Lynn commit to the experience of "Gritted teeth" to defend against revealing their experiences of pain in efforts of avoiding humiliation from others.

Here, Jennifer echoes Lynn's experience of having to persevere through pain in her following reflection:

> ***"You become conscious thinking about what are other people thinking looking at me and stuff like that. Like you think, 'they don't understand I've been through stuff'. And I think people can, are too judgmental sometimes. You know, they don't know what people are going through and they're just too quick to judge rather than, like, talk about stuff and, you know, what's the full story rather than…you know. They just think 'ah well she looks funny, so she must be funny'. You know, I just don't think it's always fair with the device. You know, people are just like 'she doesn't look right so I won't talk to her'. It really gets you down."*** **Jennifer, 3/88**
>
> ***"I just try to put up a front, you know. I just put up a front and when they say I can see you're really, really suffering, I'm like "no, no I'm fine" because they don't understand".*** **Jennifer, 4/103**

Jennifer's comments "ah well she looks funny, so she must be funny" and "she doesn't look right so I won't talk to her" appear to reflect prior experiences of judgment, isolation and withdrawal from others when she has not minimised her pain around others. Jennifer's elaboration "You know, I just don't think it's always fair with the device" clearly illustrates the awareness she has of having to consistently consider others over herself, despite having to live with continuous pain. It is important to notice that at the start of the first excerpt Jennifer uses "me" and "I" then later refers to "people" and "she" when articulating her experiences. This use of the third-person viewpoint may be a way for Jennifer to create distance from current chronic pain experiences. I could suggest that Jennifer uses this as an emotional and psychological defence as a tool to detach herself from her emotional experiences to help control and manage her pain experiences better.

"Gritted Teeth" focused on how participants manage their chronic pain experiences around others. The extracts in this subtheme demonstrate participants' efforts against their chronic pain. It seems that participants are forced to minimise more than they are manifesting as there may be consequences that arise when participants reveal their actual experiences to others and there can be perceptions that others will respond in a certain way.

3.3.3. "It affects my whole life"

Another theme that emerged among participants was the broader personal impact of living with chronic pain following successful sacral neuromodulation. The subtheme "it affects my whole life" captures the familial and social implications of chronic pain that the women face since treating their bladder dysfunction.

> ***"The pain now is still a massive factor, it still controls my life. Everyone talks about getting their life back but it just getting parts of your life back because you still have to deal with the device pain. You have to think about, you have to think about what you're doing all the time, to make sure you can handle the pain situation. Pain affects your whole life."*** **Izzie, 3/80**

Izzie user matter-of-fact language here emphasises the dominant presence chronic pain has in her life. She begins by describing her expectations of sacral nerve stimulator then asserts pain affects every facet of ones' life. Mira uses similar language to convey how her pain affects her relationships with her children. She comments:

> ***"I get really grumpy. My children hate it when I'm grumpy. I turn into the devil mom. Mom from hell. I'm stroppy, snappy, erm, there's a lot of things I can't do that my children would like to do. Erm, go to theme parks and things. Going swimming, erm."*** **Mira, 16/261**

Mira appears to notice that the emotional consequences of her pain negatively contribute to her interactions with her children. I am curious about how her children make sense of the “Trade-off” she has made, do they feel anxious and uncertain? Or do Mira's children feel a sense of guilt because they assume that they are contributing to their mothers’ pain experience? Mira also seems to express resentment on how her chronic pain has limited her ability to participate in activities with her children. Again, I wonder whether her children have expressed anger or frustration concerning their mother not being as available as she may have been before.

Moving forward, Hannah also discusses her chronic pain and its impact on her family:

> ***“It’s definitely bought the family down as a whole. I think, when you watch your family go through having to go with me to hospital two or three times a week to now… Erm, it’s hard for them to watch me not able to do anything and it gets them down, you can tell. It’s difficult for them to watch me and not being able to help me, especially since I have the device. Sometimes there’s a bit of friction and tantrums between us because of that. I think it’s the communication, you know. Not being able to tell them what’s going on and them not being able to communicate how they can help. And my dad doesn’t understand this, he just gets mad. It’s like before the device…he just gets agitated. So, we have hiccups.”***
> **Hannah 3/68**

Similarly, Mira comments:

> ***“They do try and help. But its only so much that they can do. And I think they often feel helpless as well.”***
> **Mira, 18/268**

When Hannah speaks about the tension that results from her device-related chronic pain, there is a sense of hopelessness and assumed responsibility for the strain she notices within her family dynamic which Mira’s remarks complement. I got the idea that Hannah's feelings of despair and the assumed burden of having her family “watch” her “through having to go with me to hospital two or three times a week to now…” may link to more profound feelings of guilt and shame that link with her past challenges with bladder dysfunction and current chronic pain. The latter part of her narrative can support this where she comments “It’s difficult for them to watch me and not being able to help me, especially since I have the device”. I could suggest that Hannah may feel guilt and shame for having the stress of bladder dysfunction, which has been treated but now results in constant limiting pain that causes Hannah further restrictions. Thus, she assumes the responsibility for the strain present in family dynamics which seems to stem from her difficulties in managing her chronic symptoms.

Likewise, Lynn's reflects on her familial relationships since she started experiencing chronic pain:

> ***"But, erm, you know, having, and, and, yea it does put your life on, on hold. Erm, with regards to my family, erm, this weekend I put off seeing my sister. Erm, she lives about an hour and a half's drive away. Erm, haven't seen her since May. Erm, it's her 50th on the 27th of this month. And, erm, I put it off because I was in a lot of pain. And its, again it makes, I'm embarrassed I feel like I, I, I, I feel like I, I'm letting her down. I feel like, erm, do they believe me? Erm, do my parents believe me that I'm actually in the amount of pain I am in, which is why I can't actually go down and see them. Erm, yea, erm. I'm sure my, I'm sure I, I, I think my parents are disappointed that I haven't gone down and seen them yet. Yea, I feel like I've let them down." Lynn, 17/256***

Like Hannah, Lynn places much self-responsibility on her difficulties in being able to connect with her family. An interesting difference between Hannah and Lynn statements is that Hannah appears to acknowledge that her family recognises her pain experience while Lynn questions whether her family believes hers. Despite the difference in family perceptions, both participants stress that they have a sense of responsibility for the consequences that are caused by their device-related chronic pain.

Further reflecting on the broader personal impact of chronic pain, another aspect of this subtheme was independence. Hannah describes her interactions with her partner:

> ***"He helps me quite a bit…and we have had a few arguments saying that "I'm not completely invalid can you let me do something on my own [laughs]".*** **Hannah, 3/89**

Hannah's desire to be independent and "do things on her own" appears to be the direct result of her chronic pain limitations. It seems that Hannah is aware of the constraints that her persistent pain creates which brings about feelings of invalidity as she must depend on others. Taking note of her tone in this excerpt, I reflect whether her lack of independence has resulted in feelings of frustration and perhaps resentment toward her partner and device-related pain. I particularly wondered this during the interview where Hannah would often use laughter as a way to lighten the atmosphere when she spoke about difficult emotions. Throughout this analysis, Hannah's use of laughter has been very interesting, often appearing to reduce or mask her true feelings and experiences.

Emma also suggests her desire to be independent when she discusses her interactions with others. Like Hannah, she begins by identifying a lack of independence then links her experiences to being "a normal person".

> ***"And then my mom thinks I should have complete restriction. She doesn't even want me to stand sometimes, she walks around eggshells around me. You know people are always judging. They think I don't do enough or do too much. Erm, I just want to be treated liked a normal person. Now that I have my symptoms under control and even though I now have this pain, I just wanted to be treated like I am normal. And not have to explain anything, explain myself to everyone. Just have a normal life. I just want to be a normal person. It's pretty frustrating."*** **Emma, 2/44**

This sense of impendence is also evident when Emma recalls the shift in her marriage since her pain experiences began:

> ***"Erm, ok so. I don't want people to know that I am in pain. But of course, my husband can tell. And you know it kind of makes me feel, like you know, less of a person because I do need help with some things. I try to do everything myself and I end up getting hurt. The pain gets much worse. It kind of makes me feel that I am a burden on people. You know after the pain started, I feel like I have to keep depending on people. And you know, emotionally it takes a toll on my marriage because my husband has to chip in so much more. It's kind of emotional."*** **Emma, 2/39**

On face value, Emma's description of feeling like a burden seems to reflect her difficulties with independence. However, at a deeper level, her comments place sole responsibility for her inability to contribute to her marriage in a way that she would like. It feels as Hannah, Lynn and Emma struggle to separate the consequences of their pain from themselves. That is, rather than attributing the tension and difficulties seen within their family relationships to their newfound chronic pain; they instead feel entirely responsible.

Like Emma, Mira talks about the impact of her device-related pain on her spousal relationship. She starts her comments from the perspective of having to remove the device and replacing it with a catheter bag if the chronic pain becomes too challenging to manage:

> ***"And then there's obviously, there's, I mean, I'm, I'm a married woman but there's "will he find me attractive if I've got a bag? Will he find me attr-?" See, he doesn't, he doesn't kind of, he doesn't understand this. He doesn't see this, he can see the scar but that's it and they heal. But with something else, he would see it. it would be there. And how, you know, how could he find me attractive If I've got something like that?" Mira, 10/147.***

Mira then reflects on her current experiences:

> ***"Erm, sexually, I can't remember the last time. Because it's so painful. Because when you think about, when you think about positions and things, me laid down on my back, nah. Him anywhere near my back, nah. Being sat up, being sat, moving and sat, not really an option. So, it does cause, does cause arguments, he questions whether I love him anymore because, and it's not that I don't want to be near him. It's that I physically, if I do, it's painful and when I've tried it's painful."*** **Mira, 17/242**

> ***"And I believe he questions, sometimes he thinks that I don't love him anymore and he questions whether I actually want to be with someone else. Erm, because I'm not near him. You see these things on TV, you watch, like in a series a doctor was having an affair and she figures it out because he wasn't sleeping with her. And I sometimes think that maybe he thinks that about me. But it's, it's purely because the pain is too much. I can't get into a comfortable position."*** **Mira, 17/250**

Lynn also comments on sexual intimacy with device-related pain:

> ***"Erm, funny enough, last night I was, don't know why I was thinking about it last night, because I was in a huge amount of pain last night and I was thinking to myself "you know I'm so pleased I'm not actually with anyone", because if he actually said, you know, "let's go to bed", I would have told him to "get lost". Because I couldn't imagine having sex with this! Same again with the catheter. Obviously, you know, I, I, I couldn't imagine how you'd do it."*** **Lynn, /252**

Mira and Lynn's experiences overtly show the implication for sexual intimacy that relates to their device-related chronic pain. It is unclear whether their chronic pain has decreased or eliminated their sexual desire, however, the sexual avoidance that both women speak about attest to how chronic pain interferes with their sexuality. The participants' device-related chronic pain appears to invade more than just the physical aspect of their partner relationships. Both women isolate themselves from the act of sex which appears to have generated a sense of rejection in their partners and shifted their view of self. Again, I notice a degree of responsibility, particularly for Mira, concerning her partner's feelings and his security in their relationship. It appears that Mira has had difficulties in communicating that her pain is the sole cause of their lack of intimacy rather than her attraction toward her husband.

Participants also draw attention to the challenges of maintaining social relationships and connections. In line with Izzie's earlier comments of appreciation for the device, she acknowledges the advancements it has made for her socially. However, she confesses her current limitations resulting from her device-related chronic pain.

> ***"Erm, I don't go out or stay up late because the pain is too much, so yea it does impact my social life. I mean I can go out and see people, the device has improved my social wellbeing but at the same time I can't stay long or do too much because the pain becomes unbearable, it becomes agony."*** **Izzie, 3/78**

Jennifer continues to emphasise how living with chronic pain places a strain on social relationships:

> ***"I just had to make sacrifices, you know. I can't plan anything, you know. Especially in social situations where you know you want to go but you can't give any guarantees that you can attend, because you don't know how the pain will be. It's hard. I feel like I'm letting people down. I get invited places and I can't definitely say I'll be there. And you think well do people really understand how hard it is to say, you know, I'd love to go and be there but I can't definitely say I will be there because of the pain. So, you feel really bad and you think what are other people thinking of me. Are they thinking I'm just lazy or I can't be bothered or I don't care about them enough? You just keep thinking like that."*** **Jennifer, 3/110**

The use of the word "sacrifices" here speaks to the position that Jennifer feels her chronic pain has put her in. For Jennifer, a sense of loss has developed as she cannot engage socially as much as she would like. Her comment also emphasises the repercussions on her social connections. The use of “I feel like I’m letting people down” speaks to Jennifer’s prior experiences and perhaps the experiences of her social connections feeling disappointed over her inability to socially connect. It seems that this leads to self-criticism and persistent self-questioning about how her peers perceive her. Lynn mirrors Jennifer in her reflection:

> ***“And it’s like I hear myself talk and I think if I was actually listening to someone, I would query whether or not they were being honest. You know, because like you just. It’s just like an on-going, feels like it’s an on-going excuse. It’s an on-going…”*** **Lynn, 18/268**

Lynn’s repetition of “on-going” seems to draw on the parallels of her life with bladder dysfunction, where she was not able to engage socially, and her current lifeworld with the device-related chronic pain, where she still cannot socially engage as she prefers. Her comment draws attention to the arduous journey these women have undergone and the “sacrifices” they have been forced to accept as part of the “Trade-off”.

The final aspect of this subtheme is the impact of participants’ current pain on employability. Mira shares:

> ***“Erm, I love my job. It’s what I’ve always done. I love the team that I work with. We are, and it’s real- it’s not very often you’ll find that there’s teams say this, but we are like a family. We tell each other everything, we know each- you know, we know the ins-and outs of each other, we do things together. We are, we are like a team but like a family. So, the thought of leaving that family and the support that they give me, it’s not something I want to do but then I look at the job that I do and whilst I do enjoy my job, I know that I won’t be able to continue.”*** **Mira, 14/197**
>
> ***“It also feels like I’m deskilling a bit. Because I can’t remember the last time I’ve scrubbed for a hip or a knee. So, maybe I’m deskilling, I don’t know.”*** **Mira, 14/208**

Mira describes losing her sense of identity as a nurse and the impact of her pain on work performance. She also communicates a strong sense of belonging as being a member of the team at work. Mira’s concerns about her future as an employee are not isolated, Lynn also contemplates how much longer she will be able to continue her work as a social worker:

> ***"Coming back to work and saying "unfortunately, I have to have some more tests", you know, and keep putting, and, and, there's only so much that they can take."*** **Lynn, 16/240**

Lynn's first comment voices her concerns regarding how much longer her job is willing to support her on her physical health journey. Lynn's next comment speaks to her struggle of managing pain while working:

> ***"Erm, with regards to work, erm, yea, erm, I struggle. I struggle, erm, because it hurts. Because my back hurts. Erm, I, I find when I'm on visits, although I haven't been on that many since I've been back but… Erm, I've been on like a six-week phase return going back to work, erm, I, I try, yea, erm. A couple of my visits, I've had to do it in sections, because I've had to stop. Because my back hurts too much. Erm, my boss doesn't know that. Erm, I don't, part of me would love to have more time off work, erm, just to give me more time. But, I'll then go back to my GP to, erm, say I'm in huge amount of pain. Erm, my manager would not be impressed. My manager would not be impressed if I had any more time off. Erm, I am considering, erm, being pensioned off due to ill health. Erm, mainly the last two and half years, the whole time I've had off- and I've had a lot of time off, the whole time I've had off has been due to my bladder."*** **Lynn, 15/213**

Both comments made by Lynn attest to the impact of her pain on work and the fear of how her place of employment will respond to her chronic pain difficulties. Lynn puts her fear into context in the latter part of her comment when she acknowledges the time she has spent away from work during her bladder dysfunction. Her repetition of "Erm, my manager would not be impressed. My manager would not be impressed if I had any more time off" appears to confirm her fear for the consequences of her chronic pain since she already feels that she has pushed the limit with her workplace before having the implanted the device. For Mira and Lynn, it is evident that both women would like to continue working within their respective fields; however, their current experiences of chronic pain pose a threat to this being achievable.

"It affects my whole life" illustrates the way in which the women's' device-related chronic pain impacts every aspect of their lives. For participants, their chronic pain has a ripple effect, disrupting and changing familial, social and employee relationships. Participants take a significant amount of ownership for the difficulties they experience in these facets of their lives, which often leads to feelings of judgment, feeling like a burden and worry.

To conclude, the present superordinate theme explored the impact of chronic pain has on the emotional, cognitive and psychological experiences of women who are adjusting to chronic pain following sacral neuromodulation. The superordinate theme takes a personal perspective on the emotional impact and management of device-related chronic pain.

3.4. Superordinate Theme 3:

Living with a hidden disability: The challenge of lack of awareness

This superordinate theme takes a broader societal perspective to explore the impact of the specialist nature of sacral neuromodulation and the invisible nature of chronic pain for individuals who have undergone successful device implantation. It brings attention to the lack of awareness and validation from others via three subthemes: "Believe me", "Bionic Lady" and "Take it seriously".

3.4.1. "Believe me"

Lynn alludes to the disbelief that has surrounded her experiences of device-related chronic pain in contexts outside of her friend and family relationships:

> ***"Erm, and I feel like I can't actually be honest with anyone. Because, erm, then you start wondering whether or not they're thinking and feeling, they're thinking you're a hypochondriac. Because you're constantly, you know, it's either that or that, you know? Erm, it's horrible. It's, erm, yea."*** **Lynn, 17/241**

Lynn's use of the word "hypochondriac" appears to suggest that others have previously had reservations concerning her experiences of chronic pain. She questions whether others will believe her newfound pain especially since she has just overcome symptoms of bladder dysfunction. Her comments here echo the experiences she has had with her family:

> ***"I feel like, erm, do they believe me? Erm, do my parents believe me that I'm actually in the amount of pain I am in, which is why I can't actually go down and see them."*** **Lynn, 18/259**

It appears that Lynn's accounts confirm that disbelief is not confined to those within her immediate relationships. The experience of disbelief is further expanded upon by Hannah:

> ***"I mean, I've gotten told to see a psychiatrist by doctors! Because they said it's all in my head. They said it was all in my head. "There's no physical reason why my bladder muscles should not have worked and no reason why I now have pain from this device". You know they just say "we'll just put you through to psychology" because they think it's all psychosomatic. Like there's an emotional reason behind the pain rather than a physical reason.*** **Hannah, 6/167**

Hannah's experiences with the general population, including the medical community, emphasises her frustration concerning others believing her current experiences. Hannah's comment appears to reflect a distrust of the medical community which originated from her initial interactions during her experiences of medically unexplained bladder dysfunction and escalated as a result of her current medically unexplained chronic pain.

Another facet of this subtheme is participants' experiences related to the invisibility of the nerve stimulator and its related chronic pain. Mira articulates the impact of invisibility in her comments:

> ***"[The nerve stimulator] it's not something that's visible. It's only the scars that are visible and to be fair, and they're hidden by underwear and bikini bottoms, aren't they? It's like, it's like a silent thing, nobody knows it's there. Even when I'm out and about, nobody knows it's there."*** **Mira, 11/152**

> ***"Erm, coming here, when travelling to London, especially going home, because I don't, because I have to get the tube and the train, getting on the tube is horrific. People elbowing you, oh my God the pain when someone touches you on, you know, sort of, you get a jolt on the back, you want to turn around and swear at them, really, really loud. And that makes me a bit grumpy too. How I've not turned around and not thumped somebody before I don't know [laughs]. Again, because pain is something that's unseen."*** **Mira, 15/220**

Hannah describes the impact of invisibility on her interactions with others:

> ***"You know, they don't understand. People like to have a go at you and ask you to prove things and it's because, it because nobody knows. I mean nobody knows about the bladder struggle and nobody knows about the device pain. It's not like other conditions and treatment. And it affects your confidence going***

> ***out because you don't know what people will think or say when you leave. It's hard to understand."*** **Hannah, 6/161**

The impact of the invisible nature of the participants device-related pain is further magnified in their commentary concerning disability:

> ***"It's like a disability that no one can see, so that's hard. Because people think you have your device now you're fixed or you don't have a disability and well actually, the pain from the device really does impact your life. Yes, I am not wheelchair bound but I still have a struggle day to day."*** **Izzie, 4/112**

Mira also reflects on her views on disability:

> ***"And so, when, when people, when people say to me "do you consider yourself to have a disability?" I actually, I have to sit and think, "well do I have a disability?". Because in actual fact, I act like I don't but when you think about it and you look at the definition of a disability, "well actually yes I have". Because it does affect my day-to-day life, in a way. I can't, I can't, I can't go to the toilet in the way that you can and have a wee. And now that that's sorted, I have pain that affects my day-to-day life. So, does that make me, does that make it disability? Who knows?"*** **Mira, 11/154**

Izzie and Mira consider their identity as disabled individuals, as if they have fought to prove that disability is not always visible. I wonder if society's expectations of what defines disability, that is usually determined from what one can infer from an individual's physical appearance, has influenced their self-questioning of whether they meet the criteria to be labelled as having a disability. If so, this would explain participants' emphasis on identifying how their pain has a significant presence in their lives and affects their day-to-day life in their reflections. Hannah illustrates my thoughts in her next comment:

> ***"And I'm not allowed to use the disabled toilets when I'm out in the public as well. They're [others] are horrible. The public, they get very horrible. You don't even want to know the story. Some people they look at you…because I haven't got an arm or a leg missing…you don't want to hear what some people have to say when you come in and out of a disabled toilet and all of that. It's like I want to wear a sign that says "don't judge me".*** **Hannah, 5/148**

The extracts in the subtheme “Believe me” convey the struggle participants have of convincing others that they experience device-related chronic pain. This subtheme includes narratives of participants who feel dismissed by others. Interestingly, this subtheme brings forward a sense of distrust between participants and the general public, including the medical community. It seems that the participants’ distrust stems from not being heard or believed about their experiences whereas the general community distrusts participants’ accounts of experiencing pain following restored bladder function. “Believe me” also captures participants’ views on what it means to be disabled, mainly as chronic pain is not always evident.

3.4.2. “Bionic Lady”

Participants’ perceptions of how others see them with their implanted devices were discussed during interviews. The women’s new identity from living with the nerve stimulator serves as a source of laughter but also emphasises a lack of understanding and awareness. Lynn says:

> ***“So then with, with having the battery inside, erm, yea my friends call me the ‘Bionic Lady’. Erm, which…Well, it because, because I got something, I’ve got this mental thing inside me, that, that they think it’s funny because they think that they can turn me on and off when they’ve had enough of hearing my voice [laughs]. But, erm, it actually doesn’t work like that. But you know, they think it’s, yea. I mean, we laugh about it because it’s, I think its diff- yea its weird. It, its, you know not everyone has a thing like this.”*** **Lynn, 9/135**

Izzie, who describes a time when she experienced device related pain, shares how others perceive her now that she has the implanted device:

> ***“Erm, yea, like, at times it can be really difficult to focus or manage a class room full of students when you’re in agony. But you know, my students are really good. They think that I am a robot, they love it!”*** **Izzie, 4/97**

Interestingly, both women label themselves as mechanical. Being referred to as “Bionic Lady” or “robot” speaks to the specialist nature of the sacral neuromodulator and how the general population makes sense of the device. It also attests to how an individual’s identity is influenced by their bodies. While Lynn and Izzie find humour in their new identities, the unique nature of the sacral neuromodulator and the lack of awareness create more hurdles for other participants, for example, Hannah's next comment highlights that being different is not always a positive experience:

> ***"It's okay…If I'm around somebody I know, it's funny. When you're around people you don't know and it happens [the pain], people look at you funny, you know, "what is up with you?" and you feel like "okay, I am different …again".*** **Hannah, 5/133**

The quotes within this subtheme reveal that the sacral nerve stimulator has altered participants' identity for those who do not have the device. The extracts highlight that shifts in participants' identities stem from the nature of the device itself and its related pain. Although some participants find comedy in their new identities, others express that the lack of awareness regarding the device and the subsequent device-related pain create additional challenges for the adjustment to their chronic pain.

3.4.3. "Take it seriously"

All participants view their device-related chronic pain as a highly significant matter that deserves attention. "Take it seriously" focuses on participants' desire for more understanding and support concerning their persistent pain following sacral neuromodulation. Lynn gives an opening commentary to this subtheme:

> ***"With regards to the information that you collect, will this be looked into further? Will this be taken seriously and further research will look at this? In looking at why some people have pain and others don't, what they could do differently?"*** **Lynn, 23/334**

Mira also poses questions for the current research:

> ***"The, you know, ability for the sacral nerve stimulator to work. The reasons why it does and doesn't work, the reasons why some people do have pain and why some people don't. For example, on this side I had no pain at all, zero, no pain. And all of a sudden, it's on this side and its horrific. So why is that?"*** **Mira, 21/309**

The questions that Lynn and Mira have concerning the outcome of the current study elicits a sense of hope and disappointment. Both women spoke in an enthusiastic but firm tone suggesting that they are still searching for answers. The sense of disappointment I've picked up on seems to be associated with a lack of education, research interest and awareness which appears to be integral to the participants' experiences with the medical community. Jennifer writes:

> ***"It is discrete, you know you can put it in your pocket and no one knows. A lot of people don't even know what it is. They ask what's that and I'm like "it's my sacral nerve stimulator". I think there should be more education about it. Not just with the specialist but with all the medical doctors as well because it's getting more and more common.*** **Jennifer, 5/136**

Jennifer emphasises the disconnect between participants and the medical staff concerning the education and awareness of the sacral nerve stimulator and device-related pain. This disconnect is common amongst participants who stress the importance of having support from the medical community. Lynn articulates her reasons to fix the disconnect between those with device-related pain following sacral neuromodulation and the medical community:

> ***"But if you have more input, more support once you have the device inserted, erm, even I think would help with this problem. You would know you would have someone to talk to. You know whether or not it's normal, whether you need to see the consultant, some understanding, discuss the pain you know. So, I think psychologically it would be, it would be good. Because I didn't know, don't know what to do. Even for six months, it would really reduce people's anxieties and knowledge about this incredible device. And that's what it feels like, you're given a battery and off you go. "We've resolved your bladder problem, get on with it, you should be happy". It's like "I am but now I'm also left with another debilitating condition".*** **Lynn, 23/343**

Hannah, like Lynn, emphasises how she feels the medical team dismisses her chronic pain experience since the correction of her bladder function:

> ***"That's so important. Because there's no in between. You have this problem, you get surgery to fix the problem, and then there's another problem, the pain problem…and there's no appointment for another***

> ***6 months. It would be nice to have an in-between…have that support to check in and help you."*** **Hannah, 7/199**

> ***"And they get annoyed with us because we are emailing and stuff…they act like it's really normal to have the pain and you're just like "wow" because they seem like well "what she emailing us for, we fixed her bladder problems"."*** **Hannah, 7/207**

Hannah's frustration and sense of feeling let down by the medical community is also echoed by Emma in her following comments:

> ***"I have to live with this. Why do they ask you about how much pain you're in the hospital when they are not going to help you?! I risked my life for a surgery that has now left me "crippling" in a different way. You know it has benefits, there's good parts but there's bad parts and there shouldn't be any bad parts, it should just work. If you are going to put a foreign object in my body, it better work!"*** **Emma, 4/103**

> ***"You know, they [consultants] make you choose: "is it your bladder or pain that's more important to me", they are both important to me! But I appreciate that there's people out there doing research. You know they are very quick to slice you open but there's no after care, it stinks, there's no after care."*** **Emma, 4/111**

In contrast to the other participants and aligning with overall sentiments held by Izzie during her interview, she takes a sympathetic approach toward the medical community when she rationalises why consultants have not placed enough importance or attention to her device-related chronic pain experiences:

> ***"And no, the care team has never asked me about my pain levels, so. But that could be because they don't understand the device, you know, so you can't really blame them. You know in their eyes, I am fixed to a part where I can live my life. We aren't fixed, just a solution."*** **Izzie, 5/122**

The desire for participants to be heard is evident as they reflect on participating in the current study. The women describe feelings of validation which supports their experiences of a limited awareness of the sacral nerve stimulator and its device-related pain. Mira describes her participation in the current study:

> ***"It's quite good fun, isn't it? It's quite nice to tell somebody, it's almost like a counselling session. It's nice to be able to explain, you know, how it affects you to somebody who understands the condition and the pain. I can explain it people at work and they're like "yea, whatever". Because they don't understand. So, it's nice to be able to talk to someone who understands the condition and now the pain, definitely. It's an interesting condition because there's no real trigger. Just like the pain. Nobody knows."*** **Mira, 22/313**

Similarly, Hannah, Izzie and Emma also express a sense of validation:

> ***"I'm grateful that somebody is out there trying to make people realise "okay you put a surgical procedure in but how about checking up on people that have the consequences".*** **Hannah, 7/205**

> ***"It was interesting, it was nice. It was nice to talk about life after the device. It's nice to hear from people who understand."*** **Izzie, 5/130**

> ***"Erm, I just want to get some support. You know, it gets very depressing… I loved getting interviewed. I love it! In order to get pain management we have to do research. People have to start talking about and not be embarrassed by it. I liked this interview."*** **Emma, 4/109**

All three participants were appreciative that they could participate in the study. It appears that they have found it helpful to talk about their experiences and reflect on their adjustment to chronic pain following sacral neuromodulation.

The superordinate theme "Living with a hidden disability: The challenge of lack of awareness" focuses on the implications of living with chronic pain resulting from a specialist nerve stimulator device. In each of the subthemes, participants describe their frustration with the lack of awareness about sacral neuromodulation and persistent pain within the general population, leading to their desire for greater understanding and validation of their experiences.

3.5. Summary

This chapter provided an interpretative phenomenological analysis based on the interview transcripts of six women adjusting to chronic pain following successful sacral neuromodulation. The superordinate theme of "The Trade-off: Chronic Pain for Corrective Bladder Function" explored participants' reality of living with newfound persistent pain following the implantation of their corrective device while the superordinate theme "The Impact of Chronic Pain" focused on the experiential impact of chronic pain. The final subtheme in this chapter "Living with a hidden disability: The challenge of lack of awareness" highlights the social impact of living with the nerve stimulator and its consequence of chronic pain. In summary, there are two quotes provided by Izzie and Jennifer which encapsulate the findings and the purpose of this exploratory study:

> ***"You know I think people need to know that we aren't fixed, we just have a solution to the bladder problems and now there's pain to deal with from this solution."*** **Izzie, 5/127**

> ***"It was quite interesting because I've never really been able to share my experience before. It's really interesting and it's reminded me of what I've went through and the experiences of going through it. It's also reminding me how happy I am, how successful it's been for my bladder symptoms and how lucky I am. But its reminded me that I've come a long way but I'm still being held back by this new pain."*** **Jennifer, 5/141**

4.0. Discussion Chapter

This chapter presents a more interpretive focus of the research findings. I evaluate the analysed data to the existing body of literature. The superordinate themes discussed in the preceding chapter structures this section. I will also consider the research limitations, implications for clinical practice and suggestions for future research.

4.1. Discussion of Findings

This research intended to explore the lived experiences of women with persistent pain. The findings revealed that living with chronic pain is a multifaceted experience that extends beyond the physical body. Participants described the impact of chronic pain on their interpersonal and social relationships. The findings also shed light on how the women's previous bladder symptoms influence their current pain experiences.

4.1.1. The Trade-off: Chronic Pain for Corrective Bladder Function

Participants discussed their resolved bladder dysfunction with their nerve stimulator. These findings are consistent with claims that sacral neuromodulation is effective in correcting bladder problems (Cardarelli et al., 2012; van Kerrebroeck et al., 2007; Siegel et al. 2016; 2018; Sukhu, Kennelly & Kurpad, 2016; Tahseen, 2018). This superordinate theme provides new insight into what it is like to exchange one chronic condition for another.

4.1.1.1. "It works, but there's pain!"

The findings here are compatible with literature that links sacral neuromodulation with improved quality of life (Charalambous & Trantafylidis, 2009; Banakhar, Al-Shaiji & Hassouna, 2012; Das, Carlson & Hull, 2004; Tubaro, 2004). The data shows the women's enthusiasm for having their bladder symptoms alleviated. I have come across these expressions of gratitude in my clinical experiences. However, I noticed that during data collection the women were more open to discussing the benefits and costs of their devices. Healthcare's typical focus on the initial cause of symptoms rather than consequences could explain my observations of individuals being more reserved in expressing their chronic pain. Alternatively, participants may have felt more comfortable discussing their chronic pain during a dedicated research interview. Research demonstrates that power issues can plague consultant-patient encounters (Goodyear-Smith & Buetow, 2001; Nimmon & Stenfors-Hayes, 2016). As qualitative inquiries generally aim to shift power in favour of the participant (Karnieli-Miller, Strier & Pessach, 2009), this could account for the differences seen during data collection.

4.1.1.2. "New normal"

The findings here provide a glimpse into how the women are managing their new realities. Participants' describe an all-encompassing process that is synonymous with qualitative definitions of adjustment. I was struck by participants' openness to discuss the negative and positive aspects of their adjustment. Noted in the introduction, this is at odds with prior literature. Positive aspects of adjustment refer to participants' ability to reframe their negative experiences, for example both Izzie and Mira describe a positive attitude toward their device and chronic pain that appears to mediate their adjustment to chronic pain.

Unsurprisingly, not all participants share this sentiment. In support of Esteve, Ramírez-Maestre and López-Martínez (2007), adjustment to chronic pain appears to intertwine with an ongoing process of adaption and acceptance. Stage models of adjustment to chronic illness can contribute to attempts to explain the variation in the women's responses. Although these models are not well supported (Hoyt & Stanton, 2012), they propose that adjustment to disability occurs over four stages. The first, shock, describes the initial states of disability, followed by denial, a defence mechanism which can influence the experience of disability. The third stage, anger and depression, describes the reactions to psychosocial loss, that can lead to psychological distress. The final step is adjustment and acceptance. This last stage is not about an individual being content, rather, this stage refers to the recognition of the changed self and the new roles based on ones' new limitations. I argue that the differences in participants' responses reflect the women being at different stages of adjustment. However, I oppose the view that there is a systematic linear order to adjustment which the stage models imply (Kendall & Buys, 1998). Instead, I view adjustment to chronic pain as an ongoing, cyclical process.

4.1.2. The Impact of Chronic Pain

Participants communicated the experiential impact of their persistent pain. The findings revealed that psychological distress has consequences on interpersonal and social relationships and how the effects of chronic pain are similar to bladder dysfunction.

4.1.2.1. "It's very emotional"

The findings within this subtheme support the psychological effects of chronic pain as participants described a range of emotions and cognitive consequences during data collection. The women also confirmed findings from existing literature that demonstrated the adverse psychological impact of bladder symptoms (Kinsey et al., 2016). "It's very emotional" reveals how participants seesaw between feelings of guilt and self-blame. The presence of this emotion and this cognitive process is not unexpected. Callebaut, Molyneux and Alexander (2017) point out that guilt and self-blame have a mutual relationship in chronic illness. In this study, it appears that guilt mediates self-blame and vice versa. Guilt stems from beliefs that participants ought to feel grateful for resolving their bladder dysfunction, whilst self-blame derives from participants taking sole responsibility for the occurrence of their chronic pain. Participants attribute their pain to faults in their bodies, as they did with their bladder symptoms. The use of guilt and self-blame align with research implicating these factors as coping mechanisms to manage chronic illness (Bombardier, D'Amico & Jordan, 1990; Klein, Turvey & Pies, 2007).

Moreover, this subtheme is harmonious with research proposing that psychological factors reinforce chronic pain (Chan, Hadjistavropoulos, Carleton & Hadjistavropoulos, 2012; Esteve, Ramírez-Maestre & López-Martínez, 2007; Smith, Lumley & Longo, 1999). The emotional and cognitive responses of participants were identified in the Introduction chapter as factors that have been identified to amplify chronic pain and psychological distress. It was not the specific intention of this study to examine the underlying factors that maintain the chronic pain experience. However, in keeping with the biopsychosocial theoretical approach of adjustment, acknowledging the responses that may contribute to further chronic pain is necessary for developing a comprehensive understanding of adjustment to chronic pain following sacral neuromodulation.

4.1.2.2. “Gritted teeth”

An interesting outcome of the analysis that I did not fully consider before data collection was how participants manage their pain around others. The findings describe participants’ determination to hide their pain experiences which appear to stem from their history of bladder dysfunction. Despite there being no studies to support or refute the personalised experiences of the current participants it is conceivable that the women use “Gritted teeth” as a coping mechanism to defend against stigma. Stigma in chronic pain is not well understood, however, several existing studies attest to its presence (Cohen, Quintner, Buchanan, Nielsen, & Guy, 2011; De Ruddere & Craig, 2016; Williams, 2016), particularly when there is uncertainty, confusion or an absence of a clear explanation for pain (De Ruddere, Bosmans, Crombez & Goubert, 2016; De Ruddere, Goubert, Vervoort, Prkachin, & Crombez, 2012; Williams & Cella, 2012).

Judgements that arise from stigmas of chronic pain such as individuals being “complainers”, exaggerating their pain and presence of related disability, can affect wellbeing and encourage psychological distress (Freidl, Piralic-Spitzl & Aigner, 2009; Waugh, Byrne & Nicholas, 2014). In the findings, Mira, Lynn and Jennifer discuss consequences such as judgement, humiliation and frustration. The experience of “Gritted teeth” may occur as stigma encourages judgment on participants for having chronic pain, like their bladder symptoms, as both conditions not physically visible. To my knowledge, no other study explores the process of having a chronic disability that is treated successfully with an intervention that causes another chronic debilitating condition. Thus, the findings here are valuable for bridging the gap in the literature.

4.1.2.3. "It affects my whole life"

Noted in earlier sections of this thesis, chronic pain has broad social implications and these repercussions are also seen in bladder dysfunction. Most of this research examining the wide impact of chronic pain and bladder problems use quantitative methods and although my findings are generally well-matched with these studies, they differ in depth and detail. It is not my intention to reignite the quantitative-qualitative debate discussed in the Method chapter, rather, I want to consider how an exploratory qualitative approach highlights the consequences of chronic pain following successful neuromodulation.

The study's use of a qualitative methodology revealed that the impact of chronic pain on intimate, familial and broader social relationships closely links with participants' sense of self. The women discussed how their chronic pain started a cascade of other losses that disrupted their way of living and being. Some of these losses include employment, sexual intimacy and function, self-esteem and independence. Although the transition from bladder dysfunction to chronic pain and the parallels of these experiences is not evidenced in the current literature, the findings of a relationship between the sense of self and chronic pain were not wholly unforeseen. Charmaz's (1983) qualitative analysis found that there is a shift in the sense of self in chronic conditions that can foster feelings of being a burden due to a loss of hope and certainty. Charmaz (1983) also suggests that increased social isolation stems from a lack of independence and experiences of embarrassment result from perceptions of having little power over chronic conditions.

The women in the current study are aware that they are not able to participate in things they value, for example, Mira and Jennifer discuss not being able to interact with their children and a diminished ability to participate in sports, social events and in intimate relationships. As the social relationships we have with others maintain the sense of self (Oyserman, Elmore & Smith, 2012), these shifts intensify the immobilising effects of chronic pain and impede adjustment (Harris, Morley & Barton, 2003).

The findings concerning marital and familial functioning reinforce the social context of chronic pain. Mira, Lynn, Hannah and Jennifer discuss the feelings and behaviours of their partners and children that have surfaced with their chronic pain. Highlighted in the Introduction chapter, the Family Systems Theory (1978) contends that individuals are inseparable from their system of relationships, thus, there is a dynamic back and forth effect between an individual and their larger system. As the family is proposed to be a single emotional unit, the qualitative methodology employed in this study allowed for the exploration of how participants perceive the presence of chronic pain and how it impacts their family system.

Current literature has established that lower levels of familial and spousal support are associated with increased pain intensity and maladaptive adjustment (Evers, Kraaimaat, Geenen, Jacobs & Bijlsma, 2003; Jensen, Ehde, Hoffman, Patterson, Czerniecki & Robinson, 2002; Koopman, Hermanson, Diamond, Angell & Spiegel, 1998; López-Martínez, Esteve-Zarazaga, Ramírez-Maestre, 2008; Turk, Okifuj & Sharff, 1995). In agreement with the biopsychosocial model, it is essential to consider the family system as chronic pain can cause structural and emotional skews in intimate and family relationships that can maintain and perpetuate chronic pain problems (Turk, Kerns & Rosenberg, 1992; Leonard, Cano & Johansen, 2006; Lewandowski, Morris, Draucker & Risko, 2007; Rolland, 2007). Paying attention to how the family system functions, for example isolation from the community and strained interactions among family members, can help identify vulnerabilities that support the presence of participants' chronic pain.

4.1.3. Living with a hidden disability: The challenge of lack of awareness

This superordinate theme emphasises a lack of awareness and education about chronic pain following sacral neuromodulation. The findings here illustrate that participants are not immune to the impact of misinformation and judgement from the general public. Like the other superordinate themes, participants compare their experiences of bladder dysfunction to their experiences with the nerve stimulator and described having to endure the same challenges of living with a hidden disability and a lack of awareness.

4.1.3.1. "Believe me"

Most women discussed the perils of unseen chronic pain and what it is like to live with a condition that is invisible to the general public and healthcare professionals. Participants have been labelled as hypochondriacs or suffering from psychosomatic symptoms because their chronic pain is not outwardly visible.

On the one hand, participants seem to be content that their chronic pain is not directly visible as they are "normal again" since their bladder dysfunction has been resolved. On the other hand, the invisibility of pain creates difficulties with the public, for example, even for those who know about participants' chronic pain, they are not aware of it all the time as it remains invisible in their encounters with participants. At these moments, the women appear to struggle for acknowledgement which mirrors their past with bladder symptoms.

Having an outward appearance that can pass as "normal", the invisibility of participants' pain is not always desirable and this leads to the women questioning their status of having a disability. The women appear to continuously fend against society's constricted views of disability and advocate for further awareness and education around the definition which under the Equality Act 2010 is an individual that has "a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities" (Legislation.gov.uk, 2010). Moreover, the findings agree with the wider expressed view that people with invisible conditions often have to fight for understanding from others as reactions of stigma and judgment arise from the medical and broader community (Cohen, Quintner, Buchanan, Nielsen & Guy, 2011; Joachim & Acorn, 2000; Stone, 2005; Tait & Chibnall, 1997). If the participants are struggling with having their chronic pain acknowledged, much like their bladder dysfunction, this undoubtedly will hinder their adjustment process.

4.1.3.2. "Bionic Lady"

Living with the implanted device has forced participants to educate others about the purpose and function of their nerve stimulators. The women discuss how their devices effect how they perceive themselves and their identity. It appears that there is a split in perception as some participants use humour to illuminate the positive elements of adjustment and other participants feel that the nerve stimulator alienates them from the public as they once again become "different", similar to their experiences with bladder symptoms.

My findings support the research findings by Ghojazadeh, Azami-Aghdash, Sohrab-Navi and Kolahdouzan (2015), who focused on the lived experience of twenty-seven individuals with cardiovascular pacemakers. Like the present study, the qualitative approach Ghojazadeh et al., (2015) revealed that participants were conflicted about living with their pacemakers, as they held both positive and negative feelings towards their implanted devices.

Thomson, Martin and Sharples (2013) investigation of how medical devices were integrated into individuals' lives found that positive and negative attitudes towards the participants' device was dependent on its psychosocial impact such as their ability to participate in social activities, the impingement on self-esteem and participants' constant comparison of themselves to others in a less favourable way, which fostered feelings of embarrassment and powerlessness. In contrast, other participants indicated that their devices served as sources of humour and brought them into social interaction. The findings emphasise how perceptions of the device and its impact on identity, positive or negative, influences the adjustment to chronic pain.

4.2.3.3. "Take it seriously"

The findings here link closely with the subtheme "Believe me" as this subtheme reflects the women's desires to have more understanding and support for their chronic pain after successful sacral neuromodulation. This subtheme emphasises participants' feelings of frustration and disappointment with the medical community who are unfamiliar with the nerve stimulator and its adverse effects. Unsurprisingly, the women disclosed that their encounters with healthcare practitioners often left them feeling dismissed, or that they are ungrateful as they should be content that their bladders symptoms are "fixed". Participants also feel forced into a position of having to choose between a life with chronic pain or removal of the device for a life with bladder dysfunction. Despite their experiences, I was struck by the participants' sense of hope towards this research and their expression of gratitude for being interviewed by someone from within the healthcare community "who understands" and can validate their experiences of a lack of awareness toward their hidden disability.

We know that individuals value the expertise of healthcare practitioners but want to be equally acknowledged, validated, and respected (Bastemeijer, Voogt, van Ewijk & Hazelzet, 2017; Bramley & Matiti, 2014; Evers et al., 2017; Goodrich & Cornwell, 2008; Patient Opinion, 2016; Pomey, Ghadiri, Karazivan, Fernandez & Clavel, 2015), thus recognising this subtheme can minimise the adverse effects of adjustment to chronic pain by encouraging a more positive patient-consultant experience that can facilitate adaptive cognitions, emotions and ultimately the process of adjustment.

4.2. Anticipation of Criticisms

Yardley (2000; 2008) outlined four principles for assessing qualitative research: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. As the Methodology chapter considers these guidelines and its adaption to the current study, this next section will focus on potential research limitations. Despite my efforts of applying Yardley's (2000) characteristics, upon reflection, there are some limitations of the current study's design and analysis which may potentially impact the robustness of the current research. However, before I discuss the potential criticisms, it is important to note that the current study has several theoretical, practical and ethical strengths. First, this study is primarily concerned with individuals' experiences of adjustment to chronic pain following the successful implantation of a nerve stimulator that regulates bladder dysfunction. The analysis only focused on participants' lived experiences, addressing salient issues that appear to influence the women's process of adjustment. Theoretically, this qualitative study provided the opportunity to gather insight into the women's experiences by utilising methods that would gather in-depth data. Because of this, the participant-led interviews attest to the validity of their experiences. Practical advantages of this study stem from my ability to access this participant group, who may have been opposed to formal quantitative methods. The ethical benefits of this study refer to participants being equal in the researcher-participant relationship, allowing the women to speak for themselves when discussing the sensitive topic at hand.

4.2.1. Methodological Issues

Although I have mentioned the limitations of IPA in the Methodology chapter, one notable limitation is the small sample size. Typical of IPA research, a smaller sample encourages an in-depth exploration of lived experience, however, a small number of participants restricts the current study from making certain conclusions about the experience of adjustment to chronic pain. Sharing the same purpose of IPA (Smith, 2004), the focus of this research was to gather rich data concerning lived experience rather than focusing on creating generalizable claims. Therefore, the findings of my study do not imply that the experiences elicited in the analysis are accurate for all individuals living with chronic pain following sacral neuromodulation. Instead, my findings should read as exploratory evidence highlighting the commonality amongst participants experiencing this phenomenon.

Another anticipated criticism of this study concerns the makeup of the current sample. Smith, Flowers and Larkin (2009) advocate for relatively homogeneous samples in IPA research. The current study met homogeneity as the women that participated in data collection had undergone sacral neuromodulation to correct their unexplained bladder dysfunction and experience chronic pain from their devices. While I acknowledge the participants in this study were heterogeneous in many ways, for example, age, occupation and nationality, this study aimed to explore the inner-worlds of participants, and not make specific conclusions about factors influencing adjustment to chronic pain.

Furthermore, as mentioned in the Methodology chapter men were not excluded from this study, but women were expected to dominate the sample as sacral neuromodulation is commonly used in women and as Chester and Glass (2006) highlight, women are more open to discussing their vulnerabilities that relate to more sensitive and emotive issues. Because of this, a potential criticism is that this study provides insight into women's experiences rather the experiences of both men and women. Although this can be perceived as a limitation, I argue the that the inclusion of men in this study would make the sample less homogenous.

The current study has a broad focus in that it provided insight into the various aspects of adjustment to chronic pain following the success of sacral neuromodulation. Gaining an understanding of the multiple factors involved in the adjustment to chronic pain aligns with the exploratory design of this research. These types of studies are useful for addressing topics that have a paucity of literature on the subject matter (Singh, 2007) and are appropriate for identifying the current state of a problem that is not very well understood (Burns & Bush, 2006). Employing this design did not allow for the opportunity to examine in-depth some of the critical factors that came out of the analysis, however, this research did not intend to offer final and conclusive answers to the research problem but rather explore these experiences with varying levels of depth.

4.2.2. Analytical Issues

As described in detail in the Methodology chapter, IPA was deemed the appropriate choice for generating knowledge of the subjective experiences of adjustment to chronic pain after sacral neuromodulation. Unsurprisingly, IPA has not gone unchallenged by researchers, for example, IPA is said to be ambiguous and lacking standardisation (Giorgi, 2001).

Other criticisms concern IPA's dependency on language as it is suggested that language constructs and shapes experiences rather than describe the reality of the experience (Willig, 2001), therefore, IPA becomes potentially exclusive as it requires participants to be able to articulate the meaning of their realities effectively. The dependency on language further links to Willig's (2001) criticism that IPA focuses on how individuals experience things rather than why. Regarding the current study, this debate of "explanation or description" suggests that IPA merely provides a rich understanding of participants' experiences of adjustment to chronic pain after sacral neuromodulation instead of explaining how this lived experience that is taking place. However, I argue that the emphasis IPA places on language allows researchers to consider how participants communicate their experiences, paying attention to the nuances of their speech, which allows researchers to ascertain a greater understanding of how participants experience their inner worlds (Smith et al., 2009).

Furthermore, researchers attest to IPA's ability to capture embodied experiences despite its reliance on language (Brocki & Wearden, 2006; Gillies, Harden, Johnson, Reavy, Strange, & Willig, 2004), for example, participants in the current study would show parts of their bodies while verbalising their experiences. This counters Willig's (2001) other criticism that participants may have difficulties expressing their experiences through language. In the current study, the women were all able to use language and non-verbal communication to provide vivid, in-depth understandings of their inner worlds, despite ranging in educational backgrounds. Finally, IPA's concern with cognition, as it focuses on what a participant thinks or believes about their experiences, is another source of criticism. It is argued that a cognitive focus is not compatible with some aspects of phenomenology (Willig, 2008), however, Smith et al., (2009) reject this claim by arguing that sense-making and meaning-making, resonates with phenomenology (Pringle, Drummond, McLafferty & Hendry, 2011).

4.3. Clinical Implications of Findings

The purpose of this thesis was to explore individual's experiences of adjustment to chronic pain from an implanted device that corrects bladder dysfunction. Although specific hypotheses did not drive this research, so the findings here should not be perceived as absolute empirical truths, my study offers suggestive evidence for how individuals experience the exchange of one chronic difficulty for another. There appear to be many factors that influence the adjustment to chronic pain following sacral neuromodulation. If future studies confirm my tentative conclusions, then the findings support the need to change from the traditional medicalised view of healthcare which has a history of solely focusing on physical discomfort and omitting or minimising the broader psychosocial suffering experienced by individuals.

Firstly, by bridging the methodological and knowledge gap in the current literature, the current research makes an original contribution to the field of Counselling Psychology. This research can be used to inform current uro-neurology practice as well as those medical specialities not linked to psychology services. The findings here go beyond the specialist population I have explored as we can reflect on how we deliver care to individuals. As evidenced in this study, research tells us that compared to the general population, people with physical health problems have twice the rate of mental health difficulties and have a higher risk of self-harm (Narasimhan, Raynor & Jones, 2008). Conversely, higher rates of chronic diseases and physical conditions are seen in individuals with severe mental illness (De Hert et al., 2011; Robson & Gray, 2007). Thus, this relationship between the body and mind calls for the need for an integrated approach to care. In fact, throughout this research I have found myself naturally drawing towards the growing specialty of liaison psychiatry, which recognises the mind-body interplay and how managing multi-morbidity requires a multi-disciplinary way of working (Tadros et al., 2013; Wahass, 2005).

This study adds to the discipline of psychology by reminding psychologists to remember that individuals are complex entities, influenced by many factors. When presented with clients we can quickly fall into the trap of focusing on one aspect of an individual's life. Mental health, physical health and sociocultural factors are not isolated from one another but work together to produce what we see in sessions. It may not be apparent on face value, but I argue that this research upholds the very tenets of the discipline of psychology which is to understand all aspects of the relationship between thinking, behaviour and how one functions (Goodwin, 2011). Specific to practice, the findings of the current study give insight into how Counselling Psychologists can therapeutically facilitate adaptive adjustment by working on the physical and psychosocial issues that individuals experience.

Furthermore, participants talked about a lack of support for their pain after receiving their nerve stimulator. As research advocates for postsurgical support (Simpson, Duenas, Holmes, Papaioannou & Chilcott, 2009), an implication of these findings is to give individuals the opportunity to discuss their met and unmet expectations of their nerve stimulators. Rather than having care teams solely focusing on the functioning of the nerve stimulator, postsurgical support could focus on factors that are associated with maintaining pain-related disability and hindering adaptive adjustment. This can be achieved with psychological interventions targeting factors such as acceptance, cognitions and social isolation.

As I discussed in the Introduction chapter, this study did not intend to argue that Counselling Psychologists were the most suited of applied psychologists to work with this population. Rather, this research intended to encourage Counselling Psychologists, in training or qualified, to be more comfortable in roles traditionally dominated by our counterparts, or to feel confident enough to undertake roles not established in diverse medical specialities. It may be that my personal interest motivates my desires to see more Counselling Psychologists in roles within hospitals and medical care. Even so, Counselling Psychologists have the tools and capabilities to practice in this field and work as part of a team with other applied psychologists in primary, secondary and tertiary care.

While I do not want to boast about the uniqueness of Counselling Psychology as I have mentioned earlier in this thesis that is often divisive rather than unifying, I do acknowledge our differences and their advantages. Some of the major perspectives in psychology include, cognitive, behavioural, biological, evolutionary and humanistic approaches, therefore, instead of seeing a single perspective as ideal, Counselling Psychology is integrative in that it considers each perspective to understand an individual (Strawbridge & Woolfe, 2010). The advantage of Counselling Psychology's integrative underpinning is that we are a natural fit for working within settings utilising the biopsychosocial model. A prime example is our strength in dealing with adjustment to change as we are philosophically inclined to think about the interplay between personal well-being, social relationships, health and the other aspects of one's life.

Finally, as the current findings suggest that a lack of awareness is a salient issue for participants an implication of this research is teaching, training and consultation for health professionals, NHS organisations and the broader community. Counselling Psychologists are well trained in consultation, which can inform and guide care options regarding the psychological well-being of individuals (Karademas, 2009). The ripple effects of teaching, training and consultation can lead to supervision and further research on the adjustment to pain following successful sacral neuromodulation that could produce changes in how this population is assessed and treated.

4.4. Reflections on Novel Findings

The superordinate themes “The Trade-off” and “The impact of Chronic Pain” supports current literature exploring the impact of chronic pain on individuals’ daily lives. The superordinate theme “Living with a hidden disability” reflects the novel insights provided by this study as it emphasises the many challenges participants face living with a condition that is not visible. What is surprising about the findings here is that participants choose to continue living with the neuromodulator despite its consequence of chronic pain.

What motivates the participants to endure their unforeseen persistent pain may relate to their views on choice. Sacral neuromodulation is used when other medical interventions have not been successful in mediating bladder symptoms, thus the women may feel that their implanted device is their last interventional effort to control their bladder dysfunction. This restricted sense of choice is reflected in participants ongoing questioning of whether to remove their modulators. Another motivating factor to continue living with the battery is the sense of freedom that is offered by the device. Noted in the findings, it appears that the improvements to bladder symptoms offered by sacral neuromodulation may encourage the women to tolerate their chronic pain as they can remain in control of bladder symptoms which was previously unattainable.

As the women in this study have withstood living with two long-term conditions, it is plausible that their chronic symptoms have integrated into their identities, for example, participants describe changes in their social roles and inability to participate in desirable activities and plans. This erosion to participants’ sense of self may contribute to their choice to live with their devices as they have been defined by their symptoms for so long, thus, who would they be if they did not choose to live with the persistent pain from the device? It is possible that there is an element of secondary gain which refers to the advantages that occur secondary to chronic symptoms when transitioning into a sick role. As research suggests that chronic symptomology challenges how individuals perceive themselves and their social roles (Oris et al., 2018) participants’ choice to live with the device and its consequence of pain maybe influenced by any perceived benefits to their suffering.

Finally, the stigma surrounding invisible conditions may support the willingness of participants to live with their device-related chronic pain as each participant expressed the desire to have both their previous bladder dysfunction and current pain experiences validated.

4.5. Recommendations for the Future

This project intended to generate data exploring participants' needs, behaviours and experiences without fully understanding what data would be meaningful. My successors, myself included, must consider these findings to inform future avenues of investigation. To support future action, I recommend suggestions for clinical practice and policy, academic training and future research.

4.5.1. Clinical practice and policy

Health care practitioners typically treat individuals with chronic pain within a framework of care that is more suited for acute conditions (Charmaz, 1983). As such shifts in clinical practice and policy that encourage effective treatment aimed at reducing pain and the prevention of maintenance cycles that further pain-related disability would be recommended. This flexible way of working would include a multidisciplinary approach that includes psychology, to provide a wide variety of clinical interventions that address some of the factors that have derived from the analysis, for example, the inclusion of psychological therapeutic interventions and the use of standardised clinical tools that can assess biopsychosocial impacting chronic pain.

My recommendations for clinical practice and policy are ambitious and I am aware that change of this level will take a considerable amount of time and effort to implement as our health service has been designed for individuals who have single health problems. Since the Health and Social Care Act 2012 we are beginning to see mental health as having an equal footing with physical health, however, the reality is that to see an equal standard of care, which will encourage policy change on a national scale, there needs to be continuous research that emphasises the mind-body relationship. For individuals within the current study's population, this recommendation would mean that uro-neurology services could unify a diversity of disciplines, including psychology, into an integrated team that can promptly manage individuals' clinical needs.

4.5.2. Academic Training

It will be a disservice if training of the next generation of Counselling Psychologists ignores the bidirectional relationship between physical and mental health. This research attests to how these areas are inextricably linked and how participants demonstrate that the separation of the two has led to imbalances and barriers in their experiences. It appears that post-graduate and doctoral courses in Counselling Psychology are slow to implement and encourage health-related modules and practice (Karademas, 2009; Stedman, Hatch, Keilin & Schoenfeld, 2005). This may stem from our humanistic underpinnings or our constant efforts to manage our identity as a profession. Whatever the reason, the implementation of physical health in courses of Counselling Psychology is appropriate as we are meant to focus on all aspects of one's life to facilitate growth. It should be noted that this training should not be limited to postgraduate and doctoral courses in counselling psychology but also in other disciplines (Glew & Chapman, 2016) if we are to acknowledge the interplay between physical and mental health adequately.

4.5.3. Future Research

The current research could be extended by focusing on specific variables demonstrated in the analysis. Without further research into certain aspects of the current participants' lives, it will be difficult to corroborate the experiences of individuals adjusting to chronic pain following successful sacral neuromodulation. All superordinate themes of this study provide possible areas for further investigation, for example, in "The Trade-Off" the concept of self-blame was salient in participants' experiences. Further research could explore what encourages this belief and how this influences adjustment to chronic pain after sacral neuromodulation.

The superordinate theme "Living with a hidden disability" emphasises that participants' interactions with others and the lack of awareness surrounding their device is a salient factor in adjustment to chronic pain. Future opportunities for research can focus on issues such as stigma. At present, there is a lack of literature addressing stigma and pain. Research has not given much attention to the causes and underlying mechanisms of stigma or how to mitigate its effects on the process of adjustment to chronic pain (De Ruddere & Craig, 2016).

Factors identified in "The Impact of Chronic Pain" and existing literature could focus future research on how to achieve better practice. Research could concentrate on the development of reliable and valid measures related to the psychological impact of chronic pain. These tools could be used to assist in facilitating adaptive adjustment to persistent pain by informing psychological practice with this population. Moreover, these findings could drive research that empirically tests and evaluates interventions that could be used with individuals adjusting to chronic pain after sacral device implantation.

As evidenced in the current findings some participants could be helped to reframe their negative experiences and have more of an appreciation towards their device. As we tend to see literature focusing on wanting to 'fix' problems, perhaps future prospects for research can concentrate on the positive aspects of adjustment and how they influence the process. The intention here is to develop an understanding of these strengths and use them as therapeutic targets to facilitate adaptive adjustment to chronic pain following bladder dysfunction. Hurt and colleagues (2014) provide an example of this kind of study in their investigation exploring the relationship between optimism, illness perceptions and wellbeing in Parkinson's disease (PD). The authors utilised questionnaires measuring optimism, illness perceptions, mood and health-related Quality of Life in 109 individuals with PD. Multiple regression analyses revealed optimism moderates the effect of maladaptive illness perceptions, counteracts the consequences of disease progression and predicts better well-being. The findings indicate that optimism allows for a more adaptive experience of adjustment as it may prevent negative illness perceptions and increase mood and Quality of Life. By focusing on the positive aspects of adjustment, this study demonstrates how therapeutic interventions could focus on enhancing optimism to maximise adaptive adjustment in PD. Like Hurt et al., (2014), future research could explore the specific strengths and positive attributes of participants such as their use of forgiveness and acceptance that appear to protect against the negative experiences adjustment to chronic pain following sacral neuromodulation to inform therapeutic interventions.

Given potential methodological and analytical criticisms, it would also be valuable to conduct this study on a larger scale. Conducting this research might allow for a deeper insight into the process of adjustment to chronic pain after bladder dysfunction. A large-scale study could include input from men or explore experiences across different contexts. A more extensive study may also take the form of a longitudinal approach, where data can be collected from participants experiencing bladder dysfunction and shortly after receiving the device when participants may be experiencing chronic pain. A longitudinal study will allow for a more comprehensive understanding of the process of living with chronic pain following sacral neuromodulation. I would also encourage future research to explore different methods of data collection. Although the current study's use of diary entries did not go as planned, which may attest to the nature of chronic pain and its effects on the cognitive load which may have hindered participants ability to fill out the diary templates, utilising other methods, qualitative or quantitative could further the understanding of this phenomenon.

Future research could also explore the experiences of Counselling Psychologists who work within medical settings traditionally dominated by other applied psychologists or perhaps who are forging a way to provide psychological services not yet established in medical specialties. Little is known about these experiences (Mrdjenovich & Moore, 2004) and this is worth exploring. It may be that Counselling Psychologists' experiences influence the process of adjustment as the current study brings attention to the impact of practitioners on participants' experiences.

4.6. Research Reflections

In the Methodology chapter, I spoke about the difficulties regarding participant recruitment and data collection. Reflecting on the research process I also realise my experiences of planning, conducting and writing up this project has also had significant effects on me.

As a novice researcher, I found the idea of producing my research incredibly daunting. There were moments throughout my training where hearing the word “thesis” would instantly evoke fear and a sense of panic. It was not until writing this final chapter that I began to undoubtedly draw similarities between participants’ experiences of adjustment and my own. The unexpected practical and methodological problems that arose during the execution of the research led to me feel that conducting this research was impossible. At each stage of the research process, I felt that I had to navigate my way around multiple barriers. Of course, I would have been naïve to think that the entire research process would have been completed without any difficulty, but like my participants, I had not expected so many unexpected consequences. At one stage I reached a point where I started to lose genuine passion and desire for my research and I lost my motivation of wanting to provide a piece of work that could help others. Instead I began to view this project solely as a means of qualification. When I was not able to fully engage in my research, I sought out supervisory and personal support to help me through this process. Being able to discuss how I felt openly, without judgement helped resolve the problems I was facing and restored a sense of purpose in my research. I felt this same sense of validation my participants described during data collection. Particularly during the latter parts of their interviews and within the subtheme “Take it Seriously”.

Writing this chapter was challenging for me. I often found myself reflecting on what it means to bring this research to a close. This final chapter represents more than the end of a thesis but also signifies that I too am on my final chapter as a trainee Counselling Psychologist. Writing this Discussion section has brought feelings of excitement and relief but also fear and sadness. I sometimes question whether I am “doing this right” and if my research is of any value. However, I have come to realise that my self-questioning and mixed feelings derive from the reality of my process of adjustment. I am making the shift from having multiple placements every week for the past three years to adjusting to the prospects of being a qualified, autonomous practitioner. Like so many of my participants, I have been future-focused and striving toward the outcome of qualification, which has been a constant source of anxiety. However, I do take comfort in knowing that despite my initial fears of conducting research, I have persevered. I have had to adjust to the problems of this research and the ongoing difficulties in my personal life, which was not easy to achieve.

This research study has shaped me in many ways as I have been required to engage in personal and professional support throughout this process, something I have struggled to do in the past. I have always tried to manage on my own and like participants endure with “Gritted Teeth”. Because of this research, I am more comfortable with asking for help and expressing my concerns with others. In professional practice, I find myself attending more to the body, I hold a more holistic view of clients and endeavour to include all aspects of one’s life during client formulation. Finally, this research has emphasised how I would like to develop my future career in an area where mental and physical health are intertwined.

4.7. Concluding Remarks

This thesis intended to explore the experiences of living with chronic pain resulting from a device correcting bladder dysfunction. The findings offer new insights into the parallels of two long-term conditions in the context of being moderated by an implanted device. We now have awareness into how device-related chronic pain affects individuals and how previous bladder dysfunction frames these experiences. We also now understand how participants' perceptions and expectations towards their nerve stimulator influence experiences and perceptions of adjusting. I attempt to bridge the research gap of what is not fully understood in the disciplines of psychology and medicine while also addressing the importance to Counselling Psychology. My hopes for this research is to highlight the need of supporting individuals within this population and advocate for the integration of Counselling Psychology within medical settings.

5.0. References

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Part Two

Jumping the Hurdles: The Race to Independence

The Professional Practice Component of this thesis has been removed for confidentiality purposes.

It can be consulted by Psychology researchers on application at the Library of City, University of London.

Part Three

Adjusting to Chronic Pain after Sacral Neuromodulation: An Exploratory Study

6.1. Foreword

This publishable paper has been written for submission to *Psychological Medicine.* The article follows the journal's formatting recommendations and guidelines. Thus, this piece adheres to recommended word limit of 4500 words (excluding the abstract and reference list) and the Harvard System referencing style (See Appendix N for guidelines). As noted in the preface, the selection of this journal was based on three key reasons. The first concerns Psychological Medicine's commitment to include a range of disciplines that relate to physical health. The second reason is for the journal's international reputation, varied audience and high impact factor. Finally, this journal allows the opportunity for Counselling Psychologists to contribute knowledge on the interface of psychology and physical health.

6.2 Abstract

Background: Sacral neuromodulation (SNM) is the preferred surgical method in correcting symptoms of bladder dysfunction. One notable and unexpected consequence of SNM is device-related chronic pain. This study is the first to explore individuals process of adjustment to chronic pain following successful SNM. This study aims to explore the psychological processes and mind-body interactions that influence the adjustment to chronic pain caused by a device that resolves bladder problems.

Methods: 6 female participants who had experienced device-related chronic pain for at least six months after SNM device implantation were recruited. A qualitative design using semi-structured interviews and diary entries was selected, data were analysed using Interpretative Phenomenological Analysis (IPA).

Results: The findings yielded three superordinate themes: "The Trade-off: Chronic Pain for Corrective Bladder Function", "The Impact of Chronic Pain" and "Living with a hidden disability: The challenge of lack of awareness". Subthemes that reflect participants shared experiences accompany each superordinate theme.

Conclusions: New insights into the intricate process of adjustment to chronic pain after bladder dysfunction emerged. The findings revealed that both individual and societal factors influence participants' adjustment. These exploratory results are discussed, and recommendations for clinical practice, particularly for the discipline of Counselling Psychology and future research are given.

Key Words: Sacral neuromodulation, adjustment, chronic pain, IPA, qualitative, Counselling Psychology

6.3. Introduction

The relationship between the mind and body has received significant attention over recent years (Mehta, 2011) mainly as our health service is beginning to integrate physical and mental health care. One condition that reflects the mind-body relationship is chronic pain, discomfort that persists beyond normal healing time. Chronic pain appears to have a reciprocal relationship with psychological experiences, that is, the psychological and social consequences of persistent pain influence pain perception and can maintain the physical experience of pain (Tedstone, et al., 2008; Arvidsdotter, et al., 2016; Zanini, et al., 2018). For example, pain-related cognitions, emotional distress and personality factors can intensify the experience of pain and pain-related disability (Chan, et al., 2012).

The affective and evaluative components of pain can affect an individual’s process of adjustment. Psychological adjustment can refer to the psychosocial factors that influence the ability for individuals to learn how to resume “normal” functioning (Jensen, et al., 1991; Geisser, et al., 1999; Jensen, et al., 2011). We know that psychosocial factors can impede on how an individual adapts to pain, however, the psychological adjustment to chronic pain has not been extensively studied.

Despite the increasing recognition of the mind-body relationship, there is limited research exploring individuals’ experiences of living with implanted medical devices, for example, implications of chronic pain-related adjustment after sacral neuromodulation. Sacral neuromodulation (SNM) is an electronic mechanism that facilitates accurate communication between the bladder and brain to mediate unexplained bladder symptoms. In bladder dysfunction, messages sent between the bladder and brain are either inappropriate, unwelcomed or erroneous and SNM restores bladder control by generating electrical pulses between the two systems. One of the notable adverse effects of SNM is chronic pain (Sukhu, et al., 2016; Siegel, et al., 2018; Tahseen, 2018), which manifest as painful jolts or shocks which occurs at the implantation site and radiates to the lower parts of the body.

The current study attempts to bridge the gap in the current literature by gathering knowledge about the experiences of adjustment to chronic pain following SNM. The objective is to investigate the physical, psychological, and social impact of device-related pain by exploring individuals’ experiences of chronic pain following successful sacral neuromodulation?

6.4. Methods

6.4.1. Design Overview

In contrast to research that attempts to predict outcomes or explore differences between groups of individuals experiencing chronic pain and adjustment (Lazarus, 1969; Breivik, et al., 2006), this study employs a qualitative approach to answer the research questions. A multimethod approach using semi-structured interviews and diary entries allowed for the discovery of in-depth insights into participants' experiences. Dairy entries mimicked the properties of the semi-structured interviews by having prompts that would allow participants to engage in their present experience. Interviews were either conducted in person at a central London hospital or via an online application and diary entries were completed the immediate 14 days following the interview. Six individuals who were experiencing self-identified chronic pain for at least six months' post-device implant interviewed between 40-75 minutes. The interviews were recorded and transcribed by the researcher and both forms of data collection were analysed using Interpretative Phenomenological Analysis (IPA).

6.4.2. Participants

On the confirmation of ethical approval sought and confirmed by City, University of London and the National Health Service, six women were recruited who had been experiencing pain for at least six months, had no other implanted device or other cause for chronic pain. Participants ranged between 23 and 46 years old and 5 participants identify as 'White British' and 1 as 'White American'. Table 5 provides an overview of participants, including their pseudonyms and demographic information.

Pseudonym	**Gender**	**Age**	**Occupation**	**Ethnicity**
"Mira"	Female	40	Registered Nurse	White British
"Lynn"	Female	46	Social Worker	White British
"Jennifer"	Female	31	Part-time Sales Assistant	White British

“Hannah”	Female	23	Receptionist	White British
“Emma”	Female	43	Unemployed	White American
“Izzie”	Female	32	Teacher	White British

Table 5: Demographic Information of Participants.

6.4.3. Procedure

All Semi-structured interviews were conducted in the same way regardless of whether they were in person or online. Once participants expressed interest in participating they were briefed on the aims and objects of the research before consent was acquired. The interview began with the question “To begin with, could you give me a brief history of your bladder problem from when it started to opting for SNM treatment” which continued with an interview schedule that allowed participants to contextualise their experiences (Smith, et al., 2009). Following the interview, diary entries were introduced accompanied with a completed example and thorough explanation of how to fill in the diary template.

6.4.4. Analysis

Analysis of data followed steps proposed by IPA (Smith, et al., 2009) and adhered to Yardley’s (2000) criteria for evaluating the quality of qualitative research. Except for diary data, the first step was the verbatim transcription of each recorded interview at the semantic level which included pauses and vocalised non-lexical utterances such as pauses, grunts and laughter. The next step focused on the rereading of the text at least twice to become familiarised with participants accounts of their experiences. Initial noting of the entire transcript occurred next where the researcher's emotional reactions and preconceptions to participants’ responses, psychological concepts and preliminary interpretations of the data were made. At the end of initial noting, emerging themes began to develop providing insight into participants' understanding of adjustment to chronic pain following SNM. These concepts were considered more interpretively and were based on participants’ feelings, thoughts and behaviours.

Emergent themes were then collated with supporting extracts to look for common connections and gave way to the development of subthemes based on participants own words reflecting their shared experiences. These subthemes were then amalgamated into superordinate themes.

6.5. Results

Figure 2 illustrates the superordinate themes and their accompanying subthemes that emerged following the analysis.

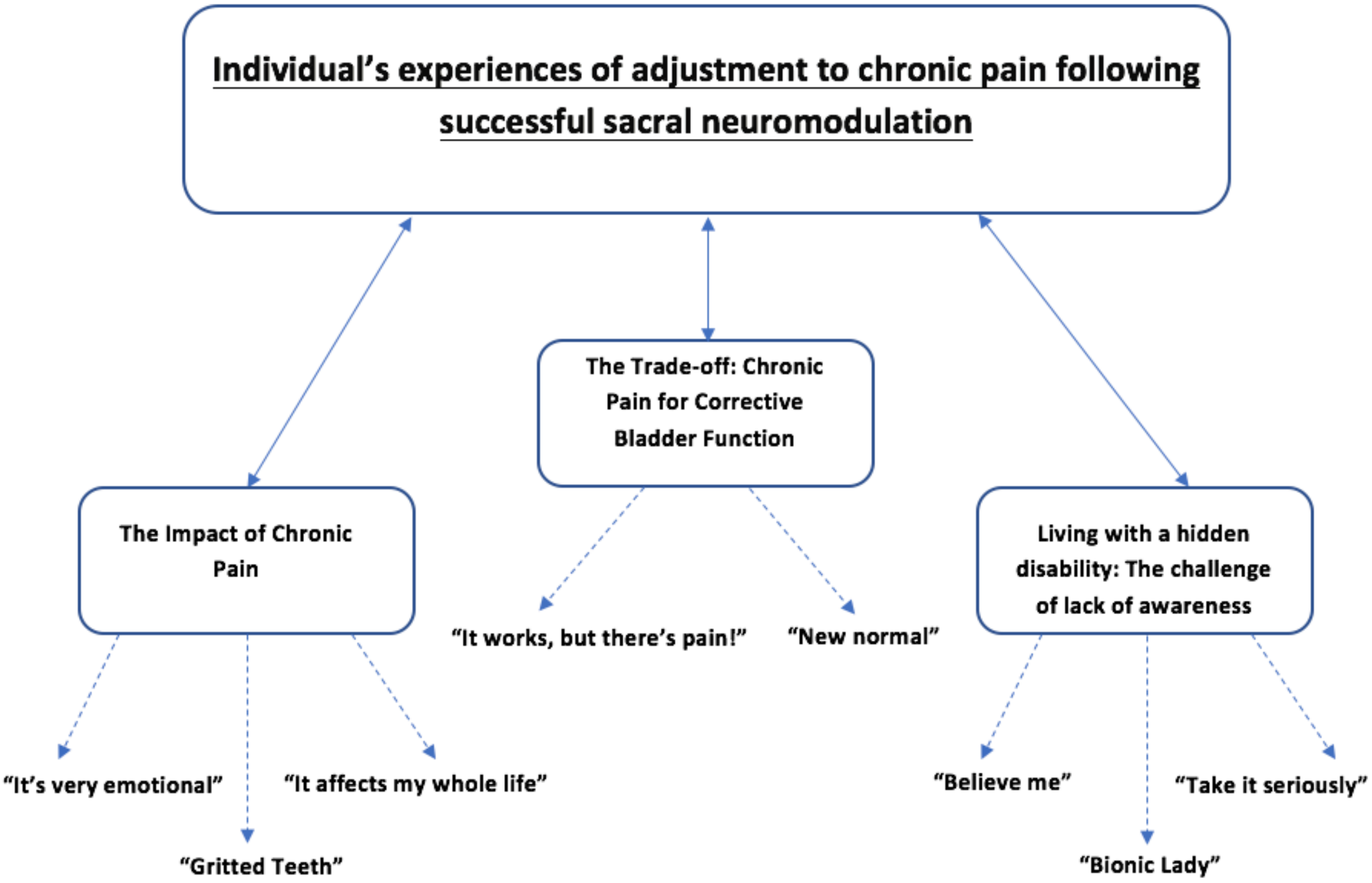

Figure 2: Diagram of presented superordinate and subthemes.

How individuals adjust to their newfound device-related chronic pain following SNM appears to be influenced by many factors. The following sections briefly outline some of the significant ways living with a nerve stimulator impacts the women. Due to the word limit of this paper, subthemes will be supported by 2-3 participant extracts.

6.5.1. The Trade-off: Chronic Pain for Corrective Bladder Function

The women spoke about their experiences of exchanging a life of bladder difficulties for life with persistent pain. The first subtheme, "It works, but there's pain!", reflects participants' awareness of how their device restores bladder function but also causes chronic pain. The latter subtheme, "New normal", brings attention to how participants manage their new pain.

6.5.1.1. "It works, but there's pain!"

The device is viewed as a positive change for participants as it resolves bladder dysfunction, however, the women also acknowledge that the device, paradoxically causes their chronic pain. Hannah says:

> *"But yea, I've been out and about more. I lost my confidence before, dealing with a lot of infections day in and out, trying to see my friends and work, I lost my confidence. It was hard doing things with my partner, booking things, seeing my family. I would have to tell you on the day really. So [laughs] in that aspect, yea. Because I can now say well I'm going to come do this with you or I want to do that with you, so. That's helped me in that aspect. So now I'm infection free but not pain free" (Hannah)*
>
> *"Yea definitely, its improved my symptoms. Erm, like if I had a choice of either catheterising for life or having this procedure, I'd rather have this permanently rather than have to, erm, have to catheterise all the time. Because I find that I'm not getting any infections like I did when I was catheterising all the time, you know. So, it has improved my quality of life, in that point of view. Erm, but pain wise, you're conscious that it's there. The pain is so difficult. But, erm, a lot of bladder problems have reduced, it's improved my infections. Erm, before I couldn't be out and about with friends and couldn't be quite social when I was younger." (Jennifer)*

The women seem to emphasise a sense of freedom that results from their devices which is echoed by other participants who discuss being able to reclaim their identities and engage in relationships and social activities. However, it is apparent that living with the nerve stimulator negates this sense of freedom as the chronic pain has significant implications on their daily living, much like their prior bladder dysfunction.

6.5.1.2. "New normal"

The "New normal" focuses on how participants are processing their new realities, highlighting participants' positive attempts to manage their unexpected pain. Izzie says:

> *"But then again, you have to deal with it or you don't deal with it. It's kind of like you have to get up and go, you can let the pain win but then what's the point of having my device in? Don't get me wrong you have to take a dose of pain killers to do it but if that's what it takes then that's what it takes. At least at the end of the day I'm not having bladder problems because that was the worst." (Izzie)*

Mira also takes a positive perspective regarding her chronic pain:

> *"Pain affects everybody, but, like I said I'm just more determined to not allow it to. There's a lot of people that, and I'm in no means slating other people or anything, erm, a lot of… I'm, I don't let it affect me emotionally. Some people do and they can't help it because that's just the type of person they are. And I think, I think that, as tough as this sounds, adds to their pain. I do. And I think having the positive attitude towards the device, I think that helps. Because I don't let it get to me. And I kind of push the pain to the back of my mind. But it is there because it's always there. Believe me I know about it when I sit down. Or lay down. Or roll over onto my left side when I'm asleep. My husband knows about it too when I go [screams]." (Mira)*

It seems that participants attempt to adopt a positive outlook concerning their nerve modulators and persistent pain which raises the question of whether participants are showing acceptance of, or resilience against, their chronic pain. Other participants depart from descriptions of having positive attitudes toward their unexpected chronic pain, highlighting a sense of unfairness and injustice which appears to stem from the women's expectations of their nerve stimulators. The women hoped for life without chronic symptoms and did not intend to have to adapt to the unexpected consequence of chronic pain. This sense of unfairness and injustice is amplified by the similarities between life with bladder symptoms and living with chronic pain.

Participants also spoke about what it means to adjust to their "New normal". Some of the women have compassion toward their device, reflected in their comments of forgiveness which seem to help with their process of adjustment. In contrast, other participants argue that they are not adjusting to their "New normal" but are instead contending with their unexpected consequence through planning and the use of strategies to manage their pain.

6.5.2. The Impact of Chronic Pain

This superordinate theme explores the experiential impact of individuals adjusting to chronic pain following sacral neuromodulation through the subthemes “It's very emotional”, “Gritted teeth” and “It affects my whole life”.

6.5.2.1. “It’s very emotional”

Every participant expressed how their device-related pain causes mental and emotional strain:

> *“You know, and now pain makes me cry a lot. It sounds very wimpish to be honest, but it makes me cry a lot. Erm, yea. Nobody else gets what it’s all about. It’s very emotional. You look at other people, and you go “how come their body does that, what’s wrong with mine?” You know [laughs]. It’s very emotional. Some days I wake up, and I’m fine, other days I wake up, and I have to get reassurance, after reassurance, after reassurance that I’ll be ok and then I get myself in a bit of a mess.” (Hannah)*
>
> *“Erm, and I think yes, I suppose emotionally I do sometimes say “it’s my stupid body, why can’t my body work, why can’t I be normal?” But I think I’m more questioning rather than getting, I don’t get upset about it. It’s more the questions as to “why me?”. You know, “what, what did I do wrong? Did I cause this myself?” But all I did was have baby and I have, you know, lots of people have babies and it doesn’t happen to everybody. So, is there, is there, you know, something to do with my body?” (Mira)*
>
> *“Pain, pain does get you down, you know. Especially like psychologically. If you're like, it’s a really good day and you know, people invite you to shopping you can't because it’s really hard to get mobile. So, you can't really walk around, so sometimes you just have to take it a bit easy and not do as much. It can be frustrating. It can be really, really frustrating. It is what it is, you know. You just try to get on with it and carry on as best as you can, really. It’s really frustrating because you know that you can do more and you kind of…you know you want to do more but you know that your pain just won’t allow you to do more. And you’re thinking “oh well I just wish I could do what all those other people are doing around me”. You know. And it’s like, I’m so young and I’ve obviously still got goals I want to meet and stuff and it's just like you can’t, you have to reschedule all your goals...because I’m not like everyone else and I can only do what I can physically do.” (Jennifer)*

The comments here highlight the multifaceted nature of chronic pain by illuminating the emotional impact experienced by the women. Participants also emphasised the evaluative aspect of pain when they described continuously thinking about their current and future experiences of having to live with device-related chronic pain. Their repetitive thoughts appear to lead to the self-questioning of whether device removal, that could lead to the return of bladder dysfunction, would be more tolerable than their persistent pain experiences.

6.5.2.2. “Gritted Teeth”

This subtheme brings attention to how participants manage their pain around others and their attempts to hide their true chronic pain experiences. Mira describes how she minimise her pain related experiences around others:

> *"And I always try and put a brave face on. I always try and be happy, I always try and be the one, you know? Somebody walks past me at work and I'll smile at them. "Morning! Alright?" That's me. That's who I am. I try and make things pleasant for other people even if It's unpleasant for myself. Even if, through gritted teeth, I'm saying morning. Whether that may be because I'm in pain or I just don't want to say good morning to that person, I do, I do it. Because that's, that's me." (Mira)*

While Mira provides an example of how participants commit to "Gritted teeth", Lynn provides insight into why participants have this experience:

> *"You can't continue telling people the shit that you're going through. Excuse my French. It's, it's just, it's embarrassing." (Lynn)*
>
> *"Erm, so it's, like your exchanging one problem for another problem." (Lynn)*

The firm tone used to express Lynn's account conveys a sense of frustration developed from her "Trade-off". Her comments suggest that she has previously told others about her bladder difficulties and now finds it embarrassing to admit that since receiving the implanted device it has fixed her bladder problems but now results in chronic pain. It seems that Lynn would rather mask her pain-related experiences instead of admitting that she is having difficulties with chronic pain as others may judge or label her negatively.

6.5.2.3. "It affects my whole life"

The impact of chronic pain on participants' family and social relationships was also illuminated in the findings. Mira and Hannah comment:

> *"I get really grumpy. My children hate it when I'm grumpy. I turn into the devil mom. Mom from hell. I'm stroppy, snappy, erm, there's a lot of things I can't do that my children would like to do. Erm, go to theme parks and things. Going swimming, erm." (Mira)*
>
> *"It's definitely bought the family down as a whole. I think, when you watch your family go through having to go with me to hospital two or three times a week to now… Erm, it's hard for them to watch me not able to do anything and it gets them down, you can tell. It's difficult for them to watch me and not being able to help me, especially since I have the device. Sometimes there's a bit of friction and tantrums between us*

> *because of that. I think it's the communication, you know. Not being able to tell them what's going on and them not being able to communicate how they can help. And my dad doesn't understand this, he just gets mad. It's like before the device…he just gets agitated. So, we have hiccups." (Hannah)*

For both women, they appear to acknowledge how their physical pain contributes to their interactions between themselves and their family members. The comments also highlight that the women tend to focus on how their families perceive them and often worry whether their family members believe their chronic pain experiences.

Moreover, participants also discuss a desire for freedom and independence. Since experiencing chronic pain, the women suggest that they often depend on others, which produces feelings of being a burden. The emotional burden associated with a lack of freedom is also reflected in participants' narratives where they discuss having to reduce or entirely omit participation in intimate, social and work interactions because of their pain.
These comments demonstrate the emotional impact that the women have experienced by having to reduce or entirely omit their participation in social activities or interactions. Again, the comments here seem to show how participants worry that they are being perceived negatively, choosing to withdraw from others rather than having to refrain from social interaction because of their pain.

6.5.3. Living with a hidden disability: The challenge of a lack of awareness

This superordinate theme presents a broader societal perspective to explore the adjustment to chronic pain following sacral neuromodulation via three subthemes: "Believe me", "Bionic Lady" and "Take it seriously". Here, the superordinate theme focuses on how there is a lack of awareness and validation of experiences, particularly from healthcare professionals, because of the specialist nature of SNM and the invisibility of chronic pain.

6.5.3.1. "Believe me"

The women's accounts suggest that during their interactions with others they often fight for the recognition and validation of their chronic pain experiences following device implantation. As Hannah explained:

> *"I mean, I've gotten told to see a psychiatrist by doctors! Because they said it's all in my head. They said it was all in my head. "There's no physical reason why my bladder muscles should not have worked and no reason why I now have pain from this device". You know they just say "we'll just put you through to*

> *psychology" because they think it's all psychosomatic. Like there's an emotional reason behind the pain rather than a physical reason. (Hannah)*

In addition to having pain experiences recognised and validated, participants also emphasised the importance of bringing awareness to the nerve stimulator so others will believe their experiences.

> *"[The nerve stimulator] it's not something that's visible. It's only the scars that are visible and to be fair, and they're hidden by underwear and bikini bottoms, aren't they? It's like, it's like a silent thing, nobody knows it's there. Even when I'm out and about, nobody knows it's there." (Mira)*
>
> *"You know, they don't understand. People like to have a go at you and ask you to prove things and it's because, it because nobody knows. I mean nobody knows about the bladder struggle and nobody knows about the device pain. It's not like other conditions and treatment. And it affects your confidence going out because you don't know what people will think or say when you leave. It's hard to understand." (Hannah)*

The lack of validation experienced by the participants brings into question how the women and the general public define and perceive disability. This shared experience of disbelief seems to derive from the unknown and invisible nature of their devices and its device-related pain which appears to negatively influence the women's process of adjustment to chronic pain.

6.5.3.2. "Bionic Lady"

Some participants find comedy in how others perceive them now that they have the device. While the perception from others can be viewed positively, participants emphasise how a lack of understanding and awareness creates difficulties for their adjustment to chronic pain following sacral neuromodulation.

> *"So then with, with having the battery inside, erm, yea my friends call me the 'Bionic Lady'. Erm, which…Well, it because, because I got something, I've got this mental thing inside me, that, that they think it's funny because they think that they can turn me on and off when they've had enough of hearing my voice [laughs]. But, erm, it actually doesn't work like that. But you know, they think it's, yea. I mean, we laugh about it because it's, I think its diff- yea its weird. It, its, you know not everyone has a thing like this." (Lynn)*
>
> *"Erm, yea, like, at times it can be really difficult to focus or manage a class room full of students when you're in agony. But you know, my students are really good. They think that I am a robot, they love it!" (Izzie)*

> *"It's okay…If I'm around somebody I know, it's funny. When you're around people you don't know and it happens [the pain], people look at you funny, you know, "what is up with you?" and you feel like "okay, I am different …again". (Hannah)*

6.5.3.3. "Take it seriously"

There is a sense of importance and urgency for the women to have the acknowledgement that they are living with pain after SNM. Lynn says:

> *"With regards to the information that you collect, will this be looked into further? Will this be taken seriously and further research will look at this? In looking at why some people have pain and others don't, what they could do differently?" (Lynn)*

The women also express the challenges they have faced within their medical exchanges and offer suggestions for improving their adjustment to chronic pain following implantation:

> *"But if you have more input, more support once you have the device inserted, erm, even I think would help with this problem. You would know you would have someone to talk to. You know whether or not it's normal, whether you need to see the consultant, some understanding, discuss the pain you know. So, I think psychologically it would be, it would be good. Because I didn't know, don't know what to do. Even for six months, it would really reduce people's anxieties and knowledge about this incredible device. And that's what it feels like, you're given a battery and off you go. "We've resolved your bladder problem, get on with it, you should be happy". It's like "I am but now I'm also left with another debilitating condition". (Lynn)*
>
> *"That's so important. Because there's no in between. You have this problem, you get surgery to fix the problem, and then there's another problem, the pain problem…and there's no appointment for another 6 months. It would be nice to have an in-between…have that support to check in and help you." (Hannah)*

The challenges experienced by participants and their suggestions for medical professionals seem to be driven by a sense of frustration and feeling let down by the medical community, for example, Emma says:

> *"I have to live with this. Why do they ask you about how much pain you're in the hospital when they are not going to help you?! I risked my life for a surgery that has now left me "crippling" in a different way. You know it has benefits, there's good parts but there's bad parts and there shouldn't be any bad parts, it should just work. If you are going to put a foreign object in my body, it better work!" (Emma)*

6.6. Discussion

The current study attempted to explore individuals' experiences of adjustment to chronic pain following SNM, within the context of prior bladder dysfunction. The findings revealed that living with chronic pain is a multifaceted experience that extends beyond the physical body and is mediated by the participants' longstanding history of bladder dysfunction.

The analysis is compatible with literature that links SNM with improvements in quality of life (Das, et al., 2004; Tubaro, 2004; Charalambous and Trantafylidis, 2009; Banakhar, et al., 2012) and the impact chronic pain has on psychological and social experiences (Bair, et al., 2003; McWilliams, et al., 2003; Breivik, et al., 2006; Kawai, et al., 2017). The presence of guilt and self-blame appear to dominate the emotional process as the women tend to take sole responsibility for the occurrence of their chronic pain. This finding was not surprising as research identifies guilt and self-blame as ways to cope with chronic illness (Bombardier, et al., 1990; Klein, et al., 2007). The findings also developed the understanding of adjustment to chronic pain following SNM by highlighting some of the psychological factors known to maintain chronic pain experience, for example, low mood and anxiety (Zanini, et al., 2018).

The analysis highlights the social implications of chronic pain following device implantation. There is a shared experience of social judgment and misunderstanding which negatively influences intimate, familial, social and professional relationships. The participants express humiliation and frustration that arises from the lack of awareness of the device and its related pain. These feelings also seem to be the consequence of stigma following participants transition from bladder dysfunction to chronic pain. Moreover, the analysis brings attention to how disability is defined and perceived. The invisibility of the nerve stimulator and chronic pain encourages the personal conflict in participants on what it means to be disabled thus illustrating the general conception that disability is only validated when it can be perceived physically. Finally, the analysis demonstrates participants' desire for further support following device implantation. The lack of follow up care by healthcare practitioners appears to manifest in emotional and cognitive consequences that further drive the psychological difficulties associated with adjusting to chronic pain.

6.6.2. Clinical Implications for Counselling Psychologists

This study aimed to bridge the methodological and knowledge gap in current Counselling Psychology and relevant literature. The current research does not intend to argue that Counselling Psychologists are the only suited practitioners to work with this population but rather to emphasise Counselling Psychologists’ expertise to be able to work in roles traditionally dominated by our counterparts.

The current study provides evidence for the closely intertwined relationship between mental health, physical health and sociocultural factors. Counselling Psychologists are well placed to work therapeutically to facilitate adjustment to chronic pain following successful SNM by responding to the psychosocial issues that individuals experience. Furthermore, these findings demonstrate the growing need for postsurgical support. The provision of psychological support will allow individuals to discuss their met and unmet expectations of their nerve stimulators. Practitioners can support this with the use of tailored psychological interventions that focus on a range of contributory factors such as acceptance, low mood and social isolation.

The findings suggest that a lack of awareness is a salient issue for participants, therefore, an implication of this research is teaching, training and consultation for health professionals, NHS organisations and the broader community. Counselling Psychology training places great focus on consultation (Karademas, 2009) which attests to our ability to advise and recommend care regarding the psychological well-being of this study’s population.

6.6.3. Recommendations for Future Research

Considering the paucity of literature exploring the current study’s phenomenon and the small sample size made up of women, future research could begin by conducting this study on a larger scale. An increase in size will allow for a more in-depth understanding of what it is like for individuals to adjust to chronic pain following SNM and can extend across a longer time frame, different contexts and could include experiences from male participants. Furthermore, an extension of this study could be to select specific variables demonstrated in the analysis and focus on how these variables influence the process of adjustment after device implantation. For example, following the superordinate theme “Living with a hidden disability”, research could focus on how the stigma of disability effects the process of adjustment to chronic pain. The knowledge gained from research focusing on specific variables can inform Counselling Psychology practice. These studies will be able to identify new therapeutic targets for individuals adjusting to chronic pain following SNM. Using the above example of stigma, findings of research focusing on this may reveal maladaptive cognitions related to participants experiences which Counselling Psychologists' can concentrate on in clinical sessions.

6.7. Conclusions

The findings offer new insights into the experiences of adjusting to chronic pain caused by an implanted device treating chronic bladder dysfunction. This study has provided a more nuanced understanding of how individuals with previous bladder dysfunction navigate their lives with unexpected post-operative chronic pain and the factors that influence individual experiences and perceptions of adjustment. The study also advocates strongly for Counselling Psychologists to be integrated within medical settings to provide therapeutic support and interventions for individuals who have complex psychological needs with a focus on the reciprocal relationship between mental and physical health.

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Appendices

Appendix A: Interview Schedule

1. To begin with, could you give me a brief history of your bladder problem from when it started to opting for SNM treatment.

2. Can you tell me what it's like to live with the permanent battery?
-how does it impact your thinking?
-You emotionally?
-Your work/ social life?
-How do you see yourself now?

3. On a day to day basis, how do you deal with having pain?
- Support

4. How does the pain affect you as person?
-Emotionally/Psychologically
-Socially
-Medically/Physically

5. What has the impact of living with pain been on your…
- Relationships
- Work/ Education?
- Family?
-Social/Physical Activity

6. Living with this pain, how do you see yourself in the future?

7. Members of your care team may have asked how you are adjusting to the pain since having the device. I wonder what adjustment means to you and whether you think that you are adjusting?

8. If you were the interviewer, is there anything you would have asked or would have liked to know more about?

9. What was it like being interviewed?

Appendix B: Diary Template

Diary Entry

Over the next 14 days, record a time when you experienced any device related pain.

An example is provided below.

Example Diary Entry:

Date: 13.2.2017

Time: 6.38 pm

Where is the pain and how does it feel: *Upper leg, 'pinching' sensation.*

Duration of Pain: *25 minutes.*

What were you doing when the pain began: *Eating out with my family?*

What happened as a result of the pain? *We had to leave the restaurant earlier than planned.*

How much of the day were you not able to do things because of the pain: *I wasn't able to do anything else for the rest of the night.*

How did the pain impact you: *I felt embarrassed and ashamed that I had to end a good night out with my family.*

Diary Entry

Date: ____

Time: ____

Where is the pain and how does it feel?

____

____

____

____

Duration of Pain? __________________

What were you doing when the pain began:

____

____

____

What happened as a result of the pain?

____
____
____
____

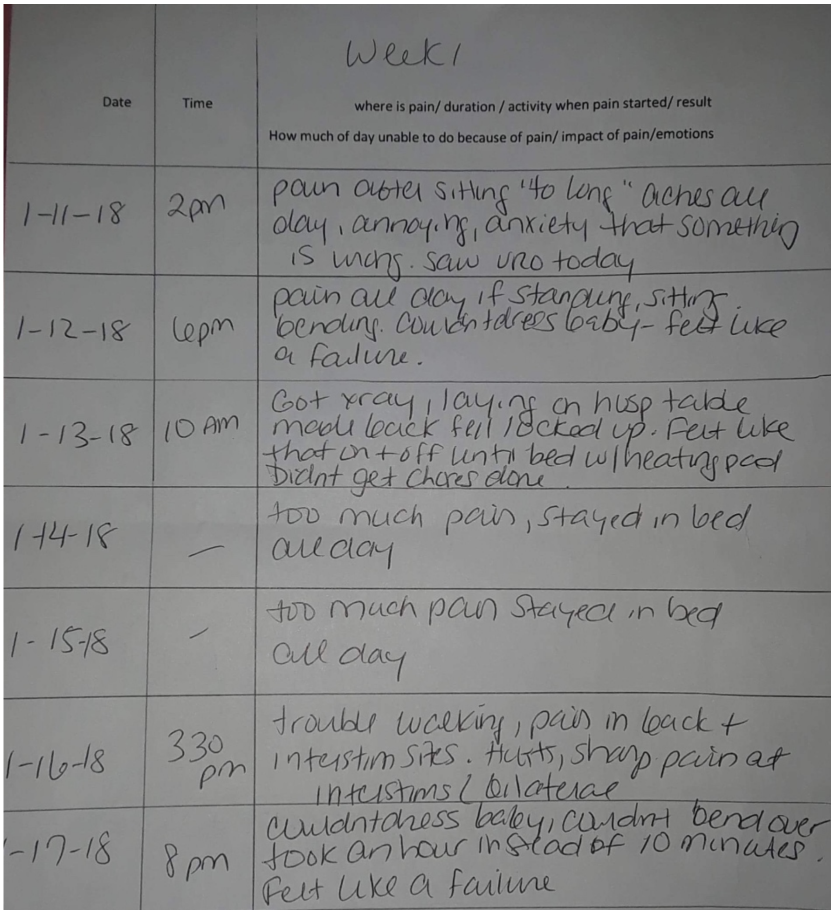
How did the pain impact you?

____
____
____
____

Other Comments:

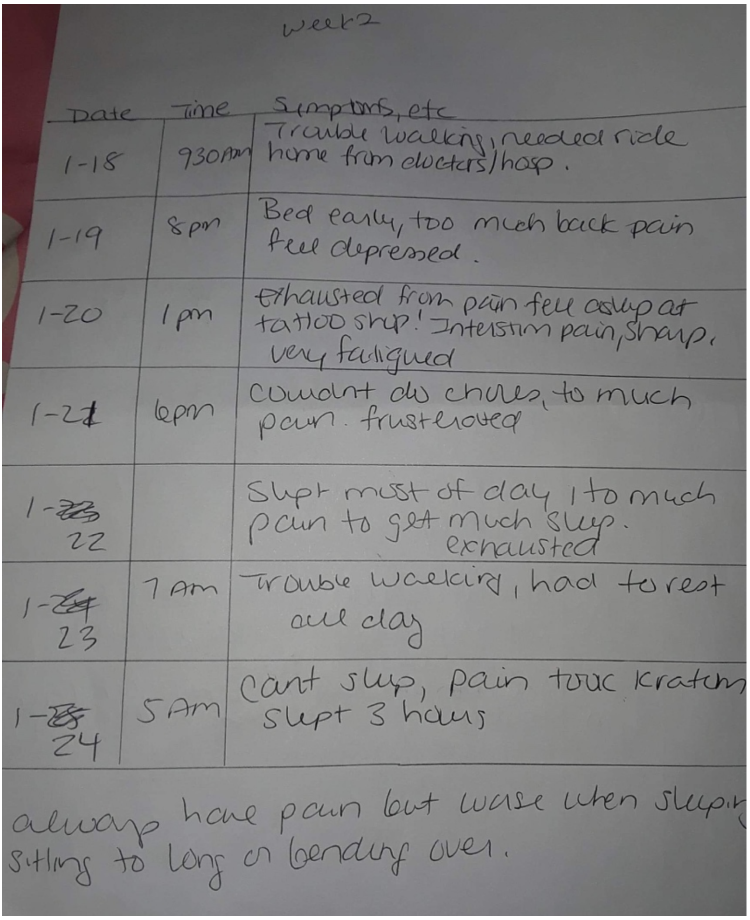
____
____
____
____

Appendix B: Diary Template Filled Example (Participant 5, Emma)



Week 1

Date	Time	where is pain/ duration / activity when pain started/ result How much of day unable to do because of pain/ impact of pain/emotions
1-11-18	2pm	pain after sitting "to long" aches all day, annoying, anxiety that something is wrong. saw uro today
1-12-18	6pm	pain all day if standing, sitting, bending. Couldnt dress baby - felt like a failure.
1-13-18	10 AM	Got xray, laying on hosp table made back feel locked up. Felt like that on + off until bed w/heating pad Didnt get chores done.
1-14-18	—	too much pain, stayed in bed all day
1-15-18	—	too much pain stayed in bed all day
1-16-18	330 pm	trouble walking, pain in back + interstim sites. Hurts, sharp pain at interstims / bilateral
1-17-18	8 pm	couldnt dress baby, couldnt bend over took an hour instead of 10 minutes. Felt like a failure



week 2

Date	Time	Symptoms, etc
1-18	930Am	Trouble walking, needed ride home from doctors/hosp.
1-19	8pm	Bed early, too much back pain feel depressed.
1-20	1pm	exhausted from pain fell asleep at tattoo shop! Interstim pain, sharp, very fatigued
1-21	6pm	couldnt do chores, to much pain. frusterated
1-~~23~~ 22		Slept most of day, to much pain to get much sleep. exhausted
1-~~24~~ 23	7 Am	Trouble walking, had to rest all day
1-~~25~~ 24	5Am	cant sleep, pain took Kratom slept 3 hours

always have pain but worse when sleeping sitting to long or bending over.

Appendix C: Ethical Approval, City University of London

Psychology Research Ethics Committee
School of Arts and Social Sciences
City University London
London EC1R 0JD

6th March 2017

Dear Adriene Berkeley and Fran Smith

Reference: PSYETH (P/L) 16/17 127
Project title: Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval
Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments
You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

(a) Recruit a new category of participants
(b) Change, or add to, the research method employed
(c) Collect additional types of data
(d) Change the researchers involved in the project

Adverse events
You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee [redacted] in the event of any of the following:

(a) Adverse events
(b) Breaches of confidentiality
(c) Safeguarding issues relating to children and vulnerable adults
(d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards
Hayley Glasford — Richard Cook
Course Officer — Chair
[redacted] [redacted] Email: [redacted]

Appendix D: Ethical Approval, NHS Research Ethics Committee

NHS
Health Research Authority
London - Camden & Kings Cross Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: [redacted]

21 April 2017

Miss Adriene Berkeley
[redacted]

Dear Miss Berkeley

Study title:	**Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation**
REC reference:	**17/LO/0267**
Protocol number:	**N/A**
IRAS project ID:	**217150**

Thank you for your letter of 12 April 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair with the Alternate Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

17/LO/0267	**Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincerely
pp

[redacted]

Mrs Rosie Glazebrook Chair

Appendix E: Online Advertisement

Department of Psychology
City University London

PARTICIPANTS NEEDED FOR RESEARCH IN:

THE EXPERIENCE OF CHRONIC PAIN AFTER SACRAL NEURALMODULATION

Are you aged between 20-55 and have had Sacral Neuromodulation?

Have you experienced pain for at least 6 months?

Would you like to inform how we think about supporting people living with the implanted device?

We are looking for volunteers to take part in a study exploring adjustment to choric pain after successful Sacral Neuromodulation.

You would be asked to take part in an interview lasting approximately 60-90 minutes, focusing on your experience of chronic pain after surgery.

For more information about this study, or to take part,
please contact:
Adriene Berkeley on [redacted]

Or Contact the Uro-Neurology department on [redacted]
'Adjustment Study'

Research Supervisor: Dr Fran Smith

This study has been reviewed by, and received ethics clearance through the Psychology Research Ethics Committee, City University of London: PSYETH (P/L) 16/17 127

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee [redacted] or via email [redacted]

Appendix F: Consent Form

CITY
UNIVERSITY OF LONDON
EST 1894

NHS
University College London Hospitals
NHS Foundation Trust

Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation

Ethics approval code: PSYETH (P/L) 16/17 127

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be videotaped/audiotaped	
2.	This information will be held and processed for the following purpose: 'What are the experiences of individual's adjustment to chronic pain following successful sacral neuromodulation treatment?' I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to have my GP contacted to advise him/her of my participation in this study.	
6.	I agree to take part in the above study.	

Name of Participant ____________ Signature ____________ Date ____________

Name of Researcher ____________ Signature ____________ Date ____________

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix G: Participant Information Sheet

Title of study: Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Sacral Neuromodulation (SNM) is an effective treatment used to control irregular bladder symptoms. Often, individuals living with the implanted device experience pain for months after surgery. The purpose of this study is to explore those individual's experiences of adjusting to chronic pain after successful control of bladder symptoms. It is hoped that that your views can contribute to the better understanding of individuals that undergo the SNM procedure and how they adjust to the consequences of bettering bladder function. This would expand knowledge of individuals experiences which could lead to future interventions targeting individuals experience.

Why have I been invited?

You have been invited because you have successfully undergone SNM as a pervious out-patient of the Uro-Neurology department at National Hospital for Neurology and Neurosurgery.

Do I have to take part?

No. Taking part in this study is voluntary, you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time of the interview phase without giving a reason.

What will happen if I take part? What do I have to do?

If you are interested in taking part of this study, you will be invited to take part in in one interview session in the Uro-Neurology department at the National Hospital for Neurology and Neurosurgery. Interviews will involve discussing living with the implanted device, experiences of SNM and adjusting to chronic pain for approximately last between 60-90 minutes. Interviews will be audio recorded reordered, typed up and analysed by the researcher. You will only be asked to discuss you experiences related to SNM and adjusting to chronic pain. At any part of the process, you are free to withdraw at any time of the interview phase or decline any questions you are not comfortable answering. In addition, you will be invited to record diary entries over two weeks. The diary entry is not compulsory and are based on what you feel is relevant to include. In addition, if you would like to take part your GP/Health practitioner will be approached to advise them of your participation. Furthermore, if you decide to take part, data will be held for the length of the study only (1 year from consent) and will be destroyed appropriately. Personal information will also be irreversibly anonymised and disposed of directly after data collection (within 3 months from consent).

What will happen if I don't want to carry on with the study?

You are free to withdraw the study, without reason, at any time before the period of analysis. You are able to request data withdrawal up to 14 calendar days after the interview. Data withdrawal after this point may not be possible after this window.

What are the possible disadvantages and risks of taking part?
Discussing your experiences may bring up various feelings due to the nature of the study's sensitive topic. If this occurs during the interview process you are allowed to have a break during questioning, decline answering any uncomfortable questioning and can withdraw at any time of the interview phase. You will have access to the Clinical Nurse Specialist if you desire further support. If you would like discuss any aspect of the study you can contact the primary researcher Adriene Berkeley or the academic supervisor Dr Fran Smith.

What are the possible benefits of taking part?
The information gathered from the study will contribute to gaining greater understanding of individuals living with chronic pain after SNM and whether there are effective ways to support these individuals. Additionally, taking part of this study may be helpful as well as empowering as you will have the opportunity to self-reflect and explore your past experiences.

What will happen when the research study stops?
You will no longer have to share your experiences when the research study stops. Information given will be destroyed when the purpose of the study has been reached.

Will my taking part in the study be kept confidential?
Yes. Abiding by City, University of London ethics, NHS ethics and The Data Protection Act your participation in this study will be kept confidential. Only the researcher and academic supervisor will have sole access to the information collected. Participant data will anonymised, which includes the audio files of interviews not having any identifying information. Furthermore, complying with the regulations of the Data Protection Act, future use of information retained in this study will be prohibited. Confidentially will be maintained unless during the time of the interview phase you are at risk of harm to yourself or others or if the researcher becomes aware of issues of a criminal nature. At this point in time, information will be shared with supervisors and those necessary parties required. These events occur in only extreme circumstances and are thus unlikely.

What will happen to the results of the research study?
The results of the research study will be used for the researcher's doctoral thesis for the degree of the Professional Doctorate in Counselling Psychology (DPsych). This thesis will be published. If you would like feedback at the end of this study, this can be provided to you in summary form through a letter after the analysis.

What if there is a problem?
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation.

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB

Email:[redacted]

In addition you can also contact UCLH PALS [redacted] or [redacted]

Moreover, City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London Research Ethics Committee*:*
Further information and contact details
Adriene Berkeley - [redacted] or Dr Fran Smith - [redacted]

Thank you for taking the time to read this information sheet.

Appendix H: Letter to GP

CITY
UNIVERSITY OF LONDON
EST 1894

University College London Hospitals NHS
NHS Foundation Trust

Study name: Minding the Bladder: Individuals Experiences of Adjustment to Chronic Pain Following Sacral Neuromodulation

Dear Dr ________________

Your patient:______________has expressed an interest in participating in a research study at the National Hospital for Neurology and Neurosurgery, Queen Square, UCLH.

This is a qualitative study, which will explore the experiences of adjustment to chronic pain following sacral neuromodulation.

Enclosed with this letter is a copy of the patient information sheet, which provides general information about the study aims, methods and procedures.

For any queries regarding the study please contact the lead researcher, as detailed on the patient information sheet.

This study is part of a postgraduate doctoral DPsych degree at City, University of London, by the lead researcher.

Yours sincerely,

____

Adriene Berkeley
Trainee Psychologist, Chief Investigator

Appendix I: Summary of NHS Research Ethics Committee Meeting and Amendments

Amendment points discussed following meeting with London - Camden & Kings Cross Research Ethics Committee

The Committee was satisfied with the responses to the following points raised in the previous letter.

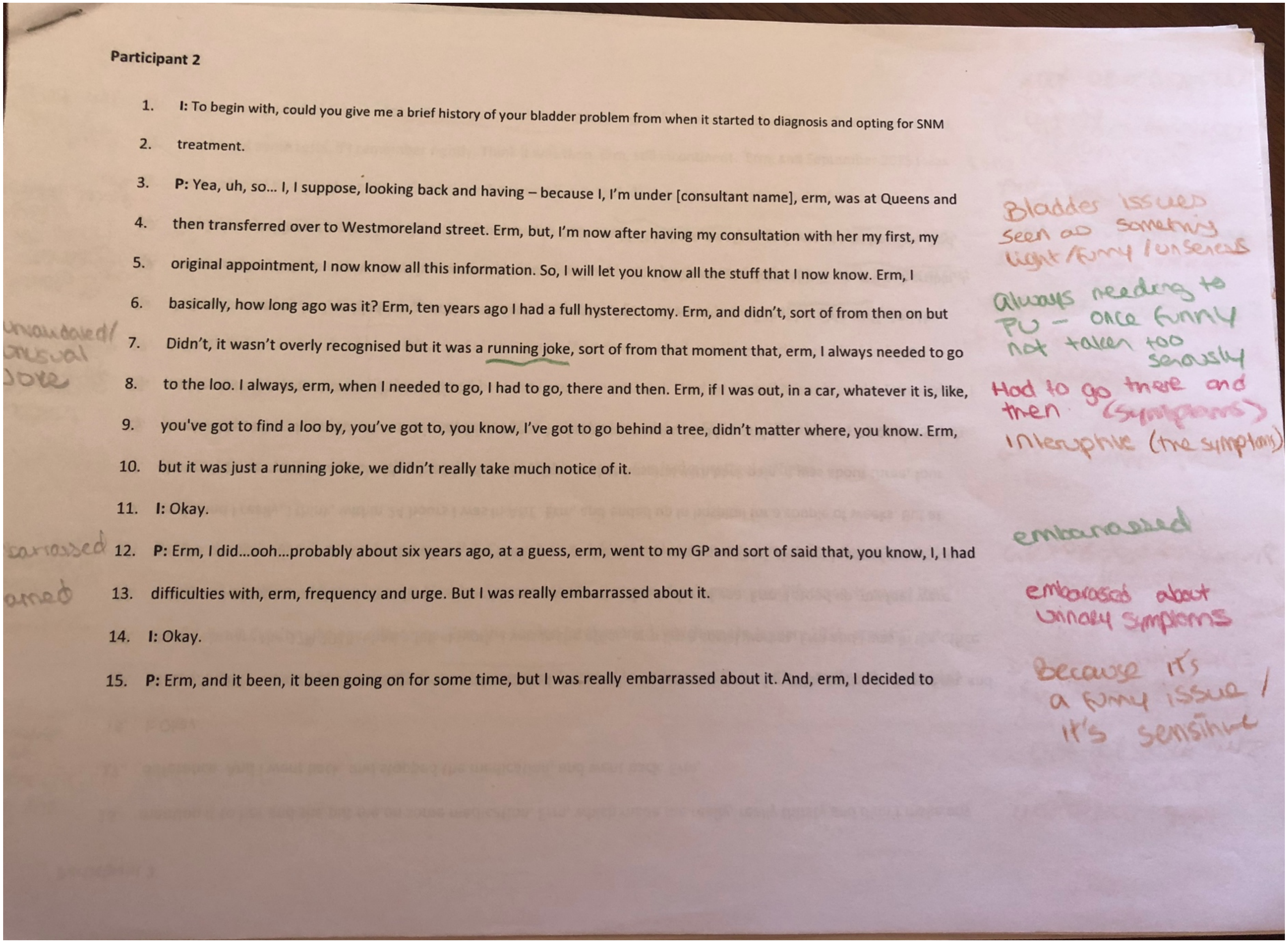
1. Confirmation that consent would not be taken over the telephone.
2. Confirmation that the debrief information sheet would not be utilised as it was unnecessary.
3. Amendment to the participant information sheet to detail what appropriate emotional or psychological support would be available if required.
4. Amendment to the consent form to obtain approval to contact a participant's GP.

Amendments from the Committee following meeting:

1. The Committee had concerns about calling people so they would be put in a position where they had to agree. The Committee would agree to this approach if it was made clear that the initial contact was by letter or email, and simply giving basic information about the study, and how to find out more, and leaving it for the potential participant to decide whether to act on this or not.

2. The Committee agreed that the diary entry was still overly intrusive and suggested that participants should share much more information other that what was specifically needed. Members suggested a shorter, simpler entry to document points regarding pain, situation, duration, etc.

Appendix J: Analytic Procedure – Example of Initial Note Taking (Participant 2: Lynn)



Participant 2

I: To begin with, could you give me a brief history of your bladder problem from when it started to diagnosis and opting for SNM treatment.

P: Yea, uh, so… I, I suppose, looking back and having – because I, I'm under [consultant name], erm, was at Queens and then transferred over to Westmoreland street. Erm, but, I'm now after having my consultation with her my first, my original appointment, I now know all this information. So, I will let you know all the stuff that I now know. Erm, I basically, how long ago was it? Erm, ten years ago I had a full hysterectomy. Erm, and didn't, sort of from then on but Didn't, it wasn't overly recognised but it was a running joke, sort of from that moment that, erm, I always needed to go to the loo. I always, erm, when I needed to go, I had to go, there and then. Erm, if I was out, in a car, whatever it is, like, you've got to find a loo by, you've got to, you know, I've got to go behind a tree, didn't matter where, you know. Erm, but it was just a running joke, we didn't really take much notice of it.

I: Okay.

P: Erm, I did…ooh…probably about six years ago, at a guess, erm, went to my GP and sort of said that, you know, I, I had difficulties with, erm, frequency and urge. But I was really embarrassed about it.

I: Okay.

P: Erm, and it been, it been going on for some time, but I was really embarrassed about it. And, erm, I decided to

Unvoudaled/
nusual
Joke

barrassed

amed

Bladder issues
seen as something
light/funny/unserious

always needing to
PU – once funny
not taken too
seriously

Had to go there and
then (symptoms)
intrusive (the symptoms)

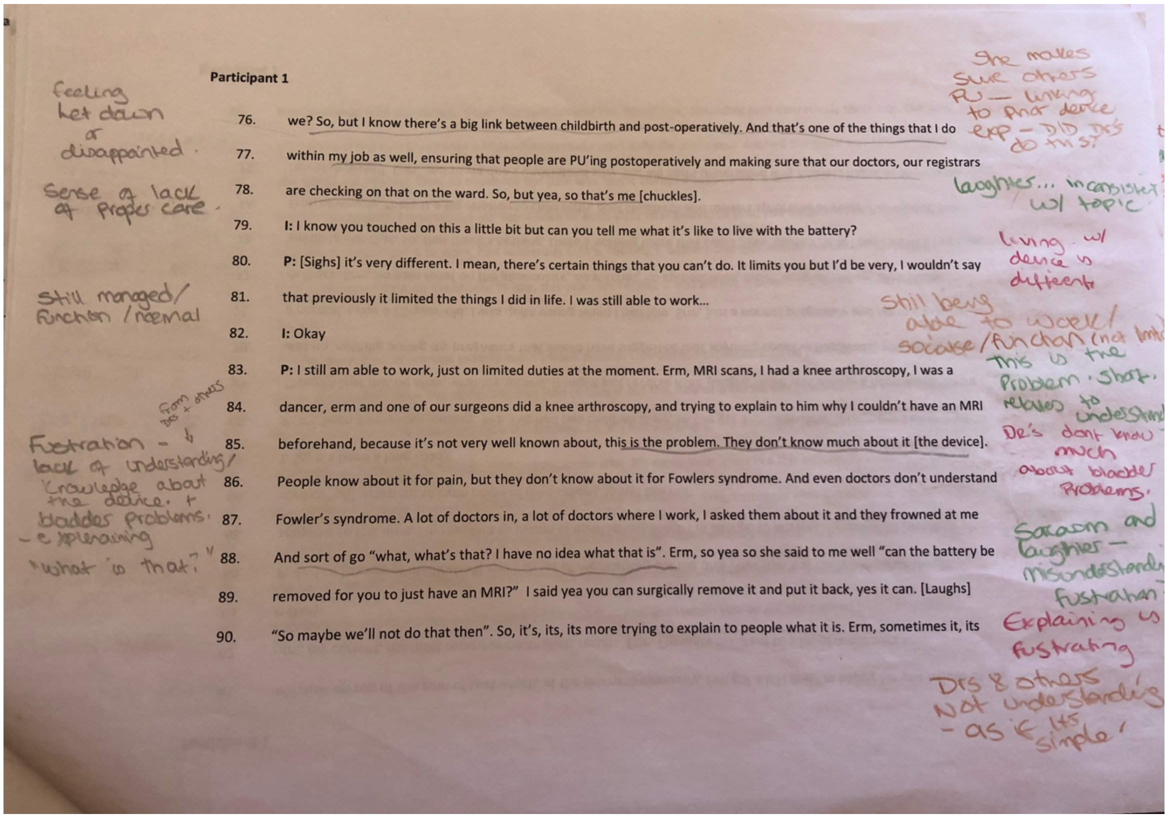
embarrassed

embarrassed about
urinary symptoms

Because it's
a funny issue /
it's sensitive

Appendix K: Analytic Procedure – Process of Organising Emerging Themes (Participant 1: Mira)

Example of Emergent Themes on left hand side of transcript:



feeling let down or disappointed.

Sense of lack of proper care.

Still managed/ function /normal

From others Drs + ↓

Frustration – lack of understanding/ knowlegde about the device. + bladder problems. – explaining "what is that?"

Participant 1

we? So, but I know there's a big link between childbirth and post-operatively. And that's one of the things that I do within my job as well, ensuring that people are PU'ing postoperatively and making sure that our doctors, our registrars are checking on that on the ward. So, but yea, so that's me [chuckles].

I: I know you touched on this a little bit but can you tell me what it's like to live with the battery?

P: [Sighs] it's very different. I mean, there's certain things that you can't do. It limits you but I'd be very, I wouldn't say that previously it limited the things I did in life. I was still able to work…

I: Okay

P: I still am able to work, just on limited duties at the moment. Erm, MRI scans, I had a knee arthroscopy, I was a dancer, erm and one of our surgeons did a knee arthroscopy, and trying to explain to him why I couldn't have an MRI beforehand, because it's not very well known about, this is the problem. They don't know much about it [the device]. People know about it for pain, but they don't know about it for Fowlers syndrome. And even doctors don't understand Fowler's syndrome. A lot of doctors in, a lot of doctors where I work, I asked them about it and they frowned at me And sort of go "what, what's that? I have no idea what that is". Erm, so yea so she said to me well "can the battery be removed for you to just have an MRI?" I said yea you can surgically remove it and put it back, yes it can. [Laughs] "So maybe we'll not do that then". So, it's, its, its more trying to explain to people what it is. Erm, sometimes it, its

She makes sure others PU – linking to prior device exp – DID Drs do this?

laughter… inconsistent w/ topic

Living w/ device is different.

Still being able to work/ socialise/function (not lim

This is the problem. Short. relates to understand

Dr's dont know much about bladder problems.

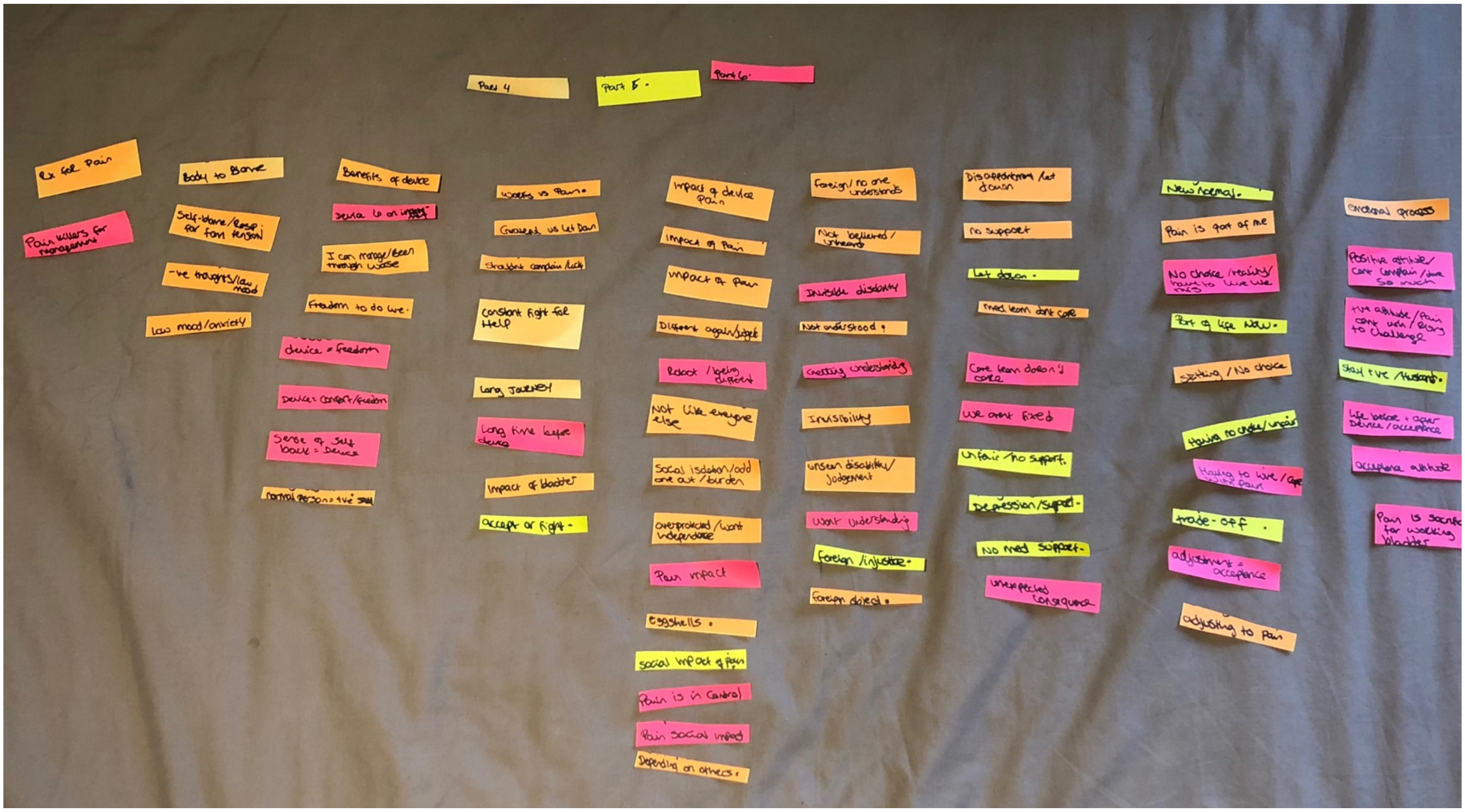
Sarcasm and laughter – misunderstanding frustration

Explaining is frustrating

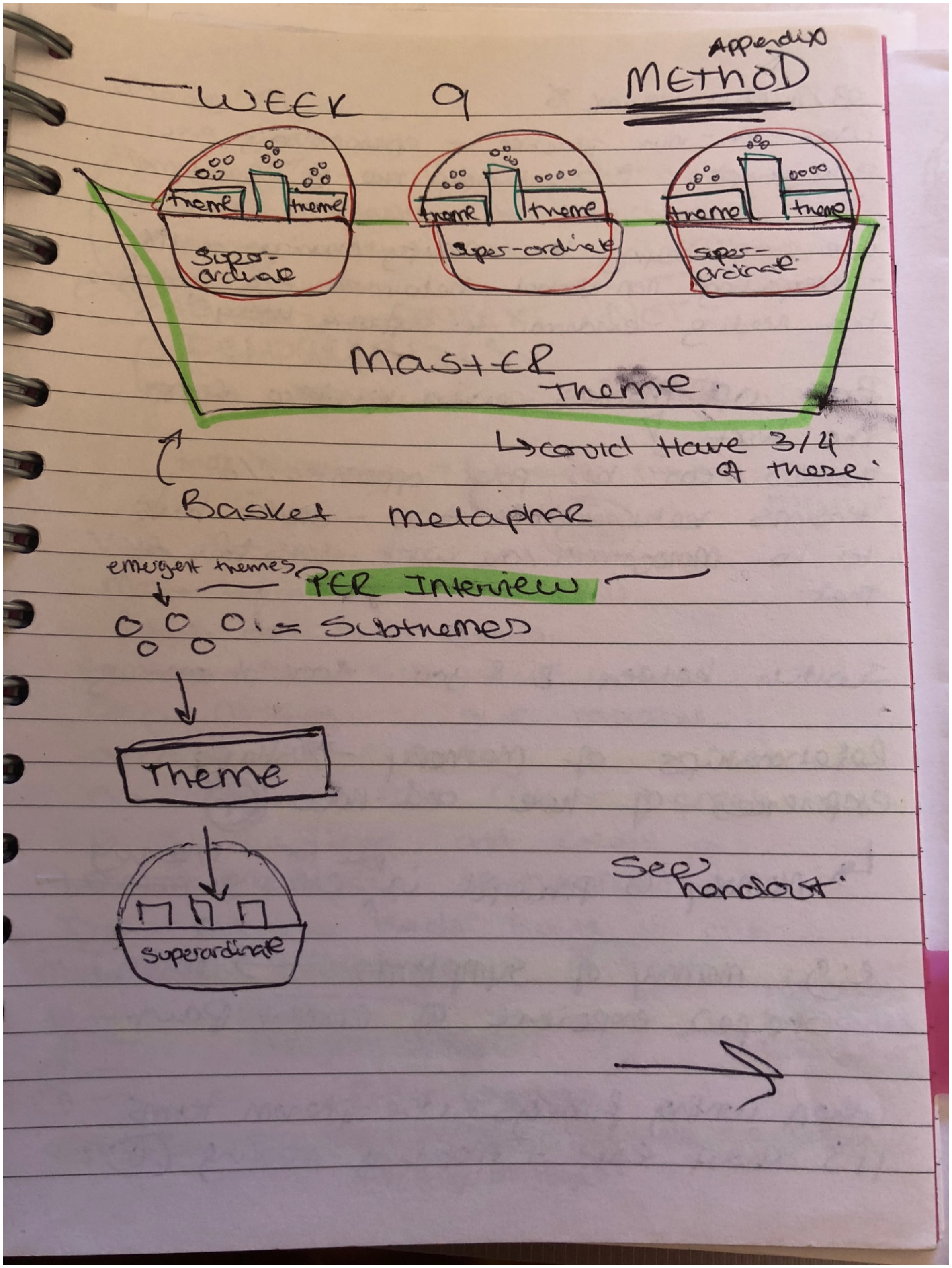
Drs & others not understanding – as if its simple'

Example of clusters of Emergent themes (Participants 1 and 2: Mira and Lynn)

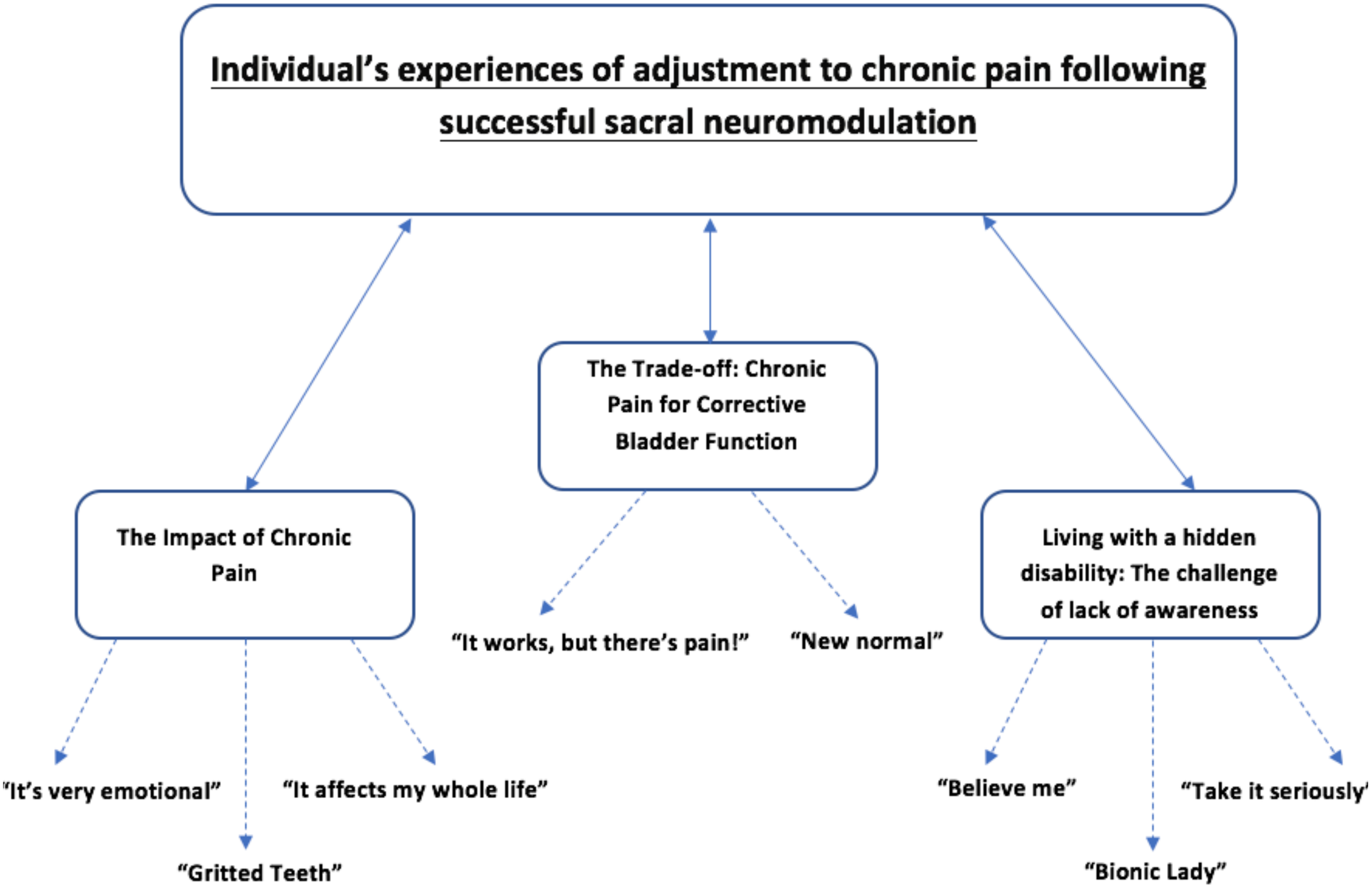
Example of clusters of Emergent themes (Participants 4,5 and 6: Hannah, Emma and Izzy)



Appendix L: Analytic Procedure – Metaphorical Understanding of how Superordinate Themes Developed



Appendix M: Summary of All Presented Themes



Appendix N: Psychological Medicine Submission Guidelines

Psychological Medicine

Editorial Policy

Psychological Medicine is a journal aimed primarily for the publication of original research in clinical psychiatry and the basic sciences related to it. These include relevant fields of biological, psychological and social sciences. Review articles, editorials and letters to the Editor discussing published papers are also published. Contributions must be in English.

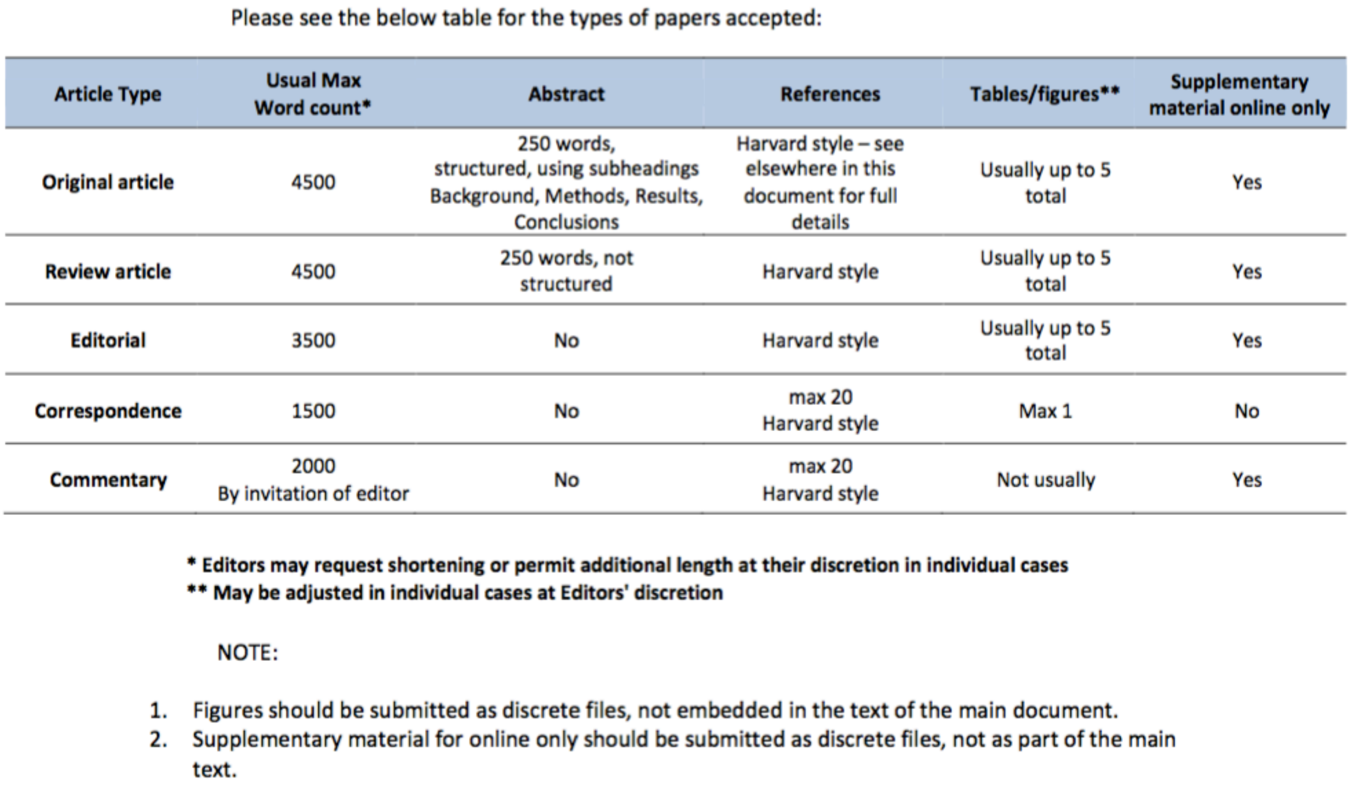
Submission of manuscripts

Manuscripts should be submitted online via our manuscript submission and tracking site, http://www.editorialmanager.com/psm/. Full instructions for electronic submission are available directly from this site. To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

Papers for publication from Europe, (except those on genetic topics, irrespective of country), and all papers on imaging topics, should submitted to the UK Office.

Papers from the Americas, Asia, Africa, Australasia and the Middle East, (except those dealing with imaging topics), and all papers dealing with genetic topics, irrespective of country, should be sent to US Office.

All enquiries should be directed to the Editorial Office at psychmed@cambridge.org.



Please see the below table for the types of papers accepted:

Article Type	Usual Max Word count*	Abstract	References	Tables/figures**	Supplementary material online only
Original article	4500	250 words, structured, using subheadings Background, Methods, Results, Conclusions	Harvard style – see elsewhere in this document for full details	Usually up to 5 total	Yes
Review article	4500	250 words, not structured	Harvard style	Usually up to 5 total	Yes
Editorial	3500	No	Harvard style	Usually up to 5 total	Yes
Correspondence	1500	No	max 20 Harvard style	Max 1	No
Commentary	2000 By invitation of editor	No	max 20 Harvard style	Not usually	Yes

*** Editors may request shortening or permit additional length at their discretion in individual cases**
**** May be adjusted in individual cases at Editors' discretion**

NOTE:

1. Figures should be submitted as discrete files, not embedded in the text of the main document.
2. Supplementary material for online only should be submitted as discrete files, not as part of the main text.

Generally papers should not have text more than 4500 words in length (excluding abstract, tables/figures and references) and should not have more than a combined total of 5 tables and/or figures. Papers shorter than these limits are encouraged. For papers of unusual importance the editors may waive these requirements. Articles require a structured abstract of no more than 250 words including the headings: Background; Methods; Results; Conclusions. Review Articles require an unstructured abstract of no more than 250 words. The name of an author to whom correspondence should be sent must be indicated and a full postal address given in the footnote. Any acknowledgements should be placed at the end of the text (before the References section).

Contributors should also note the following: 1. S.I. units should be used throughout in text, figures and tables. 2. Authors should spell out in full any abbreviations used in their manuscripts. 3. Foreign quotations and phrases should be followed by a translation. 4. If necessary, guidelines for statistical presentation may be found in: **Altman DG., Gore SM, Gardner,**

MJ. Pocock SJ. (1983). Statistical guidelines for contributors to medical journals. *British Medical Journal* **286**, 1489-1493.

Neuroscience-based Nomenclature

For papers concerning neuropsychopharmacological treatments, *Psychological Medicine* encourages authors to utilize the ‘Neuroscience-based Nomenclature’ developed by the ECNP Taskforce on Nomenclature. The need for such a change arose to address a longstanding concern within the neuropsychopharmacological community that the nomenclature of psychotropic drugs did not properly reflect the underlying neuroscience of these compounds, as well as being unhelpful to clinicians and confusing to patients (e.g. the prescription of ‘antipsychotics’ for depression).

More information about the nomenclature can be found on the ECNP website here, and in the paper here. The Neuroscience-based Nomenclature (NbN) itself is available free of charge as a mobile app (for both Android and iOS devices).

References

(1) The Harvard (author-date) system should be used in the text and a complete list of References cited given at the end of the article. In a text citation of a work by more than two authors cite the first author's name followed by *et al*. (but the names of all of the authors should be given in the References section). Where several references are cited together they should be listed in rising date order.

(2) The References section should be in alphabetical order. Examples follow:

Brown GW (1974). Meaning, measurement and stress of life events. In *Stressful Life Events: Their Nature and Effects* (ed. B. S. Dohrenwend and B. P. Dohrenwend), pp. 217-244. John Wiley: New York.

Brown J. (1970). *Psychiatric Research*. Smith: Glasgow. **Brown J, Williams E, Wright H** (1970). Treatment of heroin addiction. *Psychological*

Medicine **1**, 134-136.

Note: authors' names should be in **bold** font; journal titles should always be given in full.

(3) References to material published online should follow a similar style, with the URL included at the end of the reference, with the accession date, if known. Authors are requested to print out and keep a copy of any online-only information, in case the URL changes or is no longer maintained. Examples follow:

Acute Health Care, Rehabilitation and Disability Prevention Research - National Center for Injury Prevention and Control. (http://www.cdc.gov/ncipc/profiles/acutecare/default.htm). Accessed 7 June 2004.

British Psychological Society Research Digest, Issue 12.
(http://lists.bps.org.uk/read/messages?id=1423). Accessed 17 February 2004.

Figures and tables

Only essential figures and tables should be included and should be provided in black and white except in exceptional circumstances, eg PET scan images etc. If you request colour figures in the printed version, you will be contacted by CCC-Rightslink who are acting on our behalf to collect Author Charges. Please follow their instructions in order to avoid any delay in the publication of your article. Further tables, figures, photographs and appendices, may be included with the online version on the journal website.

All wording within submitted figures must be Arial, point size 8. To ensure that your figures are reproduced to the highest possible standards and your article is published as quickly and efficiently as possible, Cambridge Journals recommends the following formats and resolutions for supplying electronic figures. Please note that submitting low quality figures may result in a delay in publishing your valuable research

Please ensure that your figures are saved at final publication size (please see the latest issue of the journal for column widths) and are in our recommended file formats. Following these guidelines will result in high quality images being reproduced in both the print and the online versions of the journal.

Line artwork

Format: tif or eps Colour mode: black and white (also known as 1-bit) Size: please size to final publication size Resolution: 1200 dpi

Combination artwork (line/tone)

Format: tif or eps Colour mode: grayscale (also known as 8-bit) Size: please size to final publication size Resolution: 800 dpi

Black and white halftone artwork

Format: tif Colour mode: grayscale (also known as 8-bit) Size: please size to final publication size Resolution: 300 dpi

Colour halftone artwork

Format: tif Colour mode: CMYK colour Size: please size to final publication size Resolution: 300 dpi

If you require any further guidance on creating suitable electronic figures, please visit the Cambridge Journals Artwork Guide.

All graphs and diagrams should be referred to as figures and should be numbered consecutively in Arabic numerals. Captions for figures should be typed double-spaced on separate sheets. Tables should be numbered consecutively in the text in Arabic numerals and each typed on a separate sheet after the References section. Titles should be typed above the table.

Online Supplementary Material

Relevant material which is not suitable for print production, such as movies or simulations/animations, can be uploaded as part of the initial submission. Movies should be designated as ‘Movie’ and each individual file must be accompanied by a separate caption and a suitable title (e.g., Movie 1). Accepted formats are .mov, .mpg, .mp4, and .avi, though they should be archived as a .zip or .tar file before uploading. Each movie should be no more than 10MB. Upon publication these materials will then be hosted online alongside the final published article. Likewise, should there be detailed tables or figures which are likely to take up excessive space in the printed journal, these can also be published online as supplementary material [designated as `Other supplementary material']. Note that supplementary material is published 'as is', with no further production performed.

Required Statements

Acknowledgements

You may acknowledge individuals or organisations that provided advice, support (non-financial). Formal financial support and funding should be listed in the following section.

Financial support

Please provide details of the sources of financial support for all authors, including grant numbers. For example, “*This work was supported by the Medical research Council (grant number XXXXXXX)*”. Multiple grant numbers should be separated by a comma and space, and where research was funded by more than one agency the different agencies should be separated by a semi-colon, with “and” before the final funder. Grants held by different authors should be identified as belonging to individual authors by the authors’ initials. For example, “*This work was supported by the Wellcome Trust (A.B., grant numbers XXXX, YYYY), (C.D., grant number ZZZZ); the Natural Environment Research Council (E.F., grant number FFFF); and the National Institutes of Health (A.B., grant number GGGG), (E.F., grant number HHHH)*”. Where no specific funding has been provided for research, please provide the following statement: “*This research received no specific grant from any funding agency, commercial or not-for-profit* *sectors*.”

Conflict of interest

Please provide details of all known financial, professional and personal relationships with the potential to bias the work. Where no known conflicts of interest exist, please include the following statement: “None.”

Ethical standards

Where research involves human and/or animal experimentation, the following statements should be included (as applicable): “*The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008*.” and “*The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional guides on the care and use of laboratory animals*.”

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7. personal mentoring by highly published researchers and professional editors For any authors new to publishing research articles, we encourage you to make use of the AuthorAID resources before submitting your paper to *Psychological Medicine*. Through the AuthorAID network, guidance can be found to help researchers through the process of writing and submitting scientific papers, advice about responding to reviewer comments, as well as research design and grant applications. Please note that seeking support through AuthorAID will not guarantee acceptance for publication in *Psychological Medicine*, or affect the editorial process in any way.

Author Language Services

Cambridge recommends that authors have their manuscripts checked by an English language native speaker before submission; this will ensure that submissions are judged at peer review exclusively on academic merit. We list a number of third-party services specialising in language editing and / or translation, and suggest that authors contact as appropriate. Use of any of these services is voluntary, and at the author's own expense.

(Revised 4 April 2016)