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Adaptation and Connection: Exploring change and relationships

Submitted by

Susan Alexandra Taylor

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City, University of London

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Acknowledgements

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Preface

This preface introduces and provides an overview of the components of this portfolio. It is a collection of three pieces that are linked together by the theme of the role of social interaction in giving meaning to living and its importance in the maintenance of psychological health. The first piece is a thesis that describes an original piece of research aiming to explore the experience of receiving successive diagnoses for people with multiple chronic health conditions, including heart failure. The findings that emerged from this Interpretative Phenomenological Analysis (IPA) study were both interesting and surprising. A strong thread throughout was the importance of others. The second piece is a case study from a placement during my second and third years of training to be a counselling psychologist. The client was a teenager who presented with anxiety and depression that she felt were related to her 'social phobia'. The final part of this portfolio is a journal article that presents a summary of the findings of my research and will be submitted for publication. Each of these will be presented in turn and explained in more detail.

People have a varying need for social connection and are part of a social world where everything they do is in relation to another. They are connected with others, have concern for them and are cared for by them. It is suggested that the lack of satisfactory social interaction may bring feelings of loneliness that in turn may be related to anxiety and/or depression. The linking with others and having a supportive social group gives meaning to life for many. Reduced mobility as illness increases may lead to less social contact and possible isolation. The research and case study relate to people of widely different ages. The former is focused on the importance of social contact and support towards the end of life for those with life threatening conditions. In contrast, the case study relates to the expressed need for social

connections for a person who is younger and experiencing difficulties with making and maintaining social relationships much earlier in life.

The research topic grew from my experiences and beliefs. My interest in researching multiple morbidity developed from working in a palliative care service where I became curious about how people cope with receiving a succession of diagnoses. This is timely research as the number of people who have multiple morbidities is increasing, so an understanding of their perspective is germane. The study used semi-structured interview data analysed by means of IPA to explore the experiences of six people with multiple morbidities. Three superordinate themes emerged from the analysis. They are 'Acceptance of successive diagnoses', 'Importance of others' and "Meaning of time'. The importance of relationships was apparent throughout the interviews illustrated by the amount of time participants spoke about other people, the central role they had in their thinking and the important part they played in their adjustment to changing capabilities. The participants frequently spoke about the comfort, care and support provided by family members and medical staff. They all described the importance of family members and their central role in providing practical help and much appreciated emotional support, whilst longstanding professional relationships were regarded as close and protective. The findings that emerge are discussed in terms of new insights, suggestions for further research and implications for the practice of counselling psychology.

My belief, prior to the research, was that older age comprised largely of increasing illness, suffering, limitation, social isolation and emotional distress. However, although the participants became more limited in their capabilities as the number of illnesses increased, they seemed to consider themselves to be coping well with any suffering and emotional distress and did not appear to view themselves as socially isolated. Their response to receiving successive diagnoses was surprising, because

they seemed to respond in an accepting way, as though it was to be expected. The participants seemed to have the view that life, though limited, was enjoyable and their social interaction appeared to be a large part of that enjoyment. Through the process of research I became more aware of my beliefs and fascinated by the surprising views of others.

Initially I was inclined towards quantitative research as an approach with which I felt comfortable and one that resonated with the experience of research and positivist thinking of the past. However, as time progressed I became more attracted to the unfamiliar, challenging territory of qualitative research and the richness of subjective meanings. The journey through gaining understanding, conducting, analysing the data and discussing IPA has been an interesting and challenging one. Despite the struggles, I have become fascinated by the focus on the individual perspective and the methods by which we understand another's subjective experience. For the future, having developed a new range of skills, I would hope to carry out further research into the way in which people experience different phenomena.

During my training and development as a counselling psychologist I learned about and experienced different therapeutic approaches. My engagement with these and my developing understanding of my thoughts and feelings evolved and clarified the way that I view myself, others and the world. I view myself as an emerging person-centred therapist and have used the case study to illustrate this approach. The therapeutic relationship centres on the therapist being a helper and the client an expert in their own situation and therefore in the best position to make decisions about their life. Guided by the application of theory to clinical practice, the case study describes therapeutic work with a young person longing for social relationships, but experiences had led to fearfulness, isolation, loneliness and deep unhappiness. However, there was a clear desire to become a more mature and social individual,

driven by the actualizing tendency. The use of supervision throughout enabled reflection about the process.

Finally, I have prepared a journal article that will be submitted to Journal of Health Psychology for publication. The reason I chose this journal was because its focus is to support research into aspects of health psychology and accepts papers with a qualitative approach including interpretative phenomenological analysis. A particular area of interest is the contexts in which psychological processes are embedded, which is clearly relevant to this study. The paper offers a summary of the research process, findings including results and implications for clinical practice together with directions for further research.   The findings are illuminated through discussion in relation to existing literature.

This portfolio is the culmination of a four-year process of training as a practitioner and researcher. These years have shaped my life and, to some extent, limited my social interaction. As a counselling psychologist approaching the end of my training and hopefully moving on to fully qualified status I recognise that, although I have made huge gains in knowledge, my learning is a life long process. The three different sections provided above reflect some of the personal and professional learning, discovery and transformation that have been my journey throughout this course.

Section A: The research study

The experience of receiving successive diagnoses for people with multiple chronic health conditions including stage 3 heart failure.

Abstract

This study explores the experience of receiving successive diagnoses for people with stage 3 heart failure (NHYA) and at least two other chronic health conditions. The participants were all having treatment from NHS specialist heart failure nurses within the community and had been diagnosed more than six months previously. The aim of the research is to illuminate the experience of being repeatedly diagnosed with another health condition. This is timely as there are increasing numbers of people living with multiple morbidities.

Six participants (three male, three female) were interviewed using a semi-structured questionnaire to gain insight into their world. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis. The analysis is my interpretation of the participants' interpretation of their lived experience. Three overarching themes emerged relating to the acceptance of diagnoses, the importance of relationships and the meaning of time. Each of these has several constituent subthemes.

The findings are discussed in relation to the wider literature and links are made with theory pertaining to adaptive coping, embodiment and existential issues. Implications for professional practice and areas for future research are discussed.

Chapter 1: Introduction and Literature Review

1.1 Introduction

"A longer lifespan is something few people would spurn and it opens up great opportunities in our personal, social and economic lives, yet in practice it is often accompanied by living with disease." (The Organization for Economic Co-operation and Development, OECDa, 2011, p.5)

The quest to live an ever-longer life, have eternal youth, or even gain immortality is as present in modern living as it has been through the ages. It can be seen in Greek mythology, art, literature, movies and popular music. The value of longevity is reflected in many religions as they offer life after death, or even eternal life, as a reward for a life well lived.

Historical trends indicate a significant increase in life expectancy for people in England and Wales (Longevity Science Advisory Panel, LSAP, 2012). In 1841 male and female life expectancy were recorded as 40.6 and 43.0 years respectively. In 2009 this had almost doubled as it increased by 37.8 years for males and 39.9 years for females to 78.4 and 82.9 years. This marked increase can be attributed primarily to better living standards, improved medical treatments and interventions for a raft of potentially fatal diseases such as infection, cancer, heart failure and diabetes (OECDa, 2011). The King's Fund (2016) details the estimate of the expectation of a healthy life span, i.e. the number of years that an individual can expect to be lived in good health. It suggests that males are likely to have about 10 years of healthy life expectancy after the age of 65, whilst females have slightly more at about 12 years. Therefore, for most people death at an older age will be preceded by several years of

ill health, because although people live longer, they can expect to spend the latter part of their lives in poor health (OECD, 2011b).

These years are likely to be characterised by the development of a number of morbidities, which to a greater or lesser extent will impact the way people live. Multiple morbidity is more common in older people, but not by any means exclusively. This chapter will look at the existing literature to gain some insight into the lived experience of people who have a number of comorbidities including significant heart failure. The focus of this study will be on the experience of receiving diagnoses and the impact that individuals perceive that it has had on them.

Firstly, consideration will be given to the contextual factors surrounding the promotion of increased longevity. The nature and extent of multiple morbidity will be reviewed followed by consideration of the impact of diagnosis. Various aspects of multiple morbidity will be examined including interaction with the health system, self-management, quality of life, social contact, age, mental health and the role of pain. The final section focuses on the ways in which people adapt to their diagnoses. Any of these aspects may impact the way in which a diagnosis is received.

To date there seems to be little in the literature about the experience of receiving successive multiple diagnoses and so other related research will be used to gain insight into the lived experience, where relevant.

This research is relevant to the theory and practice of counselling psychology because it looks at the psychological functioning of the whole person in context. It does not pathologise the individual, but rather is concerned with helping people live more effective and fulfilled lives whatever their situation.

<u>A note on language</u>: Multiple morbidity, multimorbidity and multiple chronic

conditions are all terms used to describe the condition of having two or more chronic

illnesses.

1.2 Literature Review

1.2.1 Setting the context

Diseases such as cancers, heart disease, osteoporosis, dementia, arthritis and

Parkinson's disease have become more prevalent in the older population (U.S.

Department of Health & Human Services, USDHHS, 2010; Koné Pefoyo et al., 2015)

and although they may be treated so that they are not fatal, they are not cured

(Underwood, 2001). Consequently, the level of chronic disease builds in individuals,

so that they frequently live with decreased mobility, increased dependence and a

feeling of being much less well (Walker, 2007; Marengoni et al., 2011). Eventually,

the burden of morbidity becomes too great so that life cannot be sustained any longer

and they die.

However, in modern society the drive continues, not only to live longer, but also to

live in better health. The wellness industry is worth many billions of pounds a year in

the UK (The Statistics Portal, 2016) with its offer of wide ranging products targeted at

living longer in an enhanced way. Products available on the market include food

supplements and nutrition, weight loss, mind and body fitness and complementary

and alternative medicine (Marks, 2013). A long and healthy life is promoted as

desirable and as something to be striven for as a measure of successful living.

Doctors are trained to save lives. When a patient dies it may be regarded as a failure

of their skills. "The Rule of Rescue" is a term coined by Jonsen (McKie & Richardson,

2003) to describe the imperative felt by those in medical professions to rescue individuals whose lives are at risk, no matter what their life may be like afterwards.

The emphasis on promoting life is seen clearly as a result of government scrutiny of hospitals, where the focus on death rates highlights comparison between hospitals; the lower death rate being considered preferable without necessarily considering contextual factors. Drug companies and medical establishments are vested in the pursuit of treatments and drugs through their research programmes (The Pharmaceutical Research Manufacturers of America, PhRMA, 2016). Consequently there is a huge growth in the number of medical interventions that are being developed to treat illness and prolong life (Bunker, 2001).

People may find the idea of extending their own healthy life attractive due to fear of death, fear of age-related disabilities and fear of the dying process. There is some attraction in the possibility of good health for the duration of a long life. However, although most people may wish to extend their lives, others may be reluctant to accept life-extending treatments (Pew Research Center, 2013) perhaps due to a fear of the problems that come with age.

Generally, however, people are living longer with more illnesses, so that the quest to understand multiple morbidity has now become the focus of increasing research studies. The section that follows aims to explain the nature of multiple morbidity and the impact that the development of multiple chronic illnesses may have on the individual. Much of the research is related to the ways in which health systems manage this increasingly common phenomenon. However, there is a growing focus on how individuals respond to their changing circumstances.

1.2.2 Multiple Morbidity

Multiple morbidity is considered to be the co-occurrence of two or more diseases in the same individual (McKenzie, Pierce, & Gunn, 2015; Vos, van den Akker, Boesten, Robertson, & Metsemakers, 2015). The general focus of recent quantitative research in this area has been on improving the quality of people's lives and enabling self-care, with the intention of finding strategies to diminish the demand on the health system and consequently the cost of support. There are fewer qualitative studies but, in contrast, these examine the lived experience of those with multiple morbidities in areas such as self-care, mental impact, adapting and quality of life. This study is about the experience of being diagnosed with multiple chronic health conditions, rather than the impact of living with illnesses, although there may be some overlap. As well as looking at the factors that may be associated with multiple morbidity, the extent of the phenomenon is being researched. It is suggested that more than one third of people accumulate four or more morbidities in their lifetime (Vos et al., 2015), whilst a small number develop more than 11.

Marengoni et al. (2011) conducted a literature search and suggest that multiple morbidity affects more than half the elderly population, although there is a lack of clarity about the age of the people who were included in their study. Their focus was to provide insight into the frequency, risk factors and consequences of multiple morbidity. Older age, female gender and lower social class were identified as possible risk factors, whilst the consequences were considered to be disability, reduced quality of life and higher healthcare use.

A general criticism of literature searches (Glass, 1976) is that criteria are chosen to include studies or omit them. This may lead to important information being excluded. Some may be omitted because their methodology is considered poor, but may contain valid and useful data. Others may be excluded unintentionally. Marengoni et

al., (2011) highlight some of the difficulties experienced in their study. Firstly, there are different definitions of multiple morbidity across the literature. Definitions might include two or more concurrent illnesses in the same person, cumulative indices relating to the number and severity of disease, or the coexistence of symptoms, cognitive and physical limitations. The former definition was used in the Marengoni et al. (2011) study, therefore eliminating those studies looking at multiple morbidity from the clinical or social aspects. A second difficulty is the method used to choose the articles for inclusion. Only those that used the word 'multimorbility', or similar terms were searched and so would not include articles about people with two or three diseases that did not use the term. Additionally the different foci of studies render comparison problematic.

1.2.3. The Impact of Diagnoses

There is little in the literature about receiving multiple diagnoses. However, studies have been carried out into the effect a single diagnosis has on individuals. The participants in this study have been selected because they have a number of morbidities including stage 3 heart failure (Appendix A). Cardiovascular disease is commonly one of the chronic illnesses experienced particularly in older multi-morbid people (Blom et al., 2015).

Impact of heart failure

It seems that one of the effects of a diagnosis of heart failure is that it has a negative impact on mental health (Vaccarino, Kasl, Abramson, & Krumholz, 2001). Patients with heart failure report many distressing symptoms associated with a reduced quality of life and depression may be associated with these symptoms (Bekelman et al., 2007).

Depression is common in cardiac patients, being 47% in women and 36% in men (Jaarsma, Lesman, & van Veldhuisen, 2008) and is significantly associated with increased morbidity and mortality risk (Murberg, Bru, Svebak, Tveterås, & Aarsland, 1999; Vaccarino et al., 2001; Norra, Skobel, Arndt, & Schauerte, 2008). Vaccarino et al. (2001) conducted a quantitative study by following 391 patients after admission to hospital for heart failure. The research compared death or decline in activities of daily living at six months relative to a baseline measure on admission. Their findings indicate that the more depressive symptoms present, the greater the risk of morbidity and mortality. It may be that heart patients with moderate to severe depression would benefit from treatment with drugs and/or therapy to enhance their functional status (Westlake, Dracup, Fonarow, & Hamilton, 2005; Linden, Phillips, & Leclerc, 2007) and improve their quality of life.

Murberg and Bru (2001) suggest that social isolation is significantly associated with mortality in heart failure patients over a two year follow-up period after diagnosis. A review of studies by Pelle, Gidron, Szabó and Denollet (2008) examined the impact of depression, anxiety and social support on mortality for people diagnosed with chronic heart failure (both inpatients and outpatients). They suggest that depressive symptoms and social support are related to prognosis, however they were unable to draw any conclusions about the role of anxiety. This was a relatively small study with tentative outcomes so further research was suggested to look at associations with various psychological factors.

Norra et al. (2008) express the view that psychological intervention, along with social support, education and exercise are beneficial to both physical and psychological outcomes.

Heart failure produces significant morbidity in its advanced stages, so that any psychological, social and existential distress may be overshadowed by this and be under recognised (Leeming, Murray, & Kendall, 2014). A qualitative study by Seah, Tan, Huang Gan and Wang (2016) suggests that the participants, who were all living with heart failure, were overwhelmed with the experience of living with the uncertainty of the disease. Further, the progressive deterioration of the heart adds to the physical and psychological impact, so that individuals might become intolerant of exercise. A study by Obieglo, Uchmanowicz, Wleklik, Jankowska-Polańska and Kuśmierz (2015) suggests that people who are less able to accept the diagnosis of chronic heart failure are more likely to find that it impacts their quality of life. They frequently present with lower energy, more severe pain, negative emotional reactions, poor sleep, social isolation and limited mobility.

Beker, Belachew, Mekonin and Hailu (2014) looked at predictors of self-care behaviour in individuals with heart failure. They found that some people did not fully engage in activities such as watching their diet and getting regular exercise. It may be that these activities were considered less necessary to their survival than, for example, taking medication. They further suggest that the main predictors of poor self-care behaviour were depression, the duration that the individual had been diagnosed with heart failure, co-morbidities and knowledge of their diseases. The conclusion drawn was that intervention programmes might target those with certain comorbidities, depression and a diagnosis of less than one year's duration. It also noted that individuals at Stage 3 and 4 heart failure (NYHA) are more likely to involve themselves in self-care.

Graven et al. (2014) suggest that problem-focused coping strategies such as stress management and Mindfulness Based Stress Reduction may be beneficial in improving outcomes in terms of psychological well-being, improved self-care and

better quality of life. This was compared with negative outcomes such as psychological distress, decreased quality of life and increased heart failure related mortality for individuals employing emotion-focused coping strategies. However, as yet there has been little research into the effectiveness of stress management and Mindfulness Based Stress Reduction for heart failure patients.

Impact of receiving one diagnosis

Some illnesses pose an existential threat, as does heart failure. Therefore studies about the impact of diagnosis of life threatening conditions may be pertinent to this study.

Hannum and Rubinstein (2015) used ethnographically based interviews to look at how chronically ill older adults experienced a new cancer diagnosis. Three semi-structured interviews, focused on life history, chronic illness and previous experiences of cancer, were conducted with fifteen participants. They sought the participants' view of personal health, aging and the future. The prospect of death seems to have focused them on the time aspect of their lives so that it was described in three sections: ideas of the past, the present and an unknown future. The perception of these became related to their illness and the finite nature of life. Time became fragmented into smaller bits that were more manageable. Acute episodes of illness were confined to a point in time. The participants hoped for some recovery in the future. These findings relate to the work of Charmaz (1991) who described how chronically ill people divide their lives into periods of illness versus times when they feel better.

Sheilds et al. (2015) looked at people's stories of living with life-threatening illnesses such as cancer, chronic kidney disease and HIV/AIDS. The participants described

their lives as a delicate balance between living and an acute awareness of their own mortality. The uncertainty of their existence ran alongside their living. This links with Heidegger's existential thinking (Langdridge, 2007) about the finite nature of life and the certainty that it ends in death. Although death is a possibility at any time during the course of a lifetime, people seem able to conceal it from themselves for much of their existence. Denial of death attempts to negate anguish about it. Serious illness can bring an awareness of the fragility of existence and that death may be close so that anxiety surfaces. People may become more aware that every moment is precious and has meaning, an ontological mode of being. It is in this mode that people are able to take the power to change themselves (Yalom, 1980). The contrast is made between an ontological mode of being and an everyday mode of being in which people are unaware of the ownership of their lives. Heidegger refers to this as inauthentic (Mulhall, 2013).

It seems that the diagnosis of a serious illness has a significant impact on the person receiving it. The people in this study have received at least three diagnoses, but there is little in the literature to suggest that there might be a cumulative effect. Although there is the suggestion (Bhattarai, Charlton, Rudisill, & Gulliford, 2013: Gunn et al., 2012) that it is the number of morbidities, rather than the nature of diagnoses that has a negative impact on mental health.

1.2.4 The health system and multiple morbidity

Much has been written about the huge consequences of multiple morbidity that impact healthcare, social services and other providers (Parekh & Goodman 2013; Salive, 2013; Liddy, Blazkho, & Mill, 2014). Most of the research in this area is focused on how health systems might manage increasing numbers of people with multiple morbidity most efficiently and effectively (Koné Pefoyo et al., 2015). The

focus of developing strategies is on the co-ordination of medical services so that health and quality of life are optimised for those with multiple conditions and also the burden of their illnesses reduced (USDHHS, 2010).

The growing numbers of multimorbid people present a problem of management for doctors, as populations are living longer and so developing more diseases that are capable of being treated. Their complex care is a relatively new phenomenon, where the consequences of the interaction of one condition or medicine with other conditions or treatments may be unknown. In response, doctors' training in the United Kingdom has been reviewed. A recent report (General Medical Council, GMC, 2013) has identified the need for more doctors who are skilled in "general care in broad specialities across a range of different settings…driven by a growing number of people with multiple morbidities" (p.5).

The individual and the system

Little research has yet been carried out investigating the impact of multiple morbidities on either the people who have them, or those who are responsible for the management of them. The complexity of the management of their illnesses rests largely with the patient. They are required to medicate themselves accurately and adhere to recommended care regimes. This can be a heavy burden for very ill people, so that they do not always follow guidance for their care (Schoenberg, Leach, & Edwards, 2009). In this context, Reeve and Cooper's (2016) qualitative study suggests that the defining of health needs in terms of each disease may result in an overburden of care for some people. They comment that there needs to be new thinking about the organisation of care related to the individual.

However, it may be that people experience long-term conditions differently and so their healthcare needs are different and individual. Reeve and Cooper (2016)

examined the health care needs of 25 participants with a minimum of one long term

physical or mental health condition. Semi structured interviews were analysed using

narrative content analysis. As an outcome of their research, Reeve and Cooper

(2016) proposed three new categories of health care provision, resilient, vulnerable

and disconnected to match care more appropriately to the individual. Those who

were resilient were considered to show a capacity to understand and manage

problems and so make minimal demands on healthcare. The vulnerable group was

identified as needing additional support to reduce their demand on medical services.

It was suggested that the disconnected group, who felt overwhelmed by illness,

required something as yet unspecified to support them. Health need was not defined

in terms of disease or condition, but rather by the capacity to adapt to daily living.

Although these categories may have been the subjective view of the researchers, the

idea that some people are more or less able to adjust to their morbidities is relevant

to this study. The categorisation of people into three groups is an interesting finding,

but it does not address the individual nature of the needs of the person living with

illness. Further, there is little in the study about how the knowledge gained might

translate into practice to meet their needs more precisely.

Traditionally one illness at a time has been treated rather than viewing the individual

holistically, which may result in lack of co-ordination of care. The high incidence of

disease, together with the different combinations of them, makes this type of

management difficult and inefficient for both the person and the system. Reeve and

Cooper (2016) suggest that it may be preferable to use patient-centred approaches.

Bayliss et al. (2008; 2014a) in their studies of the delivery of primary healthcare also

suggest the implementation of holistic, patient-centred chronic disease management

based on the needs of the individual. A suggestion supported by a study by Mason et

al. (2016). Bayliss et al. (2014b) examined the context of people with multiple

morbidities to investigate the factors that might be important in reducing suffering and

improving the quality of life. They suggest that support systems, provided by healthcare professionals, community services, family and friends, as well as other public bodies need to be researched further, so that their importance might be understood better and collaborative action taken.

Interestingly, although studies have projected that there might be ways within a health system to improve self-care and promote good health, a qualitative study by Meranius and Hammar (2016) appears to contradict this. Their findings on the self management of older adults suggests that, although healthcare is able to treat and relieve symptoms, it does not enable them to achieve good health, or provide them with the support they need to function in everyday life. The healthcare system is perceived to be an obstacle to self-management due to short doctors appointments, numerous visits to different specialists and an inability to respond to the participants' rapid health changes. Participants stated that continuity of care and communicative relationships were factors that enabled them to practice self-care.

Individuals with multiple chronic health conditions frequently have reduced mobility, therefore reliable transport to access hospitals and medical professionals may be needed for self-management (Ruggiano, Shtompel, Whiteman, & Sias, 2015).

Medication

The high number of drugs people take for multiple illnesses is a relatively new phenomenon. As yet very few studies have investigated specific multiple morbidities and associated drug therapy. Most studies currently focus on chronic disease and comorbidity depression outcomes (Doos, Roberts, Corp, & Kadam, 2014). Wehling (2009) raised concerns about older people with multiple morbidities that take many kinds of drugs and that their effects are unpredictable. He proposed a new system of drug classification for general practitioners (GPs) in an attempt to reduce the drug

burden and the possibility of death due to medication. Further, Tannenbaum (2013) expressed concern that there is an increased potential for drug-drug interactions among this population. Fried, McGraw, Agostini and Tinetti (2008) investigated the patients' perspective of the interaction of their medications. Many were unaware that the treatment of one condition could worsen another, although they were aware of the adverse effects of the individual medications they were taking. This may be an area of concern for some people with multiple morbidities, if they understand the present state of medical knowledge. Further investigation of these issues might clarify them for people making decisions about complex healthcare.

Vyas, Pan and Sambamoorthi (2012) conducted a quantitative study and propose that those individuals whose multiple morbidities include at least one cardio-metabolic condition have a higher burden of medication than those individuals who do not. Polypharmacy varies with the cluster of conditions. The health conditions examined were cardio-metabolic, pulmonary and musculoskeletal conditions.

As can be seen from the above, increasingly research is being focused on the impact of multiple morbidities, but it tends to be its effect on the health system, rather than on the individual. However, there is a growing number of studies that look at the lived experience of people with chronic multiple health conditions from the individual's perspective. At the time of writing, there is a paucity of research into the experience of the individual receiving successive diagnoses of a number of serious health conditions.

1.2.5 Self-management of multiple conditions

To address the issue of the increasing number of people with long term multiple morbidities, the Department of Health (DoH, 2014) has developed a strategy that is

focused on self-management, thus putting the person at the heart of managing their care. It focuses on support to manage medical conditions, improvement of functional ability and improvement of the quality of life. However, it seems that there are factors that reduce the effectiveness of self-management. In particular, multiple morbidity is a common feature in areas of socioeconomic deprivation, so that issues such as lack of resources, transportation and support systems might in themselves be factors that reduce an individual's willingness and ability to self-manage (Marengoni et al., 2011; Walker, 2007). It seems that quality of life issues may decrease the motivation to self manage.

Liddy et al. (2014) used qualitative thematic analysis to identify common themes in 23 studies. They describe the perspective of those with multiple conditions as focused on the functional issues they face, rather than their disease. Predominant difficulties are dealing with undesirable symptoms, pain and depression.   Chronic illness is particularly intrusive in those who are younger and who have more severe disease. Perhaps because they are younger, their expectation of good health is high. They suggest that a more patient-centred approach would support better the self-management of chronic conditions by individuals. Satariano and Boyd (2013) also support the provision of care centred on the individual, rather than care that is focused on specific illnesses. Therefore, research seems to have identified a need for the person to be at the centre of care regardless of the type and number of chronic conditions, where the focus is on the person's functionality, rather than on each individual disease (Bayliss et al., 2014a). Attention is also drawn to the support needed for help in the development of self-care (Bayliss et al., 2014a; Bratzke et al., 2015).

On the theme of looking at the individual's relationship with the health service providers and self-care, Shiner, Steel and Howe (2014) suggest that health

professionals focus on the giving of advice, rather than on outcomes desired by those with multiple morbidities. They propose a flexible individualised approach that incorporates patient preferences to engage people in the self-management of their conditions and so improve outcomes.

When people do become engaged in self management, they appear to be motivated, have a sense of responsibility for their own welfare and feel that they have the capacity to carry it out (Coventry, Fisher, Kenning, Bee, & Bower, 2014). They suggest that health services and wider supportive networks might be able to intervene so that these skills are developed, but the method is not elucidated.

Health-related activities can be very time consuming for those with multiple morbidities so that they choose between managing their health conditions and participating in desired activities (White, Lentin & Farnworth, 2014). Islam, McRae, Yen, Jowsey and Valderas (2015) suggest that the time spent on the management of illness for older individuals increases with the number of chronic diseases and is particularly associated with diabetes and depression. The total number of diseases together with the type of disease involved can be predictive of more than 30 hours each month being spent on the management of illnesses. The time taken managing disease needs to be accommodated by the individual and assimilated into their life.

Townsend, Wyke and Hunt (2006) carried out interviews with 41 participants to investigate the strategies they use to self manage their multiple illnesses. Their study suggests that individuals generally felt a responsibility to manage their symptoms well, but at times their need to fulfill social roles, manage their identity and continue with valued usual activities conflicted with symptom management. The participants seemed generally to feel obliged to try to control their symptoms well, which created a

tension with the rest of the activities that they wished to undertake. At times this conflict might lead to the control of symptoms being less of a priority.

As already asserted, those with multiple morbidities are likely to be older people. Medication and its meaning for older adults with chronic, but not necessarily multiple illnesses, was studied by Ritchie (2014) using narrative analysis. The themes that emerged as part of her findings were that medication was a part of everyday life and that resourcefulness, coping and adaptation were used to manage medication. They also suggest that the participants had trust in their doctor, so that many experienced a kind of social relationship due to the length of their association.

1.2.6 Multiple morbidity and quality of life

Multiple morbidity is associated with higher rates of disability and significantly lower quality of life (Banham, Hawthorne, Goldney, & Ratcliffe, 2014; Mujica-Mota et al., 2014). Mujica-Mota et al. (2014) used data from the English General Practice Survey 2011-2012 for their large-scale study of over 800,000 patients. Multiple morbidity was defined as two or more of a list of 12 self-reported conditions, or another unspecified long-term health problem. Participants were asked to rate themselves for mobility, self-care, usual activities, pain/discomfort and anxiety/depression using EuroQol-5 Dimension (EQ5D). The overall findings point to three or more conditions being associated with greater reduction in quality of life than would be implied by the sum of the differences associated with individual conditions. This suggests that the reduction in quality of life is greater than would be expected as more morbidities are added. The difference was greater for younger people.

Walker (2007) also carried out a quantitative study, in which the findings similarly suggest that multiple chronic diseases have a negative impact on quality of life and

that this effect is magnified once other factors such as low socioeconomic status are taken into account.

Many individuals with multiple morbidity have complex drug regimes (Tannenbaum, 2013). One of the consequences is that they become reluctant to travel, as this would involve time-consuming organisation and packing of their medicines (Tudball, Smith, Ryan, Williamson, & Manias, 2015). Any unforeseen events could throw their treatment regime out and threaten their survival.

1.2.7 Impact of multiple morbidity on social contact

Reduced social connections may lead to loneliness and isolation, which are sometimes apparent in the lives of older people and those with illnesses. The link between multiple morbidities and loneliness has been highlighted in a review of quantitative studies by Petitte et al. (2015). The study suggests that loneliness is currently seen as a global health issue that can negatively influence the outcomes for people with morbidities, including those with heart disease which is pertinent to this study. Further, their findings indicate that limited implementation of programmes that address loneliness may be effective.

Linked to the above is the issue of isolation, which is sometimes a consequence of chronic illness and also increases as people become older (Barlow, Liu, & Wrosch, 2015). One ethnographic study of those who had a single morbidity, i.e. living for several years with the effects of stroke, found notable differences in the way they perceived isolation due to their disabilities (Warren & Ayton, 2014). Those with a partner felt socially isolated despite not being alone, whilst those who lived alone highlighted loneliness as a form of social suffering. However, they were able to find ways to enable themselves to feel socially more included. Living alone was found to

be a risk factor in a quantitative study of loneliness in the elderly (Zebhauser et al., 2015). However, the absence of depression and the presence of a stable social network were suggested as protective against loneliness for this group. They further concluded that income and level of education were among the factors that were considered to have no impact (Zebhauser et al., 2015).

Duguay, Gallagher and Fortin (2014) comment that the discipline required for the self-management of drugs, treatments and medical appointments further complicates lives and may impact social contact.

1.2.8 Multiple morbidity and age

A phenomenological study by Duguay et al. (2014) describes the experiences of 11 interviewees, aged between 18 and 69, with at least four morbidities. Their findings indicate that their experiences include the impression of premature aging, difficulties with self-management and issues about accessing the health system, all of which added to the complexity of their lived experience. Participants felt that they were aging more rapidly than others of their age, perhaps due to their increasing physical limitations, so that they felt older than their biological age. It seems that they regarded multiple morbidity as a phenomenon that occurs in the elderly, rather than people of their own age. Physical limitations may lead to difficulties with social relationships and consequent loneliness (Duguay et al., 2014; Petitte et al., 2015). Duguay et al. (2014) conclude that further research is needed into interventions that are tailored to the specific needs of those with multiple morbidities.

Hundt et al. (2015) analysed statistical data from older U.S. veterans with chronic obstructive pulmonary disease or congestive heart failure to seek relationships between disease severity, coping style, locus of control and the perceived

intrusiveness of disease. Their findings suggest, as do those by Liddy et al. (2014), that perceived illness intrusiveness is greater for younger people and those with more severe disease. Further, those who believe that they have lower illness intrusiveness feel that they are in control of their health and its outcomes. They conclude that psychological interventions may be useful to empower older individuals to take an active part in feeling that they are in control of their illnesses (Hundt, et al., 2015).

1.2.9 Mental health and multiple illnesses

The National Institute for Health and Clinical Excellence (NICE, 2009) proposes that there are increasing mental health issues when people have multiple chronic illnesses. This is one of the most researched aspects of multiple morbidity. There has been particular focus on the link with depression, which is often associated with a negative effect on the quality of life. A quantitative study by Egede (2005) suggests that depression is more prevalent in the presence of multiple morbidities, one of which was diabetes. As stated previously, there are other studies that suggest that it is the number of morbidities, rather than the nature of the diagnoses that has an impact on mental health (Bhattarai et al., 2013; Gunn et al., 2012). The research, therefore, suggests that people's mental health declines as the number of diagnoses increases.

As may be expected, it seems that depression at any level of multiple morbidity increases healthcare costs and so has implications for the allocation of resources (Bhattarai et al, 2013). Swartz and Jantz (2014) examined a large population (110,455 participants) to ascertain whether there was an association between a specific set of chronic medical conditions (CDCs) and serious psychological distress (SPD) or serious mental illness (SMI). Their findings suggest there is a higher probability of SPD-SMI for many CDCs in general, but there was no specific pattern

for multimorbidity and SPD-SMIs. The link between mental health and chronic illness has led to calls for integrated healthcare services (Mujica-Mota et al., 2014). One focus for this research and other studies is to understand the demands made on healthcare systems by those with multiple morbidities, so that resources can be used most effectively.

A qualitative study by Stanners, Barton, Shakib, and Winefield (2014) interviewed people with multiple morbidities and suggest that their mental state is influenced by their functional and social losses. They become increasingly unable to sustain their social connections and undertake the activities they had enjoyed when they were in better health. The consequences may be loneliness and depression. This finding links with the quantitative work of Pettite et al. (2015). Stanners et al. (2014) suggest that psychotherapy may be beneficial.

However, it seems that some people with multiple morbidities are able to make day-to-day adjustments according to their health (Duguay et al., 2014). They suggest that they maintain a positive attitude by focusing on the aspects of their disease over which they feel they have some control such as complying with recommended treatment.

A suggested consequence of the development of depressive illness in those with multiple morbidity is that it has an adverse effect on their ability to manage their pain and maintain a healthy lifestyle (Griffiths, 2012).

1.2.10 Pain

Duguay et al. (2014) suggest that diseases are experienced differently depending on whether pain is present. Those involving pain are more distressing than those whose

symptoms may be less obvious. Diseases that do not cause pain may go unnoticed. Chronic pain is increasing so that it is the most common complaint in UK outpatient clinics (Surah, Baranidharan, & Morley, 2014). Surah et al. (2014) comment that between 40% and 60% of patients with chronic pain have depression. However, although pain and depression frequently co-exist, their possible causal relationship is not known (Kroenke et al., 2011). Gilmour (2015) noted that people who were experiencing pain were less likely to have flourishing mental health than those without chronic pain. Therefore if pain is present it would seem to have a marked impact.

1.2.11 Adapting to illness

White et al. (2015) interviewed 16 adults with one or more chronic health conditions for their grounded theory study. The type of interview is unspecified and carried out in two stages. Recruitment maximised the differences between participants. Four categories of meaning were identified from the data obtained relating to living with ongoing illness. The stages the participants described were focused on the awareness that something was not right with them, what that might be, gaining control of their illness and getting on with life. White et al. (2015) noted that participants responded to the onset of new symptoms with skills and knowledge based on their life experiences. It seems that the expertise they gained while living with one health condition helped them to respond to subsequent health conditions.

In a meta-ethnographic synthesis on phenomenological studies of patient experience of chronic illness, Röing and Sanner (2015) highlighted concerns related to illness as a threat to identity and self-esteem, a diminished life world related to the physical impact of illness and a changing reality resulting from their different embodied experience.

Charmaz (1995) considers that serious chronic health conditions bring about identity changes and can undermine the unity of body and self. The ill body intrudes on daily living and can threaten identity. However, people are able to adapt to the losses brought about by changes in their body and physical functioning. She describes three major stages. The first is experiencing the extent of impairment, the second is the revision of identity as gains and losses are assessed and the third is giving oneself to the illness and accepting the experience of it. People repeat this process as new losses become apparent. It seems that very sick people are able to grow more sure of their identity and their place with others as further bodily losses are experienced.

Allied to the idea of acceptance of physical impairment is the notion of self-compassion, which has been suggested as a factor that protects against the development of depressive episodes (Ehret, Joormann & Berking, 2014). It seems that self-compassion is also associated with the ability to cope better in the context of chronic illness (Sirois, Molnar & Hirsch, 2015). The ideas of self-compassion and acceptance are akin to those described in the six core processes of ACT (Hayes, Strosahl, & Wilson, 2012). They are considered to play a basic role in determining psychological flexibility and how well people are able to adapt to changing life circumstances.

Some people with multiple morbidities appear to be more resilient than others (Reeve & Cooper, 2016). Wiles, Wild, Kerse and Allen (2012) studied resilience particularly from the view of older people and suggest that it may increase throughout life as a result of coping with adversity. The analysis of interviews with 121 participants living in areas of socioeconomic disadvantage in New Zealand suggest that older people have personal characteristics of resilience which are embedded within their social contexts. Aspects of resilience were identified as a positive attitude, accepting

changes with humour, being realistic and embracing life. It seems that some of the participants had the self-perception that they were aging well despite illness and disability, so that although they were vulnerable they maintained a feeling of well-being. Furthermore, Christian beliefs provided a sense of purpose and aided well-being for some.

The Reeve and Cooper (2016) study was limited to two communities of socioeconomic disadvantage and therefore similar results may not be found in other settings. The stated purpose of the study was to explore the understanding of resilience within a population of older people. From the beginning there may have been an assumption that the participants were expected to be resilient and therefore responded in those terms. Participants were selected as being willing to discuss resilience and further participants selected by snowballing so that those recruited may have been perceived to have been those who were similarly resilient. However, this is an interesting study due to its linking of resilience with context, adaptive coping strategies and positive thinking.

Resilience is a term that is understood generally to be the capacity to bounce back when confronted with challenging life events (Silverman, Verrall, Alschuler, Smith & Ehde, 2016). However, it is a broad term and appears to incorporate aspects of adapting to new circumstances. Newman (2005) considers it to be about adaptation in the face of ongoing significant stressors such as chronic illness. Further, Resnick and Inguito (2011) add that it also incorporates traits of the individual as well as characteristics that have been learned through experience. According to Braden (2015), it is about the way people think and the adjustments they make to their lives that enable them to continue on their life trajectory.

Religion or spirituality is sometimes considered beneficial because it aids coping. Rafferty, Billig and Mosack (2015) conducted a mixed methods study to examine the role of communication, appraisals and coping for people with chronic illness for those who reported a level of spirituality or religiosity. Their findings suggest that religion and spirituality may aid positive and supportive interpersonal processes. Participants described how help-seeking conversations with those with similar beliefs provided comfort and aided coping during difficult stages of illness.

1.3 Summary

The literature relating to the experience of people with multiple morbidities including heart failure is patchy and provides a partial picture. Most research relates to the impact on support services of the increasing numbers of people surviving with multiple chronic health conditions. Other studies look at the way in which people receive help from the system and the perception of the way the illnesses impact their living. However, these studies are of a positivist quantitative nature, with the focus being on understanding the impact of the phenomenon on the system, particularly on associated costs. Although interesting and informative, they only provide information about the specific variables being investigated, for example, the relationship between multiple morbidity, higher rates of disability and lower quality of life. They do not focus on the lived experience of the individual as they receive diagnoses, manage their treatments and medical appointments and live with the uncertainty of disease and possibility of further illnesses, limited activities and death. Information is therefore limited, and poses many more questions, which would appear to be approached better from a qualitative viewpoint, i.e. looking into the experiences of the individual. There are increasing numbers of studies that are qualitative and focus on the experiences of participants. Although the findings obtained from these may not

be generalisable to the population as a whole, they have value in that their focus is the perspective of the individual.

The findings in the literature indicate possible roles for the counselling psychologist to provide support to multimorbid people who may be faced with issues concerning their current and future existence. Counselling psychology is broadly based and focuses on well-being and self-actualization, recognising the uniqueness of people and helping them to live in a more effective and fulfilled way (Nelson-Jones, 1982). It sees the person as a whole and focuses on all areas of psychological functioning. Counselling psychologists work in a variety of settings including in the community, in hospitals and through voluntary agencies. There are four main therapeutic approaches, which are psychodynamic, humanistic, cognitive behavior and a group of more recent therapies (Nelson-Jones, 2015). The focus of intervention for those with multiple morbidities might be on well-being, adjustment and finding meaning. It may be that pain and reduced quality of life have negatively affected mental health so that depression or other mental health issues are present. The role of the counselling psychologist might be to aid the person to grow, develop and find meaning as future life becomes more limited and each day becomes more precious.

In conclusion, there are many unanswered questions about the experience of people who have stage 3 heart failure and other chronic health conditions as they receive successive diagnoses. For example, it is not clear from the literature if successive diagnoses are experienced in the same way as the initial diagnosis of a serious illness. Nor is it clear how much the experience of receiving further diagnoses impacts the experience of living. It is hoped that this study will shed some light on some aspects of this and illuminate possible roles for the counselling psychologist.

1.4 Introduction to this study

The review of literature shows little research focus on the lived experience of those who are diagnosed with multiple illnesses, including stage 3 heart failure. Research largely focuses on quantitative studies related to the needs of the health system, which in turn is charged with meeting the needs of these individuals. It seems that more research into the experiences of the increasing number of people with multiple morbidities might provide richer information. Although the findings will only relate to those participants in this study they may add to the body of knowledge in this area. For this reason, this study is qualitative and looks at how people experience successive diagnoses of multiple illnesses.

Curiosity about the experience of those who are life-limited and have a number of chronic illnesses began when the researcher was on a placement as a counselling psychology trainee in a community palliative care service with patients with advanced heart failure and other illnesses.

The aim of the study is to examine the lived experience of receiving successive diagnoses for people with multiple chronic health conditions, including stage 3 heart failure. It is hoped to illuminate the experience of living with a deteriorating body where the person is informed repeatedly that they have developed another disease.

Chapter 2: Methodology

2.1 Research Design

2.1.1.The development of the research question

Initially the focus of the research was the experience of living with multiple chronic health conditions. The title submitted in the application for NHS Ethics reflects this. However, discussions with the research supervisor identified that this was lacking specificity. It might produce data pertaining to a wide range of aspects and would therefore be difficult to analyse. Smith et al., (2009) warn against the research question being over ambitious. It was decided that a sharpening of the exact phenomenon under examination would produce a more specific focus for the research and the results of the analysis would likewise pertain to a more clearly defined phenomenon. The original idea for the research was prompted by observation of the impact of experiencing another diagnosis for those with multiple morbidities. Consequently, the research question was narrowed to target the experience of this phenomenon. This refinement took time and much discussion, not only with the research supervisor, but also with the team of heart failure nurses who were introducing the research to their patients. By the time the first participant volunteered, the heart failure nurses were aware of the shift in focus and the questionnaire had been refined.

However, the information provided for the participants refers to "coping with" and "managing" conditions which do not reflect the developed focus of the question. The information pack was distributed to the nurses for discussion with possible participants prior to the refinement of the research question. In order to ensure that the participants had been informed appropriately, the focus on diagnosis was explained when initial telephone contact was made and again prior to the interview.

The participants were not asked to sign the consent until they were clear that the interview would be about their experiences of receiving successive diagnoses, which was the phenomenon under investigation.

2.1.2 Rationale for using a qualitative approach

This research is attempting to address the question, "What is the experience of receiving successive diagnoses for people with multiple chronic health conditions including stage 3 heart failure?" The intention is to find out about their experience by asking them, listening to their answers and negotiating the meanings of those answers. Qualitative research will be used because, as Willig (2008) says, qualitative research is about the construction and negotiation of meaning and the quality and texture of experience. The data collection techniques allow participant-generated meanings to be heard. As qualitative research tends to use only small numbers of participants due to the time-consuming nature of data collection and analysis, the results cannot be claimed to be representative of people who have successive diagnoses of a number of chronic health conditions. However, what can be said will be "true" for the participants within their own experience. This contrasts with quantitative methods, which are concerned with being able to measure the phenomenon under examination (Langdridge, 2007).

Smith (2008) comments that qualitative and quantitative research methods are different in the way the data are analysed. Quantitative research requires the use of numerical values that can be analysed using statistics. This is the case whatever material is gathered, so that even verbal responses are reduced to numbers. Qualitative research is about data collection in the form of naturalistic responses and is concerned with the meanings of that data rather than reducing it to numbers and analysing those.

Smith, Flowers and Larkin (2009) describe qualitative research as tending to try to explain associations between events i.e. what happens when. It is about looking into, describing and interpreting the experiences of participants. The process involves trying to understand how they view the world through their own frame of reference, rather than trying to test a hypothesis. It is about the meanings people make about what they experience.

Within this there are a number of alternative research strategies. The choice of the question and the way that is formulated leads to the choice of the most appropriate qualitative approach.

2.1.3 Introduction to Interpretative Phenomenological Analysis (IPA)

IPA is a method that is concerned with the detailed examination of particular instances of human lived experience. It is about looking at how people make sense of their world (Smith & Osborn, 2008). In this case, exploring a person's relationship with and/or involvement in the process of being given a series of diagnoses. The researcher is required to get close to the participant's world, or in the words of Conrad (1987) to take an "insider's perspective". The researcher developed deep concern about the topic when working with a group of people with multiple chronic illnesses and felt able to relate to them due to a long-standing interest in understanding their world. However, the researcher does not have multiple chronic health conditions and so cannot view the research position as an insider in the group. As IPA is an interpretation, a double hermeneutic is involved. That is, the researcher endeavours to make sense of the participants trying to make sense of their world. This is clearly complicated by pre-conceptions and ideas, which the comments on reflexivity will address.

IPA is always interpretative, but Smith et al. (2009) describe different levels to that interpretation. Initial attempts at interpreting the text tend to be descriptive rather than interpretative. One of the challenges of IPA is to dig deeper and move to a more detailed reading of the transcript. Short extracts of interest can be analysed again in more depth, once the initial analysis has been done. Interpretation at this depth may reveal information of which the participant might not be aware. This detailed analysis can be seen to be related to analysis of the complete interview. Thus one illuminates the other. This can be viewed in terms of the hermeneutic circle, where a move is made from the whole transcript to a particular passage.

2.2 Epistemological Considerations

According to Willig (2008) epistemology is about how and what can we know. In this case it is possible to ask those with chronic multiple health conditions what their experiences are, i.e. what it is like to be them in their circumstances. Whatever they say is taken as an insight into their view of the world. It is not about predicting, but about being open enough to allow unexpected meanings and categories to emerge. It attempts to avoid the reduction of data at the point of collection. The reduction occurs at the data analysis stage.

The set of basic beliefs about how the world can be understood (Langdridge, 2007), informs the researcher's epistemological position. A real world, where things are as they really are and "truth" can be found is not the paradigm here. It is a phenomenological one because the focus is the experience of the individual's world, where each may be different and the data gathered about that world subjective. Therefore, it is about the collection of accounts of the participants' experience, which are naturalistic and which acknowledge the influence of the researcher on the way

the data is collected and analysed. This is in contrast to the subject and object

perspective of positivism and scientific approaches.

Looking at this from a realist versus relativist perspective, the realist position would

provide information about the way the world really is and know the findings to be true

(Willig, 2008), whereas the relativist position says that there is no such thing as "pure

experience" (p.12). Here the researcher's position is somewhere in between, as a

"critical realist" (p.13) in that the research aims to gain a better knowledge of what the

experience is of having several diagnoses of multiple chronic health conditions (a

realist position) with the knowledge that whatever data is gathered may not give

access to this reality.

2.2.1 Phenomenology and IPA

Phenomenology in psychology is about a focus on people's lived experience

(Langdridge, 2007). It had its origins in the early 1900s when Edmund Husserl put

the philosophy of lived experience at the centre of a new way of thinking (Langdridge,

2007). From this viewpoint there is no real world that can be measured and tested so

that it is known. Rather, that the focus is on the perception of the individual's world

and how it is experienced, which may change over time and in different contexts. To

study a certain phenomenon, participants are sought who have first-hand experience

of it and who are able to describe it (Giorgi & Giorgi, 2008).

Heidegger argued that our worlds must be seen within their historical and cultural

contexts and the role of language used in that context (Langdridge, 2007). That is to

say that it must be interpreted, which was a move towards hermeneutic

phenomenology. The shift is from descriptive phenomenology to that of hermeneutics

and interpretation.

IPA, also has a third major strand of idiography (Smith et al., 2009). This is focused on what the experience, in detail, is like for this person in this situation. Usually more than one case study is used. The analysis initially involves the detailed examination of the transcript in each case and cautiously moves to look at the similarities and differences across a number of cases. The aim is not only to produce an account for shared themes, but also allow the individual differences in experience to be described.

IPA was developed by Jonathan Smith and is probably the most widely used approach by phenomenological psychologists today (Smith et al., 2009). It is rooted in hermeneutics and so is concerned more with interpretation rather than description. According to Smith and Osborn (2008), IPA depends on sense-making by both participant and researcher. They add that there is no definitive way of doing IPA, but that the theoretical commitment to the participant assumes that what they say is connected to their thinking and to their emotional state and so is available for interpretation by the researcher (Smith & Osborn, 2008).

2.3 Reflexivity

Gilgun (2005) defines reflexivity as the awareness of the reflexive researcher about the multiple influences they have on their research and how the research affects them. In practice it is about being aware of influences and being honest and open in the approach to the research and the reporting of it. There are three areas that are important for the researcher to consider. Firstly, there is the topic and the personal and professional meanings it may have for them. Secondly there are the perspectives and experiences of those involved in the research, including

participants, settings and funders. Thirdly, there are the audiences for which the research is intended.

On-going reflection on the researcher's and participants' experiences during research may help to reveal interests and perspectives that might influence the process. Noting these ideas as they arise can help to focus the researcher on those areas which are relevant. However, Gilgun (2005) takes the view that only those parts of reflexivity that enhance understanding of the research process should be included in a research report. Reflexivity is the researcher's experience of the research and can help others to understand some of the issues.

2.3.1 Epistemological reflexivity

According to Willig (2008) epistemological reflexivity is about the ways in which the research question, design and method limited and shaped the data and the findings. Therefore, the researcher needed to be conscious throughout the research about the assumptions that are embedded in the research question and approach.

IPA is an approach that invites participants to give a rich, personal account of their experiences (Smith et al., 2009) and is therefore suited to the kind of research question posed in this study. The way in which the research question is framed suggests the most appropriate qualitative approach to employ. For example, if the question were "What factors influence how people manage successive diagnoses of multiple chronic health conditions?" then grounded theory may be the preferred research method. If the question were "How do people talk about their diagnoses of multiple chronic health conditions in close relationships?" the chosen research method might be discourse analysis. For narrative psychology the question might be,

"What sorts of story structures do people use to describe being diagnosed with multiple chronic health conditions?"

Any of these alternative qualitative methods could have been used to study the experiences of people with multiple chronic health conditions, but only IPA looks at the lived experience of the individual and allows that to be valued as a "truth" in its own right. It is therefore the method chosen to answer the question in this research study.

2.3.2 Personal reflexivity

Throughout the study the researcher was aware of their own contribution to the construction of meanings (Willig, 2008). According to Willig (2008), this is concerned with "the ways in which our own values, experiences, interests, beliefs, political commitments" (p10), in fact all experiences and beliefs, have impacted the research. She argues that it is not possible to put aside personal perspectives and understandings whilst undertaking research.   Reflexivity provides a way for the researcher to look at the ways in which their personal involvement impinges on the research. It, therefore, provides a process for looking at how the researcher's perspective may have shaped the data collection and analysis including interpretations.

Throughout this study, the researcher has reflected on the personal impact of the process and how it might have changed her and how her perspective might have impacted the research processes. These were noted throughout the study and are presented in Chapter 4, Discussion. The intention throughout is clarity and honesty as far as possible about perceptions, assumptions and feelings.

2.4 Research strategy

2.4.1 Semi-structured interviews

Smith and Osborn (2008) state that IPA requires an instrument to collect data flexibly and notes that a semi-structured interview is the best way to do this. The reason is because it enables the participant to speak about their experience and the way they make sense of what is happening to them with the minimum of intervention from the interviewer. This can then be analysed in detail and is the method most widely used with IPA. It is flexible because it allows modification of the questions asked in the light of the participant's responses and so facilitates questions to be asked that go further into their perception and sense making. It allows gentle guidance from the interviewer to elicit their experiences included prompts that could be used to the extent that they were needed (Appendix F).

The schedule used was modified after the first two interviews. Two questions were changed so that they were couched in more accessible language. For example, "What does the term "illness" mean to you? How do you define it?" was replaced by "Do you regard yourself as an ill person? How do you think others see you?" The miracle question was added to provide a further opportunity for participants to talk about aspects of the phenomenon.

Once the participant understood the focus of the interview, the first question was used to begin engagement with talking about the experience of multiple diagnoses and their impact. Most of the interviewees spoke freely and confidently, sometimes checking that their comments were relevant. Asking further questions was sometimes not necessary as the participants covered them as part of their contribution. The focus of the interview was the participants' experience of receiving

successive diagnoses, but also allowed the participant space to talk about matters they felt relevant.

As a trainee counselling psychologist the researcher has had experience of working with people to elicit their thoughts about their world in a professional context. The skills of listening, checking meaning, asking further questions and rechecking were used to gain insight into their thinking. These are useful skills in this context. Further, the use of understanding and empathy allowed awareness of any areas of difficulty for the participant and so changes were made to the pace and style of the interview to facilitate their continued conversation.

Other methods of data collection, such as personal accounts and diaries were rejected, because the researcher wanted the direct contact with the individual so that a rapport might be established. Areas of interest were probed as they came up and the participants' ideas and concerns were followed as suggested by Smith and Osborn, 2008.

2.4.2 Pilot interview

A pilot study was carried out to assess the effectiveness of the proposed semi-structured interview schedule and as practice for the interviewer. It also facilitated practice for setting up and using two audio recording devices. Two devices were used in case one failed.

2.4.3 Sampling and participants

Discussion at an early stage focused on the participants to be recruited. The starting point was that they should have multiple morbidities. Through discussion with the

research supervisor it was decided that 3 or more conditions that needed regular treatment would be the basic criteria. Heart failure was selected as one of these, because there appeared to be less research into the experience of receiving a diagnosis of significant heart failure. It was decided that the group might be made more homogenous by choosing a certain level of heart disease. Stage 3 heart failure was chosen because it is at this stage that the person's physical abilities decline markedly. Detailed discussion with the nurses produced agreement that the participants would have multiple morbidities, each of which needed regular treatment or monitoring, but the illnesses were not specified.

The accounts were elicited from those who are able and willing to provide their view of the phenomena under investigation (Reid, Flowers & Larkin, 2005). In this case, the participants were selected because they have Stage 3 heart failure (NYHA, Appendix A) alongside at least two other illnesses for which they were receiving treatment. A minimum of three morbidities was chosen because it was hoped this number would provide insight into the phenomenon of receiving successive diagnoses. It was felt that setting the number higher might have made recruitment more difficult as there would have been fewer people with greater numbers of morbidities and the impact of their morbidities might have been such that they would have felt unable to take part. This area of research is particularly interesting, because people are living for longer periods of time with stage 3 heart failure, due to the improvements in drugs and treatments. The participants had received their diagnosis of stage 3 heart failure at least six months prior to the beginning of the research, so that they had some time to consider its meaning for them. As this group of people has a number of illnesses, they are potentially vulnerable and so care was taken to ensure that they were willing participants and that the interview process did not cause them any harm.

The Palliative Care Service, where the research was conducted, routinely uses the Distress Thermometer (Appendix H) to assess the patient's emotional well-being. Any patient with a score of between eight and ten is generally considered by The Palliative Care Service to be in some significant distress and therefore those with high scores were not approached for the study. They were excluded because it was felt that interviewing them might cause further distress. Those with lower scores would have experienced multiple diagnoses and might be able to describe what it was like for them, including any distress. However, it should be noted that, when used for cancer patients generally, the Distress Thermometer has 4 or 5 as the cut-off score for optimal sensitivity to specific areas of difficulty (Donovan, Grassi, McGinty & Jacobsen, 2013; Jacobsen et al.,2005; VanHoose et al., 2014).

People with on-going mental health issues would be included, if those were being well managed and the person felt able to sustain the interview. However, there were no participants included who had identified mental health issues. It may be that the nurses interpreted the criteria as relating only to chronic physical conditions as they may have taken a purely medical viewpoint without considering mental health conditions. It would have been prudent to have checked with the nurses that they had understood that the criteria related to all conditions.

The initial selection of possible participants was carried out by the Clinical Nurse Specialists (CNS) Heart Failure. They identified those who appeared to fulfill the criteria and discussion with them provided information about whether those identified were considered stable enough and well enough to take part in the interview. Consideration was given to whether or not the CNS believed that the person had the physical capacity to sustain conversation for the duration of an interview.

It may have been that some of the prospective participants would not speak English fluently enough to manage the interview without an interpreter. In this case they would have been excluded because richness of the participant's experience might have been lost in translation. In practice, although not all the participants had English as their first language, they were all able to express themselves well.

IPA researchers usually seek a fairly homogenous sample of participants (Smith, 2008). This is because it would not be helpful to consider random or representative sampling with a small number of participants. In this case the number used was six. The intention of the sample was that there would be an amount of homogeneity across it because all participants would have had the experience of receiving multiple diagnoses. Some heterogeneity was retained by allowing for diversity of experience across the group, as there was a range of additional illnesses.

The sample consisted of six participants of whom three were men and three were women, aged between 64 and 93 years of age. These were the only volunteers. The criteria used for selection and recruitment limited the number of possible participants. According to Smith et al. (2009) they must be sufficient in number to allow some similarity and difference to show across them. The number identified and willing at the time of the study were recruited, but this was not so many as to overwhelm the data collection and analysis stage.

The demographics of the participants were gained by information supplied by the Heart Failure Service team, so that some similarities and differences in these factors were apparent. Information such as age, ethnicity and gender was readily available, whilst other factors such as occupation and marital/family status, were gained through the interview process (Appendix J).

Any patients the researcher had worked with during the trainee placement with the Palliative Care Team were excluded from the study due to concern that the participants should in no way feel that the research and their clinical care were connected. Separation of these was important so that there could be no confusion about the role as a researcher as distinct from the role as a clinician.

2.4.4 Recruitment

NHS Heart Failure Team Clinical Nurse Specialists identified possible participants through their knowledge of the patients on their caseload. The criteria for inclusion (given above) were used for the initial identification by the nurses, so that patient records would remain confidential. Reliance on selection by proxy presented a challenge because the researcher had no control over those selected.

Further discussion with the Consultant Systemic Therapist was arranged so that the appropriateness of the patients participating might be determined.   The Clinical Nurse Specialist discussed the study with the patient (possible participant) on one of their regular visits to the patient's home. Once the selection was made and assurance given that the person was physically and emotionally able to participate, an invitation letter with reply slip (Appendix C) was given to them, with a Participant Information Sheet (Appendix D). If the reply slip was returned showing that they were interested in being a participant, a telephone call was made to them to answer any questions they might have and, if they were still willing, to set a date and venue for the interview. Close liaison with the heart failure nurses was effected throughout.

2.4.5 Inducements

No inducements were offered in this study.

2.4.6 Interview procedure

The initial part of the interview was focused on ensuring that the participant understood what the study was about and how the interview would be conducted. If they were happy with that, they were invited to sign a consent form (Appendix E). Six participants were interviewed to gain access to their lived experience. The feedback received at the time of the interview indicated that they had enjoyed the experience and were pleased to take part because they felt that it may help others. Most of them seemed to be reluctant to end the interview. They did not appear to find the experience upsetting.

2.4.7 Ethical considerations

My research was carried out in line with the four principles stated in the British Psychological Society's Code of Human Research Ethics (2010) and Code of Ethics and Conduct (2009). The four principles are that participants should be treated with autonomy and dignity, that the study should have scientific value, that social responsibility is exercised and that the study should maximise benefit and minimise harm.

Risk

At all times throughout the study the researcher was conscious of the potential for doing harm. Although the participants were vulnerable people, they had the capacity to consent. The interviews were conducted so that some equality of relationship was established in the hope that the participants felt able to speak freely.

Valid consent

The participants were fully informed about what would happen during the interview prior to it taking place. The CNS (Heart Failure) informed the participants about the process and spoke about the information contained in the Participant Information Sheet (Appendix D). On the day of the interview the process was reiterated so that the participants had clear, accurate information about the project, particularly about confidentiality and that the interview would be recorded. When they said that they understood and were willing to participate, their written consent was obtained (Appendix E).

No deception

The researcher has endeavoured to be open and honest about the aim of the research, which is to try to understand the lived experience from the participant's perspective. There was no intention to deceive the participants in any way.

Right to withdraw

The participants were told that they were able to withdraw at any time until the data had been collected and analysis had begun. It was clearly stated on the letter provided and was reiterated at our meeting that they could withdraw from participation without any fear of being penalised. In particular, there may have been concern that their treatment might have been affected and so care was taken to make clear that this would not be the case.

Debriefing

The participants were given an accurate description of the full aims of the research. A debriefing took place (Appendix G) during which the participants were offered access to a short version of the results. All participants said that they would like to

receive this as well as access to any publications arising from the study. If there was any distress apparent during the interview, there was a planned protocol to refer them to the relevant clinician for appropriate support. The interviews did not take place late in the day because the availability of support might be reduced. Additionally, the participants all had a telephone number for their CNS, if they felt they needed to contact them following the interview.

Confidentiality

The participants were assured that complete confidentiality about any information given during the interview process would be treated in line with Data Protection legislation. In practical terms, all transcriptions are being stored anonymously. Any information which might link the participant to their transcription has been kept securely at the West Hertfordshire Community NHS Trust. Information will be kept for ten years so that it is available in case of a complaint. Any information held by the researcher is anonymised and kept securely. Consent was gained from the participants to use anonymous quotations from the transcripts in the research findings. Any identifying elements have been omitted to prevent the identification of the participants.

2.4.8. Necessary Ethical Approval

Initial ethical approval was given by City, University of London (Appendix B). As this study arose out of a need established at a trainee placement with the Palliative Care Team at West Hertfordshire NHS Trust, it was agreed with their MacMillan Consultant Systemic Therapist, that the study would recruit participants from that service. Ethical approval from the National Health Service Research Ethics Committee was sought, as well as approval from the local research and development team at Welwyn Garden City. This took several months to complete, but was a useful process in that it

provided the opportunity to think clearly about the detail of the research purpose and method as well as protection of the participants. Attendance at the local Research Ethics Committee (NRES Committee South Central – Oxford C) on 31st October 2014 provided further points for consideration prior to ethical approval being granted on 3rd December 2014. Appendix I is my response letter to the committee's concerns.

2.4.9 Transcription

The whole interview was transcribed, including the interviewer's questions. The transcription included all the words spoken, pauses and significant sounds. This was a time-consuming activity, carried out by the researcher and was considered to be a useful activity because it required repeated careful listening to what the participant was saying as well as how they were saying it.

2.4.10 Analytical strategy

The purpose of IPA is to provide an understanding of the complexity of the meanings that the participant has shared during the interview. The analysis processes were based on the suggestions given in Smith et al. (2009) who stress that the process is sufficiently flexible to allow individual ideas and creativity. It is not a rigid process, but one that is evolving and adaptable to suit researchers' personal ways of working (Smith & Osborn, 2008).

IPA follows the idiographic approach to analysis, looking at the particular prior to moving slowly towards general claims.

For this study six participants were interviewed. Each case was examined individually, looking at each one in detail prior to moving on to the next. According to

Willig (2008) the role of the researcher needs to be acknowledged throughout the process and therefore thoughts in response to the interviews and the texts were recorded in a research diary.

A flexible approach was maintained throughout as there is no correct recipe for doing IPA analysis (Smith & Eatough, 2007). Willig (2012) describes the range of meanings that interpretation might generate such as understanding the participant's meanings, their unconscious communication, the context in which they said what they did, or perhaps a more general psychological concept.

Reading and re-reading

The transcript was read a number of times to gain familiarity with the account as suggested by Smith and Osborn, 2008. The attempt was to immerse oneself in the data so that a sense of the overall interview is gained and that the researcher becomes open to that text and familiar with the participant's world and begin to gain understanding. Listening to the recordings whilst viewing the transcripts helped recall the experience of the interview.

Initial Noting

The next stage was making initial, exploratory comments, which included anything that stood out, including connections and initial interpretations. Sometimes the comments were about the use of language and sometimes an understanding of the person. All the time the researcher endeavoured to stay close to the data so that claims made later could traced back to the participant's account and evidenced*.* Focus was maintained on the whole interview whilst at the same time looking at individual parts. There was a temptation to reduce ideas during this stage, but it is

important to delay reduction until later, after the initial analysis is complete. This was a time consuming exercise, which entailed detailed examination of the text. The focus was to stay open to the text and take the time needed to consider the descriptive and phenomenological aspects presented. In particular, looking at the specific ways in which a participant talked about and understood an issue.

Exploratory Coding

The third stage (exploratory coding) involved a detailed examination of the text, looking at it word by word and line by line, The three main areas of interpretation were labelled 'descriptive', 'linguistic' and 'conceptual' (Smith, et al., 2009, p84) and facilitated the detailed and disciplined examination of the data. The descriptive level focused on what the participant was describing. It is at a superficial level and is what is immediately apparent to the researcher. The linguistic focused on the specific use of language used when describing their lived experience, including repetition and laughter. The conceptual level focused on interrogation of the data and looking for meanings behind it. The questions posed may have led nowhere, or caused re-analysis of the data and perhaps some tentative answers, sometimes moving on to a more abstract level of analysis (Smith et al., 2009). This process of analysis enabled the researcher to draw on professional and experiential knowledge to help in the understanding of the experience of the participant. These comments were handwritten during a process which was extremely time consuming as the script was reviewed time and again to ensure that all that might be of interest had been included. The researcher noted that on different days there might be a different awareness of certain aspects of the participant's world and so re-examination of the text was invaluable.

Development of Emergent Themes

The initial emergent themes were developed from the exploratory coding notes and involved the synthesis of interrelationships, connections and patterns. The idea being that the theme attached to a specific part, or parts, of the text provided a succinct statement. Therefore, they reflect not only the words of the participant, but also the researcher's interpretations of their meaning.

During this process it seemed as though the experiences of the participants were being fragmented and, at times there was the feeling of losing the participant in the chunking up of notes into themes in order to reduce the volume of detail. The idea is that the notes are transformed into psychological concepts and abstractions. Theme labels were applied, but subject to change as the overall picture changed. The connection between the participant's words and the researcher's theme labels was maintained. The script is fragmented in the hope that it will be brought back together to create a new completeness at the end of the analysis. Smith et al (2009) identify this as a manifestation of the hermeneutic circle. An example of the development of emergent themes is presented as Appendix K.

Looking for connections across emergent themes

As a result of the above process, a list of emergent themes in chronological order was typed up and printed (Appendix L). The items on the list were cut up individually and laid out on a large table so that themes might be identified which might relate to each other. This is one method identified for this stage of the analysis by Smith et al.

(2009). The number of themes identified for a particular passage varied in number and indicated the richness of the text. These were reduced to a manageable number by grouping those that overlapped, so that there were between 30 and 50 emergent themes to take to the next stage to be put into clusters. The clusters formed were of those concepts or ideas that were considered to be related. They were labelled in such a way that their label captured the essence of the themes within it. A summary table of cluster themes and the related emergent themes was constructed for each transcript as advised by Smith et al. (2009). Each theme was connected to the text by reference to page numbers and a short quotation. An example of this table is included at as Appendix M.

Moving on to the next case

To maintain the idiographic approach of IPA each interview was viewed separately using the above steps. Once the process was completed for one transcript, the next was examined, attempting to analyse each case on its own terms. An attempt was made to bracket the ideas that had emerged from previous transcripts, although this is not entirely possible. The desire was to engage with the individual's subjective experience and be open to what they were saying at face value, and, perhaps, be surprised by what emerged.

This involved considerable thought about which themes might be emerging. At this stage, the data were reduced. The transcripts were repeatedly reviewed in the light of the emergent superordinate themes.

Looking for patterns across cases

Each table of superordinate themes, clusters and theme labels was laid out on a table to see what connections might be made between the cases. Initially the strongest themes were identified. The higher level themes produced were grounded in the transcript text. This led to an iterative process of relabelling and resorting of themes. The aim was to produce over-arching themes that captured both the lived experience of the participant as well as looking for higher order qualities the cases might share. As suggested by Smith et al. (2009) a table of themes for the group, showing how each theme sits within a overarching theme with an illustration for each participant was constructed. (See Appendix N)

2.4.11 Methodological and procedural reflexivity

All of the participants involved were generous with their time and appeared open and trusting. They expressed themselves willingly and genuinely seemed to want to help with the research study. Consequently, by entering into their world during the interview and analysis, there was awareness that the resulting conversation was a product of the interaction between researcher and participant. As an active participant in the process, the researcher must have had some impact on the data collection and on the analysis. This is in line with the researcher's epistemological position as a critical realist, where the participant makes sense of their reality in a context followed by an interpretation of what they have said.

A diary was kept throughout the data collection and transcription stages in which responses to and thoughts about the interviews were noted. Any relevant comments made by participants outside of the recorded interview were also noted as well as the

researcher's personal reaction to the person just met. The researcher reflected on the level of empathy felt as well as a consideration of how much the outsider status affected the process of the interview.

After the initial interview there was a supervision meeting that was used to talk through the perceived effectiveness of the process and whether the desired depth was being achieved. As a novice interviewer there was concern that the interview schedule might have been adhered to too rigidly due to anxiety about achieving appropriate data. In subsequent interviews increased familiarity with the schedule allowed less rigidity in approach and so the focus was more on allowing the participant to talk, only intervening when needed. This was considered to have improved the quality of the data, as the participants were able to talk freely about their experiences. At this stage, the researcher also reflected that part of the difficulty might have been concern that experience as a trainee counselling psychologist might reduce the effectiveness as a research interviewer.

Time after time there was an element of surprise at the views expressed by the participants in the interviews. The unexpected permitted the researcher to reflect on the level to which prior knowledge and belief had not been bracketed, but had influenced expectations.

2.4.12 Validity

The question of validity was raised at the Regional Ethics Committee. The researcher was asked to explain how the validity of the research would be assured. According to Willig (2008) validity concerns the extent to which the "research describes, measures or explains what it aims to describe, measure or explain" (p.16). The research in this case is into the experiences of certain participants. It does not

claim to provide results which can be generalised, or hold true for other people with similar experiences. As long as the attempt is made to try to understand what the participants are saying and reflection is part of that process, there may be a reduction in the imposition of meaning on the data and validity promoted. Oversight by the research supervisor aided this process.

Chapter 3: Analysis

3.1 Introduction

This section aims to present a range of data relating to the analysis of the transcripts of the six people interviewed that focuses on their experiences of receiving successive diagnoses. The data will be presented, explored and discussed systematically with reference to the themes that have emerged. Quotations throughout will relate the analysis to the evidence base.

Three overarching themes emerged during the process of analysis and offer fresh insight into the phenomenon being investigated, about which there is little in the literature. Priority was given to those themes that appeared to relate most closely and significantly to the experience under investigation, which is "What is the experience of receiving successive diagnoses for people living with multiple chronic health conditions including stage 3 heart failure?" This chapter is an interpretative account that aims to highlight the pertinent and interesting aspects that have emerged from the research process and represent one way of making sense of the data obtained. The results presented are the researcher's interpretation of the participants making sense of their experience of the phenomenon under investigation. Other researchers may have highlighted and focused on different aspects of the accounts, as they might bring a different personal perspective to interpretation. Each participant has been given a pseudonym to ensure their anonymity and the names of people and places are shown as { } for the same reason. Whilst the themes presented were common to each of the six participants' accounts, there is also a degree of divergence, which will be highlighted when it occurs.

The three overarching themes that emerged from the participants' narratives are listed below and will be commented on in turn. Each was present in the analysis of most of the participants. They are:

1. Acceptance of successive diagnoses
2. Importance of others
3. Meaning of time (Temporality)

The hermeneutic commitment of IPA was honoured, as the participants spoke about making sense of their experiences and responding to them in their own individual ways, whilst the researcher interpreted through personal understanding.

Throughout this chapter, participants' words are quoted and have been very minimally edited for clarity. Utterances have only been omitted where they were not directly relevant to the theme being outlined and do not affect the overall meaning as conveyed by the participant. These omissions include false starts and hesitations, where they are perceived to have no relevant meaning. Laughter, pauses etc. are shown within brackets ( ). Where words have been omitted, they are represented by "…". Great care has been taken to remain as close as possible to the participants' dialogue. The quotes used are otherwise included as they were spoken, enabling the reader to gain a sense of each participant. Quotes are labelled with the participant's name followed by the page number and the first line number of the transcript from which it was taken. For example, (Angela, 15/16)[1].

The list that follows shows the three overarching themes and the subthemes within them.

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[1] Quotations are cited with the participant's pseudonym and the page/line number of the quote in the transcription.

LIST OF THE THREE OVERARCHING THEMES AND CONSTITUENT
SUBTHEMES

1. Acceptance of successive diagnoses

    1.   The relationship with illness

    2.   Adjusting to life with illness

    3.   Impact of diagnoses

    4.   Managing emotional responses

2. Importance of others

    1.   Social self – the need for others

    2.   Dependence on professional support

    3.   Relationships with family

3. Meaning of time (Temporality)

    1.   Importance of the past

    2.   Hope for the future

    3.   Focus on death

The three overarching themes are detailed below with quotations from the

participants, which are described and interpreted in terms of the research question.

During the data collection I made notes about my observations of the participants in

relation to the research question. These reflections are presented in italics

throughout this chapter.

3.2 Overarching Theme 1: Acceptance of successive diagnoses

The acceptance of diagnoses and the impact of illness are complex. Four subthemes emerged from the analysis. These are: the relationship with illness, adjusting to life with illness, impact of diagnoses and managing emotional responses.

3.2.1 The relationship with illness

Each of the participants has developed a relationship with their illnesses due to the prominent role they play in their lives and the impact they have had on their life expectancy. Paradoxically, the participants showed an acceptance of their morbidities and adjusted their lives, whilst not perceiving themselves as ill. They seemed to be saying that they have diagnoses and so recognise that they have illnesses as defined by the medical profession, but unless they are feeling much more ill than is usual for them, they do not perceive themselves as ill. Perhaps there is a perception of degrees of illness, where there is a tipping point beyond which they consider themselves to have become ill. It seems that four of the participants have been given labels for their illnesses that do not relate to their felt sense and so they are able to disregard them to some extent. Janet explained:

> I suppose whatever I've had go wrong with me has not made me what I consider ill. I've still been able to walk around, do things. I think of really ill when you see some of these poor devils who are lying in bed, being knocked out and God knows what else. To me, that's ill. I mean, I know I'm ill and I know deep down I've got a lot wrong with me and things like that, but when you've got no pain or discomfort or anything from that particular thing, you don't think about it, do you? (Janet, 24/17)

She thinks positively about her own precarious situation. Janet would have to feel much more unwell than she does at present to make her identify herself as ill, despite her acknowledgement that she has multiple diagnoses. As long as she still has some capabilities that give meaning to her life, she does not identify herself as "ill" (Janet, 24/17). She implies that pain would provide her with a reminder of her serious illnesses, but the lack of pain does not mean that she is well, just that she is unaware of illness. This seems to be a protective strategy by which she is able to hide it from herself.

Further, she compares herself to those she considers ill, who she refers to as "poor devils" (Janet, 24/20) showing her pity for them and regarding them as being in a much worse situation than her own. It is as though she sees them as victims, as unfortunate people who are suffering from adverse circumstances. In contrast, she does not seem to view herself as a victim, but feels that she is still in control of living her life. Her ideas appear to involve both split and polarised thinking. She regards her own situation as superior, contrasting it with those she considers to be "poor devils". She acknowledges that she is ill "deep down" (Janet, 24/22), indicating that this notion is hidden somewhere within her, so that she attempts to ignore its existence and shield herself from any consequent anguish. Throughout the interview she expressed fears that she may become critically ill at any time, which would result in her suddenly being in the position of one of those people she pities. She spoke of her concern, "…especially if I'm really poorly, you know, you think, this is the start of the end…" (Janet, 20/18). There is a tension between the burying of illness that may allow her to feel in control and illness suddenly bursting out of hiding and taking over.

Embedded within Janet's thinking is the notion that she still retains control over what she is able to do, unlike the person who is "knocked out" (Janet, 24/21), has had control removed by a third party and is powerless to change it. The idea she

expresses is that ill people are unconscious, unaware of life, lying lifeless in a bed and have no control over their fate, including death. Perhaps, the idea of being really ill includes loss of control over what she is able to do, something that might occur at any time.

Lilian attempts to demonstrate acceptance of illness by saying that it's something that she "just has to put up with" (Lilian, 11/15), which shows tolerance, but not necessarily acceptance. It feels as though she is sweeping the notion of illness away and does not want to talk further. She appears to refuse her nurse dialogue so that she is able to defend herself against hearing any further unacceptable aspect of her illness, "Because {HF nurse} said something to do with having a stroke, but it goes in one ear and out the other. I don't, I don't listen to these things. I don't" (Lilian, 27/7).

She is quite emphatic that she does not listen to "these things" (Lilian, 27/7). The vagueness in her language suggests her reluctance to identify illness, indeed a desire to hide herself from the illnesses she faces. She is aware of what is being said as it goes into one ear, but rejects it by saying that it goes out of the other.   The rejection of illness implies that she does know about her illness on some level. Interestingly she goes on to explain, "That's why when I go to {hospital} I have one of my daughters with me, so that they can hear it" (Lilian, 27/9).

Although she is resistant to hearing what the doctors say to her, she implies that she would like someone that she trusts to hear what is said and to be the keeper of that information. It seems that her daughter is able to hear what is being said, but that Lilian is unwilling. Thus, she appears to control any negative news so that she can protect herself from its possible devastating consequences. In contrast, she seems unconcerned about protecting her daughters from news that she does not want to hear, perhaps implying that she regards them as much more able to cope. It seems to

be that Lilian attempts to control her relationship with illness through a strategy of trying to ignore it, or at least, not knowing too much about it.

Perception of the self as not ill appeared to be common throughout the quotes above. Douglas candidly stated his view, "No, I see myself as medical problems, but not ill" (Douglas, 28/14). He perhaps regards the illnesses he has as bringing problems that he must solve. He does not regard himself as ill, because the way he lives his life does not seem to accord with his idea of being an ill person. This view of not being ill is embedded in the thinking of all the participants except for the youngest one, Lilian.

Pain seems to have a particular significance to the participants. Angela describes how she thinks about the meaning of feeling pain, "If something hurts me and I can put my finger on it then it means something, but if I can't tell" (Angela, 6/14).

She observes that if something hurts her that she would be able to point to a precise location of illness within her body. However, if she doesn't hurt, she is able to disregard unfelt illness. This links with Janet's comments about the significance of the lack of pain enabling her to disregard an illness (Janet, 24/23).

Douglas acknowledges his multiple morbidities and that pain is a concern. He minimises this by referring to it as "discomfort more than pain" (Douglas, 6/7). He laughed as he said, "I take co, co-codamols at night. And that eases it and I've got other problems, so one, the one that hurts the most is the one that you worry about. The rest takes a back seat" (Douglas, 6/8).

His light-hearted approach leads me to think that pain is perhaps a major focus for him, but that he is trying to reduce its significance by joking about it. He alludes to life being like a ride in a car where the diseases that are not paramount in his thinking are

consigned to the back seat. He is able to turn his back on them and continue to move forward with his life. However, they are following close behind him.

All the participants acknowledged that they had experienced a succession of illnesses and diagnostic events that involved their bodies deteriorating. Most of them regarded this cycle of illness, diagnosis and deterioration as inevitable and unsurprising. Robert uses the metaphor of a snowball to describe the process, "…then I've had this last five years when things have snowballed a bit. One thing has led to another" (Robert, 13/15). As a snowball grows progressively bigger as it rolls along and becomes more difficult to manage, so it might also refer to the increased effort required to push the burden of increasing morbidities through life. Robert expressed understanding that these illnesses are linked so that each contributes in succession to his growing ill health. However, he did not seem to be unduly disturbed by this, talking about it in a matter of fact manner. He appeared accepting and tolerant of the process, rather than fighting it. As he has aged his morbidity has increased, "…it's been one thing after another. And, and the older I get you seem to get more things go wrong and they take longer to get better…" (Robert, 14/5).

Not only does he accept that age brings increasing morbidity, but also that recovery times are longer. Despite this it seems that he does expect to "get better" from the things that have gone "wrong" (Robert, 14/5). He does not name these as illnesses, but couches them in vague terms, possibly so that he is able to disregard them. Whether he expects a complete recovery or simply an improvement in his physical condition or abilities is not clear. Whichever, the increasing number of morbidities along with the longer recovery time intimates that the morbidity burden is growing in size.

Lilian, too, appears to understand that her condition is deteriorating. She accepts this, despite her displeasure, "It's another, just another thing that I've got to contend with and I don't want to contend with it" (Lilian, 28/6).

The use of the word "contend" (Lilian, 28/6) to describe her feelings with regard to increasing illnesses implies that she is battling to surmount difficulties. The struggle is unwanted, but she reduces its importance with her comment that it's "just another thing" (Lilian, 28/6). She reveals her reluctance to identify any illness by calling it a thing, something that she does not want to give a name to so that it might be denied significance and definition. There is a feeling of weariness and acceptance about her response, as though the battle will never end. She is powerless to stop the tide of illness, but despite this, she seems willing to continue to "contend", at least for the moment.

It was interesting to note throughout the analysis, how often participants referred to their illnesses as problems; the implication being that they might be able to find solutions to them. However, it is my belief is that it is not the illnesses themselves that needed solutions, but the physical challenges that accompanied them. It was this aspect that the participants were looking to address through finding solutions to difficulties they experience in their life world. Throughout the next section the participants show their understanding of their morbidities, but they also show that they are seeking ways to adjust to their deterioration.

3.2.2 Adjusting to life with illness

The participants all made adjustments to their living in relation to the way they made sense of their morbidities and their limited futures within their own life world.

Two of the participants expressed their experience of living through the impact of very long-term illness and their attitude that life goes on whatever. Angela commented:

> I don't think that it has made much difference to me, because they have looked after me very well, and got me better as quickly as they could and life just had to go on. As I said to you, I had four children. (Angela, 15/16)

She asserted the idea that long term illness has made little difference to her, which implies that not only did she feel able to go on with her expected life, but also that she felt that she, herself, was little changed by her experiences. She emphasises the centrality of her role as mother by stressing the importance of having four children when her illnesses began. Her judgment was that the medical care she had received was very good and effective, highlighting the crucial importance of quality medical care for the seriously ill participants in the study in order to maintain their existence. This significant idea will be developed later in this analysis in 3.3.2. Further, Angela uses the word "had" (Angela, 15/18) to demonstrate that her family responsibilities drove her to recover quickly so that her life could continue. She showed that she felt compelled to go on living as she had previously by using "just" (Angela, 15/18) indicating that there was no alternative, so that the continuation of her expected life was simply her only option. She describes how she overcame adversity so that she could continue her life roles of wife and mother.

Robert seemed to show a similar attitude after his first heart attack at the age of 53, some 40 years prior to my interviewing him. At the time that his heart problems began he describes himself as "having a lot of worries" (Robert, 4/1). He regarded his first heart attack as a "warning" (Robert, 4/6) and described his response to these events

Well, it didn't stop me, because I had a disabled son and my problems were still there. And I still had, I'm not blaming it onto him, don't think that, not one bit, but the problems were still there…but we, we got over it. (Robert, 4/12)

Robert continued to live his life after his heart attack, because he felt compelled to do so in order to solve his problems. It seems that he almost ignored his serious illness, so that life could go on. In contrast, "we got over it" (Robert, 4/15) suggests that this was a significant hurdle that needed to be surmounted, and not easy, as otherwise implied. Using the pronoun "we" is indicative of working together with his family as a supportive group, so that he recovered with the help of others. Repetition of the word "we" provides emphasis of the importance of his family to him. Robert's attitude, too, seemed to be that life must go on, so that he returned to his previous role.

Independence was a strong and positively viewed aspect of this theme. All of the participants expressed their determination to be independent and to remain so, continuing to live life as they wanted. This desire seemed to drive their approach to adjusting to their increasing incapacity. Janet showed a marked wish to improve her independence, despite her poor state of health. She spoke about her plans to buy a stair lift to help her if she deteriorated further. However, she also showed that she did not accept this yet, expressing hope that she might become more independent, whilst, at the same time, being flexible enough to prepare a solution for the alternative. In her words, "All these things are in my mind, but not, you know, not this immediate, only because I'm trying to see how independent I can get" (Janet, 14/16). Although she is focused on increasing her independence, the acknowledgement of needing a stair lift perhaps also demonstrates an understanding of her deterioration.

Lilian regarded herself as independent whilst also acknowledging that her capability was reduced, "Yes, well, I mean I'm still independent even though I can't do things for myself" (Lilian, 14/16).

Her self-perception is of one who is independent, even though she requires support in order to live her life; thus her understanding of independence would appear to be unrelated to a state of physical dependency. Paradoxically, the idea of dependency is acknowledged alongside that of independence, implying that she is both, perhaps indicating a fluid understanding of the meaning of independence.

Lilian was clearly experiencing a significant level of pain during the interview due to a very swollen hand, for which she was being treated. Despite this she presented as happy and cheerful. She laughed when she bumped her hand so that it hurt.

The self-perception of independence is echoed in Douglas' assertion about himself, "They know that I am an independent old sod" (Douglas, 25/1). This is a forceful statement and relates to the way that Douglas believes his family perceives him. Despite being in a wheelchair and therefore perhaps appearing less able than others, he asserts his view of himself as independent. His use of language, that he is both "old" and a "sod" (Douglas, 25/1) indicates that he regards himself as stubborn and that at his age he does not intend to change. Further he commented about the perception of others who do not know him well, "Some even regard me as incassap, incapacitated, because I am in a wheelchair" (Douglas, 28/6). He struggled with the pronunciation of "incapacitated" as if it were something he did not want to say. It may be that he fears increasing disability. He stressed his capability by saying, "I can stand of course" (Douglas, 30/18).

Throughout the interview Douglas appeared keen to impress me with his view of himself as independent and as a person who planned all aspects of his life.

Douglas presented as someone who was in control of his life, needing little support of any kind. Interestingly, in the middle of the interview he expressed the view that his approach was not what the researcher had expected to find. It seems that he felt that the research had a particular agenda when he commented, "It's making your job rather useless though, isn't it?" (Douglas,18/12). He seemed to assume that the study was intended to show that he was struggling with living his life, which was an opposing view to the way he viewed himself.

There is also a practical element to this subtheme. The participants' life conditions of health and capability were declining, so that they felt that they needed to adjust their activities accordingly. Angela, Robert and Janet described their thinking about this process. Angela humorously explained how she manages the practicalities of housework:

> If I need to do something and it's hard work, I'll do it in bits and pieces. I'll sit down a while and then I'll go and do a bit more. I mean, I can go cleaning all around the house, can take me a whole day. I do a bit here and a bit there. (Angela, 18/22)

Her desire for independence is reflected in her determined approach to maintaining her home. She reinforces this by saying, "I just like to be independent" (Angela, 22/4). The use of "just" (Angela, 22/4) indicates her single focus. She continues to regard herself as independent because she feels that she is the one in control of her home environment.

Angela shows how she accepts that she cannot do what she used to do:

> I mean, some days I haven't got the energy to pull the vacuum cleaner about, then I think, well, oh bugger it, whoever doesn't like it, they can come and do it. (Angela, 25/16) ….Sometimes I just can't do anything. So therefore because it is like that and because it has been so long, I think you just get used to it. You can't do anything about it, so you might as well get on with it. (Angela, 25/24)

Angela shows, not only acceptance, but also self-compassion. She is kind to herself and does not try to push herself to meet others' expectations. Her acceptance appears to be associated with resignation.

Robert explained how he has adjusted his thinking and his activities and expresses pride in the way he does everyday tasks. He commented, "I think it's to do with your heart and your balance. It's all to do, you've got to learn to do things slowly, not to think what you used to do" (Robert, 14/24). He explained, "You adjust yourself for what you can do. You know you're limited of what you can do and you, and you've got to live with it" (Robert 15/12).

He recognises that his condition changes over time and adjusts what he can do so that he compensates for his physical deterioration. He also shows some self-compassion in that he accepts the way he is. It might be expected that he would use "I" throughout this, but instead he uses the pronoun "you" as if advising another as though he were an expert, thus appearing capable and in control. Perhaps it also enabled him to distance himself from his situation.

He presents as knowing and accepting what he is able to do by saying, "you've got to live with it" (Robert, 15/2), stating clearly that there is no alternative. He talks about doing things in a different way, illustrating flexibility of thinking and an ability to adapt. He is able to continue to live independently in the home he shared with his wife with all its connections to the past. He spoke about his late wife at length, stressing how much they shared each others company, "…we always did everything together, and we always discussed everything together" (Robert, 26/12).

It seems that the participants were all keen to maintain a view of themselves as independent and capable of living in their own home.

3.2.3 Impact of diagnoses

All the participants commented on the impact of receiving further diagnoses. There was a feeling of resignation to these events and an implicit acknowledgement that further morbidities were to be expected.

Lilian spoke unemotionally about her response to recently receiving a diagnosis for cancer, "Because when they said to me that these were cancerous. Oh well, it's just something else to add to everything else that I've got wrong with me. And I've never been afraid of dying" (Lilian, 27/17).

Once again illness is expressed in vague terms relating to the body being "wrong" (Lilian, 17/17) or not as it should be in some way. Lilian seems resigned to adding a further illness to those she already has. She extends her thinking to a link with the threat to her existence that the diagnosis of cancer may bring. Although she alludes to the possibility that she might be moving towards death, she appears to neutralise any anxiety about this by asserting that she has never had a fear of dying. Although

Lilian might be unafraid of death, she does not anticipate that it will be soon and so defers concern, "…because I don't know when the end of my time's up. It probably won't be for years…" (Lilian, 28/12).

LIlian has experienced diagnoses, been treated, survived, albeit with increasing morbidity, but nevertheless has continued to live her life. Her thinking seems to show that she expects that this pattern may be repeated with her latest diagnosis of cancer.

Douglas also described his thinking that further diagnoses are to be expected:

> It's just another thing and I think you normally get a clue anyway beforehand, don't you? Well, like the legs, if you can only walk 100 yards and then you've got to stop and look in a window and pretend to look at things while the rest of them walk on and things like that, and you're only young, you know there's something wrong. (Douglas, 14/4)

It seems that he has been unsurprised to receive diagnoses, because of his observations of his symptoms. He described trying to put on a front to hide his increasing physical difficulty. This is resonant of the way he presented the capable and independent self in the interview. He described how the others walk on, as he is left behind and isolated from them by his physical condition.

Tony continually reflected on the circumstances surrounding his serious heart attack and, unlike the other participants, expressed surprise by becoming very ill at the age of 88. He said, when asked if he were ill before his heart attack, "Well, no, no, no, in fact, yes (pause). We say that I was far less well than I realised" (Tony, 11/1). The realisation that he was unwell is acknowledged reluctantly. He uses "in fact" (Tony, 11/1) to emphasise that in reality he regarded himself as very ill, but implies that he is

well on the way to recovery. He refers to "we", instead of "I", which seems to be about his role in the family. He feels that he is part of a team that brought him through his critical illness. Interestingly, he reverts to the first person to comment about his diagnosis, implying ownership.

Angela recalled that she has recently needed blood transfusions for a newly diagnosed condition, "I get so bad that I have to have blood transfusions…I forgot about that (laughter). That's new, that is" (Angela, 21/2). This appears to signal a serious deterioration for her, which she had initially not mentioned, perhaps because she did not perceive this diagnosis as significant, or perhaps because she realised the significance, but preferred to sweep it to one side. Her laughter may indicate humour that she had forgotten to mention something so significant, or it may be an attempt to minimise her concerns.

Janet was the only participant who expressed that her diagnoses have had a marked impact on her and the way she lives her life. She increasingly needs aids to help her to live day to day:

> And boy, oh boy, within a year I must say, you know, I do. The only reason I can't use it is, I can't get me leg wet. So that causes me a problem, but it does change your life rather a lot really. (Janet, 22/14)

She accents the impact of deterioration in her condition by saying, "boy, oh boy" (Janet, 22/14). Once again there is a reference to a "problem" (Janet, 22/16) that seems to need adjustment.

None of the participants seemed distressed by their diagnosis of heart failure. Tony commented, "The heart is not too bad as far as I know" (Tony, 13/1). He continued

that he was taking "various heart pills" (Tony, 13/16) and enjoyed a "hilarious game" (Tony, 13/23) with his wife when he takes them. He seems unconcerned about his heart and does not seem to be curious about it. Playing a game with his medication may be a way of using humour to minimise its importance.

Lilian asserted that her pacemaker was "a waste of time … it's not doing anything. I mean I still get very out of breath and I've got problems with my liver, problems with my kidneys" (Lilian, 11/6). Her confusion about the impact of heart failure appears to be shown by her comment that her heart is now "50% better" (Lilian, 25/13) so that she has been discharged by the cardiologist.

There appears to be a lack of understanding of the meaning of having a significant level of heart failure. As Angela said, "I mean what is it supposed to do to me? What am I supposed to feel?" (Angela, 6/15). She questions the meaning of the diagnosis and asserts that it has had little or no meaning for her, so that there is a disconnect between the way she is perceived by medical personnel (i.e. that she is very seriously ill) and the way in which she perceives herself. She understands that she has a diagnosis, but is confused about what the meaning is for her in terms of her lived experience.

Angela spoke about her diagnosis of heart failure implying that it might have been there for years without her knowing:

> I know this heart failure only sort of came to light before Christmas. Oh yes. I haven't lived that long with it. Well, I must have, but not knowing. (Angela, 5/16) … I mean somewhere it must have been written that I had heart failure, before then. I never knew anything about it and since then as I said it

makes me laugh. I've lived like that all these years and now all of a sudden I
have heart failure and they treat me with kid gloves. (Angela, 5/21)

She continued to laugh off the idea that the diagnosis had changed her in any way,
"…I couldn't do any of these things before they told me (laughter). I mean I haven't
been very good at walking for years. I used to get short of breath, which apparently is
all part of it" (Angela, 6/18). She continued, "I can't really complain about my heart.
Occasionally it plays up and it does a few funny jumps but, just lately, it's been very
good" (Angela, 5/5). It seems that she feels that her heart does not cause her a
significant problem. Her reference to it being "very good"(Angela, 5/6) implies that
she considers it almost as a wayward child that might be corrected easily. She
acknowledges that she may have had heart failure for some time but, if so, it seems
its impact has been unremarkable.

It seems that her shortness of breath and poor mobility have been there for years, so
the diagnosis has made little difference to her, merely providing a name for her
existing symptoms. Thus perhaps she is able to minimise its impact. However, she
has observed that she is now being treated gently with the utmost care, with "kid
gloves" (Angela, 6/2). There seems to be a disconnect in her thinking between the
very special care that she is being given and her perception of the seriousness of her
illness.

The participants seemed to minimise the importance of receiving further diagnoses.
Janet appears to be an exception to this, in that she acknowledged a marked impact
on her life world.

3.2.4 Managing emotional responses

The participants' response to the diagnosis of illness was varied. One of the striking aspects of the interviews was the unwillingness of some of the participants to talk about their emotional response. Douglas, for example, said, "No, I don't, I don't think. At the moment, anyway, I don't get depressed" (Douglas,10/3), implying that sometimes he does, but he seemed unwilling to talk about that. Instead he changed the subject by talking about his wife's early death, "I felt robbed, I don't know about disappointed. Yes, you planned your life out for something and then it's just gone. There you go. You've got no plans at all for that" (Douglas,11/7). However, he said little about having any emotional response to his own morbidities.

Lilian also expressed very little emotion throughout the interview. Her response to being asked how diagnoses might have affected her was, "It doesn't do anything to me because it's just there" (Lilian, 13/1). She denied that there is any impact on her sense of self and that, in some way, it is separate and exists alongside her without bothering her. Perhaps in that way she is able to create distance between her self and her response.

Although accepting of more recent diagnoses, Lilian poignantly spoke about missing out on activities throughout her life, due to the accident when 14 years old and the morbidities that ensued. She tearfully expressed her thoughts, "It stops me from doing things and I mean (pauses, sighs) sorry, I haven't been able to live life as I should have been able to. I mean I've missed out on a lot of life" (Lilian, 13/7). The accident was the single event that had caused her the most distress. Her deep sadness for the loss of the life she feels that she should have lived was apparent. Interestingly, she apologised for her spontaneous show of emotion, as if it was something she should not have done. Perhaps she would have preferred to have hidden the extent of her feelings.

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Tony described the time he spent in hospital following his heart attack in great detail. He ruminated about the events surrounding his illness, trying to understand what had happened and why, so that talking about these thoughts ran throughout most of the interview. There was a disconnect between the obvious substantial impact of his heart attack and his comment, "I wasn't really aware, wasn't really aware" (Tony, 19/22). When asked about the amount he thinks about those events, he said, "Quite a lot yes, yes, yes. Yes, I am one of these people who likes to know what's going on, and preferably why" (Tony, 19/24). Perhaps his lack of knowledge of awareness of events at the time had prompted his rumination in an attempt to fill in the gaps of what had happened and so facilitate his sense-making. The repeated "yes" (Tony, 19/24) shows emphasis of his driving need to know what had happened.

Although Tony spoke little about his emotional response to his illness, he frequently showed displeasure and disappointment about his medical treatment. He commented, "I could hardly understand what they were saying of course, but I was left out of it" (Tony, 3/12). He expressed irritation that he was left out of discussion, so that he felt disregarded and disempowered. He later describes his displeasure saying, "…I was somewhat peeved. Somewhat peeved" (Tony, 6/18). This annoyance related to being excluded from discussions about the practical arrangements for adjusting his home ready for his discharge from hospital. He seems to have felt a loss of control over his life as others made significant decisions on his behalf, reducing him to the role of bystander, thus threatening the person he is.

The only words Tony spoke in response to a direct question about his everyday emotions were "intensely lonely, intensely lonely" (Tony, 27/13). A powerful comment emphasised by repetition, but not developed further. His felt sense of isolation was in contrast to his situation, as he was the only participant who did not live alone. Loneliness would seem to be more than just having a person in close proximity, but

may be more about the quality of interaction and connection. This links with the second overarching theme focused on the need for others.

Although Robert talked about his emotional response to major events in his life, he did not seem willing to talk about his emotional response to the diagnoses he had received. When asked about his feelings, he avoided answering directly by talking about his illnesses:

> I didn't, well, at the time, I mean I had this heart attack and well, I dunno, you know, they told me to do this, yes, fair enough, that's alright. Then they said I'd got kidney trouble, I thought well, what's that, you know (laughter). I didn't really, and you know, what does kidneys do? (laughter) (Robert, 13/19)

He seemed to be struggling to express himself in sharp contrast to his fluency when he answered other questions, perhaps because he really did not want to answer. It seems that he acknowledged the heart attack, but was rather confused about his "kidney trouble" (Robert, 13/21). He seemed to accept its problematic nature, but expressed lack of understanding about the purpose of his kidneys and making sense of this diagnosis. He covers what he says with laughter, perhaps to hide the deep impact it has had on his life. This maybe a protective strategy that distances him from the seriousness of his condition and its associated emotions by enabling a lack of knowledge about it. When asked whether he regarded himself as ill, he commented, "No, not really. I suppose I am, but when I consider all the things, I don't, I don't think, I don't think, oh, you poor old sod…Oh dear, you are ill (laughter). I get depressed sometimes" (Robert, 22/5).

He denies feeling self-pity, laughing as he talked, perhaps using humour as a protective strategy. His comments quickly changed to a brief acknowledgement of depression and continued to discuss his inability to understand his emotions:

> Oh, I don't know why, but all of a sudden. I don't know why it hits me, but I start thinking about different things and I burst out crying. Yes, and then I, then I thought get hold of yourself, you know. (Robert, 22/9)

He described the sudden force of emotions that "burst" (Robert, 22/10) out of him taking him by surprise and briefly overwhelming him. He is hit by them implying that there is a sudden and sharply painful impact. He seems to counteract this powerful emotional episode by saying that he is able to "get hold" (Robert, 22/11) of himself, implying that he is able to grab hold of the person he perceives himself to be and bring that to the forefront. It is as though if he did not grab himself he would lose himself in the moment.

Janet and Angela described intense emotional responses. Janet described her fear of hearing what medical staff might have to say to her in case it should be news about an unwelcome deterioration or another diagnosis:

> …they've only got to say one little thing that sounds, shall we say, to me, slightly bad, shall we say, and I don't hear any more. My, I seem to blank off, you know, I'm aware of it, you hear it, but from a distance. All you're thinking about is that, oh my God, you know. (Janet, 11/6)

What she spoke about is her panic at what she might be about to hear that seems to be triggered instantly as if there might be a threat to her existence. Her focus on anxiety blots out the immediacy of the present. She pushed the voice giving bad

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news into the distance away from her. In other parts of the text she described this in more detail:

> Now he was a very efficient doctor, but it was like he told you all the bad things. And before I knew where I was, I was almost in tears thinking that, well, you might as well say my number was up … I started to feel that I've got no chance of getting better basically, and I got quite depressed. (Janet, 12/9)

She presented as constantly waiting to hear the bad news, of which she is so afraid, as it might herald the end of her existence. She talked about her number being up as though her death is a random event decided by somebody else, leaving her feeling disempowered and powerless. Her concerns feed into her fear that she may not get better and might be close to death, resulting in a lowering of her mood.

Angela related her extreme distress during a recent bout of ill health in which her lungs had filled with water. She explained that her response was compounded by the death of a patient in the next bed with the same illness:

> I was dead frightened. I was dead scared. And I really, I'm not, I'm not over that. As soon as I get a funny feeling in here {patient} comes to mind. It's ridiculous really when I think about it. (Angela, 24/11)

Her struggle to find the words to explain her feelings seems to indicate her continued distress. She appears to be trying to make meaning from these critical events. Her use of the word ''dead'' (Angela, 24/11) repeatedly to emphasise her fear, echoes the event she fears most, i.e. death. Any unfamiliar feeling in her body has become a source of fear and anxiety for her as it might signal her demise. She calls her

thinking "ridiculous" (Angela, 24/13), perhaps mocking it in an attempt to reduce the seriousness of her situation.

The participants' emotional response to further diagnosis or deterioration in their condition seems to vary from acceptance to panic. However, all of the participants commented on their experience of maintaining a desired emotional state. They seemed to resist letting unwanted emotions dominate the way they lived and thought. Robert, 93 years old at the time of interview, has experienced much in his long life. Over the years he has adjusted to a range of adverse life events. He spoke movingly about the death of his son, recalling the pain at the time, "Yes, so he passed then and that was a nasty, long business. Love him" (Robert 10/6).

He simply and briefly acknowledged the pain of past events. However, he seems also to try to dispel the emotions he does not want. It is as though some emotions are acceptable and helpful, whilst others are not:

> Well, I, I suddenly think, what's it all about? What am I living for? If this is your life, what is it? What are you doing? You know, and I don't think like that and then I, then I let it go and I'm, then I'm alright again then. (Robert, 22/15)

On occasions, Robert questioned the very essence of his life, which depressed him. He described these thoughts as suddenly happening, as though the awareness of the fragility of his existence had suddenly surfaced. He felt down, but then recognised his perceived identity that he is not a person who thinks in a negative way. He was able to let this go and then consider himself "alright" (Robert, 22/18) again, signifying his return to his expected mental state.

Angela similarly showed that she seemed to want to suppress unwanted emotions, such as sadness, by simply not letting herself feel sad. Despite her efforts, it seems that emotions suddenly burst through in an unguarded moment, resonant of the sudden appearance of sadness and feeling down that Robert (22/15) described above. Angela explained:

> I just feel as though I want to sit in a corner and cry. I don't let myself. Stupid little things just all of a sudden happen and … I think oh, I've had enough now. It's peculiar. Perfectly cheerful one minute and the next minute you feel as though you want to just curl up and go away. (Angela, 11/1)

Angela's husband had died very recently. His funeral had been held on the week of my visit. Despite this she was very willing to talk, with a sense of humour that permeated the interview.

It may be that her sadness is connected to her husband's death, rather than the experience of having multiple morbidities, but she did not seem to recognise that her recent bereavement might have impacted her "peculiar" (Angela, 11/5) emotional state. The use of "peculiar" implies that she regards her sad feelings as unusual for her. Further, she commented that it's "stupid little things" (Angela, 11/4) that upset her, thus trivialising the triggers for her sadness, as though she is being unreasonable. She also acknowledges that life is difficult and there are times when she would like it to be over. Her idea of hiding from existence is implied in her wishing to be in a corner, curling up or going away. These are places where she and her emotions would be hidden from others' eyes.

Angela seemed to attempt to rationalise her feelings of sadness that suddenly happen by thinking about other possible reasons, including the idea that it might be to do with being older:

> But I do think that's to do with old age as well. I think that because you can't do anymore, you can't do all the things you used to do and I think that is why it is. I've got an enormous garden and I can't do anything anymore. (Angela, 11/7)

Angela recognised that one possible reason for her sadness may be related to the losses she feels as a result of her increased incapacity. She is unable to live the life she once did and her large garden is a constant reminder of her active past and the capability she previously enjoyed. It seems to reflect her acknowledgement of her reduced capability over time.

Tony commented briefly about the emotions he experienced following his recent bout of serious illness, "…the first three months or so, I wondered, I didn't despair, no I never did that, I never considered it in a sense my business…" (Tony 23/7).

He uses the word "business" (Tony, 23/7), which is a routine, unemotional, distant word to describe his feelings, indicating that he did not concern himself with despair. He may be demonstrating some black and white thinking in that despair is either present or absent, with no shades in between, thus polarising experiences. He described himself as wondering, but not coming to any conclusion about his feelings. Is it possible that his vagueness about his emotions helps him to hide them from himself as a protective strategy? Perhaps in this way he is able to maintain an emotional state he finds comfortable.

Janet suggested that she had discovered a way to improve her feelings of well-being. This links with the idea of independence expressed by other participants, suggesting the hope that she is able to improve the way she feels perhaps further, "I do try and do as much for myself as I can, you know, the more I do, the better I feel." (Janet, 23/19)

Some participants spoke about their contentment. Janet (21/16) commented that she was "very content at the moment". She continued, "I don't moan about it. I'm happy for it" (Janet, 21/20) when talking about her visiting family. Robert considered himself to be "a very lucky man to have lived as long as I have and to be as well as I am" (Robert, 19/14).

This subtheme illustrates the ways in which the participants experience a range of emotions and how they seem to strive to return to a wanted emotional state.

3.3 Overarching Theme 2: Importance of others

Each of the participants strongly expressed the need for contact with other people for their company as well as the support they provided. All the participants, except for Tony, lived alone. The amount of support each of them received varied, but they were all dependent on other people to maintain their independent living. Some of the participants talked about the value that connecting with others had for them, whilst others spoke about the special nature of their relationship with medical professionals. This is particularly pertinent considering their dependency on medical support for their continued existence. All had family members on whom they were dependent to some extent. The three subthemes are, social self – need for others, dependence on professional support and relationship with family.

3.3.1 Social self – the need for others

The participants expressed the importance of others in their lives, citing the comfort and support that they provided. Social support, social interaction and care are complex processes that can give the lived experience meaning. Being in the world involves engagement with other people. Some of the participants described the sheer joy of connecting with others. For all of them it was also about the necessity of support to be a kind of safety net, ensuring comfort when emotionally stressed, as well as practical, or medical support when needed to ensure survival.

Robert told how he had become housebound recently. His body had deteriorated to a point where he no longer felt physically or emotionally able to rise to the challenge of going outside, but he strongly expressed the importance of contact with the people who come to see him:

> I'm glad to get home in the security of my own home. I feel happier at home.
> No, no, I'm quite happy with my lot really. As I say, if I was all on my own and
> I never saw anybody, I would probably have a different outlook. But I'm so
> well looked after by everybody and everybody is so concerned and kind,
> that's, that's what, that's what I like. (Robert, 25/19)

Robert's limited physical capability renders him housebound, but he is not hiding from the world. Rather, he appears to welcome the outside world into his home. He speaks of being quite happy with his "lot" (Robert, 25/20) implying that he is content with his changed quality of life. It also suggests that he is the passive recipient of events that have changed his abilities. He seemed accepting and did not exhibit frustration or anger. He emphasised by repetition his satisfaction that he is "well looked after" (Robert, 25/22) by people who have concern for his well-being. Implicit in this is his dependency on them for his continued survival and that a nurturing

quality is a comforting integral part of that support. Being looked after appears to be indicative of care that is holistic, addressing the physical, social and emotional, almost as one might be cared for by a close family member.

Lilian is also housebound. Apart from weekly telephone conversations with her friend and visits from two of her daughters, she has little social contact. She poignantly explained with laughter that her only other visitors were Jehovah's Witnesses:

> I mean, I have Jehovah's Witnesses come to the door (laughter) and it's always the same. They happened to be around when I lost my Dad, which would be thirteen years ago and I was able to talk to them. (Lilian, 19/13)

This brief contact seems enough for her to maintain a link with the past and perhaps also give her hope that support may be there for her in the future, if needed. She laughs off that this is her only social contact outside her family, presumably to hide her distress and embarrassment that she perceives herself as "boring"(Lilian, 20/8).

Janet also expressed a need for others particularly to help her through the panic and anxiety she experiences as a result of her illnesses. She illustrated this by talking about a trip to a supermarket with a family member:

> …because I am wandering round there thinking of what I'm going to get, you don't think of what's going on in there (indicating body) and when you get back in the car and you start being…because when you don't think about it. People keep saying to you well try and think about something else and not think about your breathing. And it is better if you can do that, but it's surprising how difficult that can be. Especially when you're on your own. If you're with somebody, you've got somebody to take it off, but when you're

on your own, you can dwell on these things and that doesn't help. (Janet, 16/12)

Janet eloquently described that her illness is often present in her thinking and its symptoms cause her anxiety. She is aware that she uses distraction to help her to overcome her concern. The importance of company is that, not only do others take her out of her usual environment to somewhere that she can focus on matters other than her failing body, but also that they provide her with company that is distracting. She describes the lightening of the burden of morbidity with her notion about having another to "take it off" (Janet, 16/19). If not distracted she dwells on her illness, highlighting that it is frequently in her thoughts. Throughout the interview Janet expressed her constant dislike of being alone as she was liable to panic. It could be that her panic is related to her concern that her condition may suddenly deteriorate so that she might suffer and perhaps die without company.

Tony who, unlike the other participants, does not live alone, showed his appreciation of those who provide him with distraction from his physical state, "…that part of the day when I've got my wife, or my daughter, or my grandson, but it's the first two that I see most, in the room, one can almost forget oneself, almost" (Tony, 27/14). It seems that he values social contact because it goes a long way towards enabling him to forget his physical self. He describes how much he looks forward to visits by other family members, "My son and his wife come down at weekends, because he's got a job in {city} and I quite often think, goody, goody, goody, you know they're coming" (Tony, 24/6).

Tony expresses a childlike delight about his anticipation that others will be visiting him. His daughter-in-law's monthly visits provide him with the stimulating conversation he craves:

…happens to be a brilliant conversationalist and she's also had, has had a
very interesting career, so much of it parallels my own career or thoughts.
She will sit over there for a couple of hours and we'll both be divinely happy.
(Tony, 27/18)

He reflects how being engaged in conversation takes him to a state of blissful
happiness, where he seems able to forget about his ailing body. It is interesting that
this dialogue allows him to escape from the present to link with his previous identity of
a professional self. This perhaps provides him the opportunity to think about his
achievements at a time when he was fit and well. It sounds like he is able to reflect
on not only his past competent self, but also on his past happy mood, which impacts
his emotional state in the present.

As can be seen, all of the participants described the importance of other people in
their lives, although there was variation in the part they played.

3.3.2 Dependence on professional support

This theme describes the central importance of the relationship with medical staff for
the participants in the maintenance of their bodies as part of their continued
existence. Four of them felt that they are being cared for by the professionals in a
way that is extra special. It may be that this enables them to believe that their
survival is also extra special. They appeared to take meaning from the way their
doctors interacted with them, so that they did not feel as though they were just
another presentation of illness, but that they maintained their individual identity. This
may be part of the development of a longstanding relationship with medical
professionals. Janet expressed her perception of a close relationship with her
hospital doctor:

> …it was a bit like being taken under her wing. And she's been really very
> good and looked after me ever since and we've had, it's a bit of, a bit like a
> bond, in a way, because every time I go up there to see her, she always says
> "Hi Janet", you know. We've become almost like friends, you know. (Janet,
> 4/19)

It's a relationship that Janet seems to perceive is not only close, but also protective.
The relationship appears to fulfill her need to feel "looked after" (Janet, 4/20), which
has a sense of nurturing about it. She described a "bond" (Janet, 4/21) between
herself and the doctor indicating a linking together which may indicate shared goals.
It is as though she feels that the relationship is very special, perhaps more so than for
other patients.

However, Janet also expressed deep concern about her treatment. She commented,
"…one of the awkward things is now I'm being treated by multiple doctors, multiple
clinics and no one's collating together" (Janet, 9/27). She refers to it as being
awkward implying that it is difficult to manage. Her underlying emotion may be a fear
that the lack of co-ordination may mean that her treatments or medication may
interact to her detriment.

Similarly, Angela describes her long term relationship with her doctors as one in
which her emotional state is improved by contact with them:

> I have to go to see the liver doctor on Friday, him and I have a little laugh and
> little smile and I have all these doctors that I've had for so long and they are all
> so lovely and they make you feel better. (Angela, 20/22)

She implies a closeness and unspoken understanding of her situation, as well as a connection through lightheartedness. She makes no mention of the medical treatment she receives, but interestingly focuses on the personal value of the relationships. The use of the word "lovely" (Angela, 20/24) seems to refer to the doctors' gentle charm rather than their professional skills. It would appear that just connecting with them in a personal way is a factor in helping her to feel better about herself both physically and emotionally.

Robert expressed appreciation of the way he is supported in his home by nurses, "…they all come to me now and they look after me like they do. What the, what the nurses, and they all know me …" (Robert, 2/25).

The maintenance of strong personal relationships with professionals seems important to Robert. He again mentioned being looked after that suggests total care providing him with everything he needs, as a parent might do. The bond he has developed with the nurses seems to support his existence. It may be that through appreciation of these close relationships, he perceives that the nurses will want to continue to care for him, "…there's one nurse in particular up there, she's an Irish nurse, {name} her name is { } and she's a wonderful nurse" (Robert, 3/7).

Tony readily expressed his opinion about the competency of medical staff, which is so vital for his continued existence. He described a polarised experience of GPs, on the one hand dismissing his concerns and on the other listening attentively to him. This may have produced confused feelings in his sense-making about how he is regarded as a patient. He seems to describe feeling disregarded and powerless with one doctor and well regarded and valued with another. About his previous GP, he said, "Oh, well, you know, he would just dismiss it" (Tony, 11/7). However, he feels

that his current GP is "very good" (Tony, 11/23) and that he is listened to, "Most of them don't listen, you know. She listens alright" (Tony, 11/24).

This variation in the perceived competence and engagement of his doctors seems to be a source of anxiety for Tony. He expressed a strong desire to be listened to and involved in his care. He commented angrily about being left out of decisions such as the one denying his resuscitation, " …nobody's going to tell me that I can't be resuscitated (laughter)" (Tony, 2/14). This seems to have left him feeling powerless, disregarded and vulnerable. It is interesting that he laughed whilst expressing deep concern, which may be related to not knowing how to react to this existential threat.

Tony seems to feel that his anger towards the medical profession is justified, because he perceives that it was their incompetence that was responsible for his loss of vision:

> Incidentally, I feel pretty sore with them. I've known {hospital name} for many
> years and I've had a very big major operation on one eye there. …. We knew
> the place and had always found them utterly charming and competent. This
> time I thought what a ham-fisted lot. (Tony, 8/1)

He seems to have a split and polarised view of the competence of the staff at the hospital where he was treated. His experiences might contribute to confusion in his understanding of the reliability of the medical treatment he is receiving. This perhaps, resonates strongly with the imposition of a Do Not Resuscitate (DNR) notice in the past (discussed in 3.4.3) that threatened his life. The anger he expressed previously seems to be maintained due to his continued fear for his existence and the perceived unreliability of doctors' capabilities.

All the participants are dependent on medical staff to provided treatments that are vital to their continued living. They acknowledged their dependency and the value of their relationships with those staff who are considered skilled.

3.3.3 Relationships with family

All six of the participants spoke frequently about the importance of their family and their relationships with them. Families play a central role in their lives providing practical help and much appreciated emotional support. They also provide love, either explicitly expressed, or embedded in what they say and do, which is so important in giving meaning to their lived experience. Robert commented on the contrasting ways in which his daughter and granddaughter show their love for him, "Well I know my granddaughter loves me very much. I know because she said, she told me. My daughter don't, I know she does" (Robert, 18/17).

Angela also expressed certainty about the affectionate relationship with family members. She was explicit in her knowledge of the love of her family. She said of her four children, ten grandchildren and four great grandchildren, "They just love me. They always tell me they love me" (Angela, 15/23). The reiteration of love and affection by all her loved ones is important to her. These relationships appear to be very important, perhaps because they give meaning to her life and emphasise her value to her family as the person she has always been, despite her ailing body.

Douglas, who generally avoided talking about his emotions, spoke movingly about the emotional connection he has with his family. The family photographs were set out and he was keen to explain his relationships, "I think sometimes that we are closer than what we were. More or less, because they think they've got to help me and all that, I suppose" (Douglas, 24/14).

Although he maintained his independence and carried out most practical activities himself, Douglas welcomed the perceived increased closeness that had come as a result of his family's perception of him as increasingly vulnerable. He tacitly acknowledged that the family understood his needs. It seems that his perception of himself as "an independent old sod" (Douglas, 25/12) did not conflict with this. Perhaps the very personal nature of family relationships sustains independence by the subtle knowledge of the individual's needs. It may enable the person to maintain their front as independent whilst accepting help and support behind the scenes.

Lilian is also housebound. Although family members continue to visit her, she spoke fondly about a time when her grandson used to come for lunch regularly:

> Because I don't go out, I don't see anybody…my eldest grandson, I used to see him all the time…so consequently he used to come home and see me at lunchtime, have his lunch, twenty minutes and he'd be back to school. I missed him, I missed him not coming at lunchtime. It was only twenty minutes, but that twenty minutes made my day. (Lilian, 20/10)

Lilian eloquently explained the importance of the contact with her grandson by saying that it made her day. The implication is that her day is now incomplete without it. However, despite her enjoyment of her brief sessions with this grandchild, she went on to comment, "… but of course now, my children, my grandchildren, I hate to say it, but they annoy me" (Lilian, 20/21). She explained that she enjoyed a limited time with them:

> I do like to see them. Yes, I do enjoy seeing them. I mean they come for about … an hour and a half…I mean I play games with the seven and four

year old. We've got a cup game there and we play that so that I'm interacting with them. (Lilian, 21/8)

It seems that when she is with them she feels that she should interact with them, perhaps giving meaning to her role as a grandmother. Interestingly, it would seem that she would like contact with family members, but only for a restricted time. It may be that the demands on her during longer visits are too great in her poor state of health. However, the sense of joy gained during the brief lunchtime visits by her grandson indicates a connection that gave meaning to her lived experience. This may be related to the regaining of a caring role resonant of her past identity. To provide food for her grandson put her in the role of the giver of nurture, rather than as one who is needy and requiring to be nurtured.

Janet talked about how much her sister's constant support meant to her, particularly when she is feeling anxious and worrying about herself:

…it does worry you … because I've got no-one here and I'm on my own, I've got no-one to, you know, chat to about. I mean I've got a sister, who's brilliant. She's always at the end of the phone for me. She don't live near here, but she's still there. (Janet, 13/14)

She spoke repeatedly about being alone throughout the interview, presenting this as a major preoccupation. She and her sister share an understanding about their experiences of anxiety:

I mean my sister has this problem, she's had it for years. … my Mum always used to faint and things like that. Whether it's something in the family, that, I

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mean my Mum died young, so I can't say from old, but my sister still gets it

now. You know, she'll phone up with a panic attack. (Janet, 16/25)

Their understanding and support seems mutual. There may be a concern that her mother's death at a young age was linked to their shared anxiety. This might be a reason behind Janet's heightened anxiety and consequent need for support. Perhaps her sense making links panic and anxiety to death, so that each time she panics she fears that she is moving towards death. In panic she would be aware that her failing heart is beating quickly and that she may be overstressing it, so that it may cease to beat.

Finally, Tony has a faith in God that sustains him, but acknowledges the importance of his family supporting him as well:

…one is not used in British society to mention it, but I'm a rather firm believer in God. And we've said all along that three people got me to where I am, it was Him, my wife and my daughter. And I mean it. I mean it. People don't talk about it really. (Tony, 21/8)

Perhaps Tony usually keeps his belief hidden. However, he believes that his relationship with God was an important factor in his recovery. He uses the pronoun "we" throughout the interview indicating that he does not feel alone, but part of a team. His use of language may show that he regards God in almost human terms as another supportive member of his team. His strong belief appears to be that he does not feel that he would have survived without the help of those in his team, and perhaps implies further criticism of medical professionals.

All the participants emphasised their need for others for a variety of reasons. It seems that they had all developed support systems of one kind or another. Two of the participants have become housebound, so that their worlds have become much smaller. By having social contact they continue to connect with lives and events beyond their front door.

3.4 Overarching Theme 3: Meaning of Time (Temporality)

The final overarching theme is focused on the participants' perception of their place in time, which in turn is related to their perception of where they are with regard to their expected life span. The past is important to all of the participants, illustrated by the amount of time that they spoke about the past in their interviews and the significance they ascribed to previous experiences. They all recognised that their future is limited and that they are moving towards death. Their approach to life, in the moment, appears to be influenced by their awareness of their fragile existence. There are three themes in this section, which are: importance of the past, hope for the future and focus on death.

3.4.1 Importance of the past

 Each of the participants spoke about the influence of the past on their present. The participants were aged between 64 and 93 and so have had long experience of living. They recalled events that they considered to be significant for them in the formation of their current self and their approach to their life world. For some, the past is seen as enriching their present. However, others seem to regard the past as having had a negative impact. The past gives unique context to current events.

Lilian described poignantly how her past has deeply affected her present in a negative way. She recalled her thoughts about her belief that her serious injury in a road traffic accident at the age of 14 has blighted her life. It was clear in our conversation that its lifelong effects are omnipresent in her everyday thinking and experiences:

> …I was told that I would have headaches for 18 months to 2 years after I was knocked down. Well, nearly 50 years later and I've still got headaches, which, well, there is nothing that I can do about them. (Lilian, 3/19)

It seems that she is acknowledging her powerlessness to change this enduring morbidity that has been part of her lived experience for over 50 years. She expressed resignation about there being no intervention to change her condition and she feels powerless to do anything about it herself. It sounds as though she feels disempowered and helpless to secure any change and so has learned to accept and tolerate morbidity. It is possible that this has influenced her thinking whenever she has received a new diagnosis, so that her response is that it's "just another thing" (Lilian, 28/6). It is interesting to note that Lilian seems to be experiencing disappointment with regard to medical professionals. In her expressions above, she indicates that her doctors were mistaken when they told her that her headaches would be limited in duration, perhaps also illustrating a continuing distrust of medical professionals.

Lilian asserted, prior to the recorded interview, that doctors had never fixed her. She spoke slowly and deliberately throughout the interview, at times exhibiting difficulty with finding the words to express herself. Although she did not specifically say that her speech and language had been affected by the head injury, it may be that these difficulties may have originated at that time.

Douglas and Robert described with some pride how the skills that they developed in the Armed Forces have helped them to live their lives independently. The importance of independence for the participants was noted in 3.2.2. The skills learned seem to have gained a new value as these participants have adjusted to their increased morbidity and reduced capability:

> I think a lot of it goes back to me being in the Navy, I was in 12 years and I think a lot of my life goes back to that because from that I could, I could cook, clean, make beds to a high standard, you had to. There was no choice…
> (Douglas, 19/4)

Douglas' (19/6) reference to "a lot of my life" stresses the importance of the impact of his Navy experiences throughout much of his life. He commented about the forced nature of his learning, implying that it has left him with the attitude that he has no choice, but to use those skills in the present, whatever his capability. It is as though he is programmed to get on with it in an automatic fashion. The idea of his capabilities being to a "high standard" (Douglas 19/7) sounds as though he tries to do whatever he is able to do to the same consistently high standard today. His approach seems to give him control over the day-to-day management of his home. It may be that Douglas and Robert did not have to use these skills previously, at a time when they had partners to support them and their medication would not have been so complex. They are now alone and, falling back on skills developed in their past, are able to manage aspects of their lives independently. This may give them confidence for a future in which they will be able to adapt and remain independent.

Robert commented on his well-developed organisational skills with regard to his medication:

I've got little pots, every night religiously, before I go to bed, I get all my pills

and all my pots and divide them all up for the day. And then, they've got

different colours, pots and then different positions and I know when to take

them. That's my routine. I think that comes with the Army. (Robert, 21/10)

He refers to his Army past, many years ago, when he learned the discipline of

routine. He has worked out a system with colour coding, specific positions and

timing, resonant of planning a military operation. He seems to have confidence in the

approach he uses. He uses the word "religiously" (Robert, 21/10) to illustrate his

scrupulous and meticulous approach, showing no deviation from his planned system.

His felt success in self-care perhaps reinforces his confidence that he will continue to

adjust to any changes in his medication into the future. The regular and accurate

administering of medication are of paramount importance for all of the seriously ill

participants in the maintenance of their lives.

Angela, a German, who had come to the UK just a few years after the Second World

War, poignantly described the unpleasant treatment she received. She explained

that this has had an impact on the way she has lived her life since then, "….in the

early days, I didn't have such a good time, because I'm, because I'm German, people

used to, were quite horrible to me at times and that way I learned to keep away from

people" (Angela, 14/9). She emphasised a perceived causal link between her

treatment and being German by repetition. As a consequence, she made the

decision not to invest in long-term relationships with friends. This appears to be a

protective strategy, so that she did not expose herself to further disappointment and

unpleasantness.

Four of the participants described the impact of the death of a partner as being a very significant part of their history. They had all lived through the emotion of bereavement and loss, but adjusted their lives to being alone.

Janet spoke about the impact of the loss of her husband, with particular focus on the moment of his death:

> It's not like I didn't know he was going to die, but there's still that day when it happens, that is unreal. Whether you know it's going to happen or not and it happens and, you know, I remember little … nurse up the hospital said, 'Well you know he's going to die, you know, you've just got to prepare yourself' and I thought how do you prepare yourself? (Janet, 27/17)

She continued, "You know you live on that hope and when that minute comes, you sit there and a complete world has been wiped out" (Janet, 27/26).

She describes a "world" being "wiped out" in a moment (Janet, 27/26). Not only did her husband's physical life end, but her world was obliterated suddenly as well. The use of "complete" (Janet, 27/26) illustrates the feeling of totality about it. She described herself sitting there as a passive and disempowered observer of events. She perceived that her feelings were disregarded by an unsympathetic nurse, as she was told to prepare herself for the novel experience of witnessing her own husband's death. She was unable to do as advised, which seems to have left her feeling incompetent and questioning how she should have responded. She recognises the unrealistic nature of the expectation of preparation, but, nevertheless, continues to ruminate about what she might have done. Her confusion persists years after the event and impacts her present thinking. Perhaps this has a bearing on the view she

might have of her own death and how she might prepare for it. There may be a concern that her family might be left similarly confused by her death.

All of the participants have had many experiences throughout their long lives that have impacted the way in which they view their present existence and current events. Whatever their past, they all present as survivors, some expressing pride in their accomplishments as well as their ability to adjust.

3.4.2 Hope for the future

This theme is presented in two parts. The first is centred on the hope that participants expressed for the future and the second describes the unwillingness to plan for the future. There seems to be a split discourse between feelings and thoughts. On the one hand there is the emotion of hope for a future to be enjoyed and on the other the thought that planning for that future might be futile, because it may never happen.

All the participants except for Robert had a view of the future that included some perceived improvement in their physical condition. Robert, at 93 years old, did not seem concerned with becoming better physically; his hope was based on the anticipation of seeing his wife and son in the afterlife. He lives one day at a time, focusing on the hope of a family reunion:

> I think about today and when I go to bed of a night, I think, 'Oh that's another
> day' and I say to {wife} at night…I say 'Oh well, I've got through today dear. I
> won't be long now before I'm with you'. (Robert, 23/25)

He speaks to his wife as though she is listening to him, implying perhaps that she is living alongside him. He demonstrates the effort required to live for another day by using the words "got through" (Robert, 24/2). His continued connection with his wife in the present, alongside his hope for their future together, seems to give meaning to his existence. It is as though he is counting a limited number of days. He did not appear to want to give up his life voluntarily, but nevertheless he seemed to want it to end.

Lilian, the youngest of the participants, reported an improvement in her heart condition, perhaps giving her hope for improvement in her physical capability:

> I had to go to see the cardiologist over in {town} and he told me that my heart was 50% better and that he discharged me, which I was over the moon with, you know, one less. (Lilian, 25/11)

Lilian expressed delight with this outcome. "One less" (Lilian, 25/14) perhaps refers to there being one less appointment to attend, because her limited mobility complicates attendance. Her socio-economic circumstances mean that it is necessary for her to use NHS transport to take her to hospital appointments, or rely on a family member, resulting in feelings of disempowerment and dependency.

Janet described the hope she has for every new day that she might feel good and enjoy it:

> Well, you do always hope. I mean, everyday when I wake up and, you know, you wake up and think, oh good. You know, you might not have an ache; you might not have a pain there. You think, well I feel good today, and you get up and think thank God, it's lovely to get up. (Janet, 28/10)

Janet described her hope for every new day, believing that it has the possibility to be enjoyable. The absence of physical pain seems to have a bearing on her feeling of well-being. She described how she determines that she feels good before she leaves her bed. The implication is that once she has decided that it is a good day, it will be. On these days she expresses thanks to God, implying that her good days are God given and outside of her control. There is an interesting juxtaposition between her illness and approaching death and the desire she has to find pleasure in life. Perhaps this is because life is limited and so becomes much more valued and precious.

Tony commented about the improvement he feels that he has made, "Once I was firmly on the moving up, it, it, I don't really remember, but it must have been three months to get me from fixed here to being able to jolly well get up" (Tony, 20/15).

The idea of "moving up" (Tony, 20/16) describes his perceived rise in his improvement. It sounds as though this is expected to be a continuous process and so gives hope for the future. His description of being "fixed" (Tony, 20/17) when he was very ill implies being kept where he was by some mechanism outside his control. It is resonant of an extreme level of dependency and disempowerment, almost as though he were glued to the bed. When he is able to get up it seems akin to a resurrection. He was almost dead, unable to move, but now is able to move himself back into life. His past improvement seems to offer hope that this will continue:

> I've already an enormous confidence that we didn't expect, we didn't expect, of movement. I mean, I shan't do it I'm afraid, but I could easily get up and see you to the front door. I couldn't take you over the edge and round the garden, but if there was somebody with me, I most certainly could. As I say, yesterday, was a miracle. (Tony, 25/5)

Once again he referred to "we" indicating that he is part of a team in his recovery and that he is not alone. He described a walk on the previous day as being a miracle (Tony, 25/10), as though it were an exceptional event that contravened known laws governing the universe. He asserted that it would be easy for him to take me to the front door, but contrasted that with being afraid that he won't do it. If it were so easy, why did he back away from doing it? It would appear that "I'm afraid" (Tony, 25/7) might refer to his fear that he might not have been be able to manage it, evidencing a contradiction of his assertion of improvement. Perhaps Tony is putting on a front, similar to Douglas', of capability. Or, is he trying to persuade himself that he is in better shape than he perceives himself to be?

In conversation after the interview, Tony's wife described his progress as slow and that he over estimated what he was able to do without support. She commented additionally that he was not very active prior to his heart attack and had been treated for diabetes for some time, which he did not reveal in the interview.

Angela, too, describes her perception of improving health, "I get so tired and I'm so anaemic and then I need to have blood transfusions. So the last time I went I didn't have any and everybody went, 'Hooray' (Angela, 21/7). It seems that any improvement is a cause for celebration.

As can be seen from the above, most of the participants talked about perceived improvements in their physical state, perhaps implying hope for the future. In contrast, when asked about the future, most of the participants said that they did not plan more than a week ahead and that they did not plan holidays or complex events, as these might have to be changed or cancelled due to the impact of their morbidities. Their responses to being asked about their future were brief, perhaps because they gave it little thought, but rather lived a day at a time. Douglas' brief response to being

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asked about his future, "I mustn't say much, I think" (Douglas, 31/8). He spent little time focused on the future, although he had spent some time planning for a family event for others later in the year, "But normally I wouldn't plan that far ahead because you don't know what's going to happen" (Douglas, 32/5). His uncertainty about his physical state is a barrier to his planning events for himself. He comments about the future in vague and veiled terms, but seems to shy away from speaking about explicit future possibilities.

Another brief response came from Angela when asked whether she had plans for the future. Her categorical answer was, "No" (Angela, 20/17). When asked again she said, "I don't" (Angela, 20/18). She was dismissive of the possibility of planning for the future. It may be that this is too difficult in her in her weakened physical state, or it may be that she perceives that any expectations of the future will lead to nothing.

Tony struggled to answer my question about the future and initially avoided it, talking instead about despair. His eventual answer was, "Thinking daily, which I can't help do, it's very much probably a week ahead" (Tony, 24/5). Like Angela, Tony seems to have little hope that he is able to plan for a future.

Lilian answered the question about the future briefly by saying, "I really don't look much into the future" (Lilian, 28/10). When asked the reason for that, she responded:

> Because I don't know when the end of my time's up. It probably won't be for years, but I don't want to become a burden to my girls. I mean, they worry enough about me…they couldn't cope with everything that was wrong with me. They worry about me. (Lilian, 28/12)

Lilian talks about the uncertainty of her future. She expresses the view that she has a certain allotted time decided by a force outside her control, quickly adding that death might not be for some considerable time. It seems that it is her continued living that causes her concern, rather than her dying. She expresses the view that her morbidity is a cause of stress in her relationships with her three daughters.

Janet seemed to sum up the feelings of the participants to the issue of their future:

> Haven't got a future, have I? …I live from day to day now. I do what I can, when I can. I don't like planning too far ahead, because…to have planned anything, the whole lot would, you know. … I wouldn't plan for a holiday now. I'd love to go away again, but I won't, because I've got far too many tablets, and the thought of trying to sort all that lot out. (Janet, 25/3)

There is a feeling of being overwhelmed by the practicalities of leaving home for a holiday so that travel is no longer contemplated. This necessarily results in a loss of a desired activity and the consequent shrinking of her world.

The participants all seemed reluctant to plan too far ahead. It seems that they generally only planned a week ahead at the most. There appears to be a concern that anything planned too far ahead, or requiring much effort would come tumbling down, resulting in disappointment and chaos.

3.4.3 Focus on death

All of the participants talked about death with ease. Their serious illness allied to their age gives it a central place in their lives and in their thinking. They are aware that they are close to death, which will bring the end of the possibilities of their living.

Robert seemed to welcome the possibility of death more than the other participants, recognising that it was unlikely to be far into the future. He spoke calmly and easily about how his fear of death has reduced over the years:

> If somebody was to say to me, 'I'm afraid you're going tomorrow', I would say, 'Oh,well, that's it. Thank you very much'. No I am not, I think the older you get, the less you fear death, if I'm being sensible. I mean I used to think it was awful, you know, but now... (Robert, 24/17)

He referred to death as "going" (Robert, 24/18) implying a journey somewhere rather than the end of his life. He sounds accepting and resigned to the perceived imminent death he is powerless to change. He has no control over when and how he will die, so seems to accept the unpredictability of it. He goes as far as to express gratitude that death might come, implying that he would welcome the end of his life. He contrasts this with his thinking as a much younger man, when death would have been a terrifying prospect. As an older person, who is "sensible" (Robert, 24/20), the responsibilities of a family have gone, so death is no longer the same devastating prospect. He also implies that sometimes he is not sensible, so that sometimes he may fear death. It is interesting to note that as he has become older he fears death less, but stops short of saying that he no longer fears it.

Douglas seemed to have a similar point of view, and showed acceptance that his life may be coming to an end, "It's all part of life, part of life. Blimey, I think I've had a fair run if I die tonight, ain't I? Eighty-four, it's, it's more than I expected anyway" (Douglas, 21/6). He laughed as he spoke, perhaps indicating that he was trying to reduce the significance of death. His comment that death is part of life implies that it is ever present in his thinking. He appears to show no disappointment with life, but rather he feels that life has been generous and fair to him. He seems to express a

preference that he might die at night whilst he is asleep. The powerlessness to control his moment of death implies that it is approaching, but the moment is unknown. Death whilst sleeping, implying a gentle easy death without suffering, seemed to be in the thinking of some of the participants. In that way they may feel that they would be unaware of what was happening to them.

Angela also spoke about passing in a peaceful, quiet way. She commented, "I'm hoping that when my body can't cope anymore, I just go to sleep. I certainly don't want, if anything happens, I certainly don't want to be brought round and live there like a vegetable" (Angela, 19/19). She seems to indicate that she is beholden to her body for life so that it would be her body that would make the decision about the moment of her death. From this powerless viewpoint she seems to detach herself from responsibility. She expresses fear as she rejects the idea of the possibility that she might survive in a vegetative state, echoing Janet's thinking about the "poor devils" (Janet, 24/19).

The phrase "if anything happens" (Angela, 19/20) seems to be used to refer to the vague possibility of an unspecified event in the future with a significant impact, in which she might be rendered incapable. She expresses fear of the idea that she would be revived and conscious of her situation, but trapped in a body unable to move.

Janet described her fear of death when talking euphemistically about "losing people" (Janet, 20/14) around her, as though they had merely gone missing. Deaths of others focuses her on "the doom part of life" (Janet, 20/15). She recognises that she may die soon, but is afraid of the prospect:

And it does make me think when I get something or other, I think, especially if I'm really poorly, you know, you think, this is the start of the end sort of thing, you know. I do think like that and that ain't a good thing to think about, but personally I do and it panics me. (Janet, 20/18)

Janet spoke often during the interview about her fear, panic and anxiety that she attributed to her illness and the prospect of death.

Lilian and Tony expressed the view that life would probably go on for some time. Tony, in particular, was very resistant to the idea of death. When he was seriously ill and there were discussions about him being resuscitated, he said:

…the thing that shook my family and me afterwards was a paper in the file said 'do not resuscitate' … I said, 'who the hell do they think they are to say that?' … I do remember a conscious effort in my brain to say that nobody's going to tell me that I can't be resuscitated. (Tony, 2/13)

He expressed outrage about the loss of control over the moment of his death which appears to have brought feelings of powerlessness and disregard. He described a time when he was very ill, scarcely aware of his surroundings, but able to make the effort to survive.

All of the participants were older people in poor health. They were aware of the nearness of death, which, of course, marks the end of life's possibilities. Some thought about how they might prefer to die and others how imminent death may be.

3.5 Summary

This analysis presents an interpretative phenomenological analysis of the interview transcripts of six people. Three overarching themes emerged, namely acceptance of successive diagnoses, importance of others and meaning of time. Within these three overarching themes a number of subthemes have been presented to answer the question: What is the experience of receiving successive diagnoses for people with multiple chronic health conditions including stage 3 heart failure?

The first overarching theme, acceptance of successive diagnoses, focuses on how participants demonstrate their acceptance of increasing illness and cope with their morbidities so that their flexible approach enables them to adjust to life with changing capabilities. The second of these themes looks at the great importance other people have in the participants' lives, not only to provide practical and emotional support, but also just the basic human need to have contact with people they know. The final overarching theme concerns the participants' experience of time, with a particular focus on the past and on a future that impacts their living in the present. As older people who are experiencing a deteriorating body, their past has great personal importance. Whilst their future is certain to be shorter than their past, the length of the future is uncertain and will end when they die.

The overarching themes relate to each other to some extent. People play a central role in the participants' lives. The acceptance of illness seems to be related to both the relationship with the medical staff who support them and the care and love of families that seemed to give meaning to their lives despite their illness. Their uncertain and limited futures appeared to provide value for living for today so that the focus was on living and the illness an accepted part of their existence.

Chapter 4 Discussion

4.1 Introduction

This chapter begins by summarising the three overarching themes that emerged from the analysis and their relationship to the aims of the research. This will be followed by a more detailed consideration of the findings with regard to the extant literature. Each overarching theme will be discussed in relation to other research studies, followed by a consideration of the findings with regard to the underpinning theory. Further, the chapter will contain my thoughts about the quality of the research study I have undertaken, by considering the strengths and limitations of the design and analysis. Within this I shall provide my reflections on the impact that I perceive I have had as researcher on the study. Consideration will be given to possible future avenues of research that might be undertaken to further this area of enquiry. Finally, I shall consider the implication for counselling psychology practice as well as wider implications for society.

4.2 Research aims and main findings

The aim of the study was to examine the lived experience of receiving successive diagnoses for people with multiple morbidities, including stage 3 heart failure. It was hoped to illuminate the experience of having a deteriorating body, where the person is informed repeatedly that they have developed another disease. The findings suggest that this is a complex phenomenon involving a synthesis of many aspects of the self, such as past experience, present life world including connections with people, and the perceived closeness of death.

The first key finding is related to the impact of successive diagnoses. Surprisingly, perhaps, the participants rarely dwelt on the moment or time when they received another diagnosis, but rather seemed to show a marked acceptance of these events, as though they were to be expected. Their central concern appeared to be a continuation of living with their changing capabilities and finding ways to maintain their independence. They described how they have developed strategies for coping with their increasingly limited capabilities as well as any mental distress they may experience. As stated previously, the participants had all been diagnosed with a significant level of heart failure. However, they did not appear to experience the level of social, psychological and existential distress that might be expected to accompany this diagnosis (Norra et al., 2008; Leeming et al., 2014). This was a striking aspect of the analysis that seems to indicate that the participants displayed the ability to adjust when events became challenging.

The second key finding is about the importance of others in the participants' lives. They frequently spoke about the comfort, care and support provided by family members and medical staff. Other people often seemed to give their lives meaning.

The third key finding relates to the age of the participants and the seriousness of their illnesses and focuses on the meaning of time for them. They tended to have a very short-term view of the future and all of them expressed understanding that death might be imminent. This, together with their increasing morbidity seemed to produce a reluctance to plan. They appeared to live for the moment and value each day.

Background

My initial choice of research was influenced by a placement in a palliative care team where some of the patients seemed to exhibit emotional distress each time they

received a new diagnosis. (However, the patients I worked with were receiving

therapy due to their emotional distress and therefore not a cross section of response.)

I thought that research might be a way to explore the lived experience of receiving

diagnoses and the impact on the recipient.

It should be noted that, for this study, I interviewed only those who scored less than 8

out of 10 on the Distress Thermometer (see Appendix H). These are scores that did

not indicate significant distress at that time.

4.3 Discussion of Analysis

4.3.1 Overarching Theme 1: Impact of successive diagnoses

Discussion in relation to the literature

In the context of the research question, most of the participants expressed the view

that receiving a diagnosis did not cause them any significant distress. However, they

described in some detail the effects of their illnesses in terms of the impact on their

everyday lives. They were aware that their bodies were deteriorating as a

consequence of their multiple illnesses, so that they needed to adjust their living

accordingly. This was a major focus for all of them. Most of them talked easily about

their illnesses, although interestingly on occasions they failed to recall a diagnosis.

For example, Tony omitted to say that he had been diagnosed with diabetes some

years before the interview. Angela recalled towards the end of the interview that her

condition is sometimes so poor that she needs blood transfusions, which was the

treatment for a recent diagnosis. This would appear surprising in the context of an

interview focused on multiple morbidities and may be an indication that they had

become somewhat inured to the impact of receiving another diagnosis. Douglas said,

"It's just another thing" (Douglas, 14/4), which is resonant of the findings of White et al. (2016) who suggest that people who have expertise gained by living with one condition may find that it is useful when responding to subsequent health conditions. Alternatively there may be an aspect of denial involved perhaps as a protective strategy. It also may be seen in terms of a defence in which the person may not have the capacity to deal with the possibility of internal conflict and so a kind of self-deception is used.

A recent study looking at multi-morbidity in Australia by White et al. (2016) suggests that a new diagnosis was unsurprising because symptoms would have been experienced beforehand. Once it was confirmed, the participants worked to control their emotional response, before getting on with living their lives by incorporating further strategies to manage their new circumstances. The participants in this study seem to have had a similar response. Three described their belief that more goes wrong with people as they get older, so they have not been surprised to find that they had increasing numbers of illnesses as older people. It seems that disease may become conflated with age, so that illness was to be expected. Robert (14/5) commented, "the older I get…you seem to get more things go wrong and they take longer to get better". Therefore another diagnosis would be unsurprising and the pattern of response a familiar experience. Studies suggest that people with multiple illnesses live an experience that is similar to growing older (Duguay et al., 2014; Mason et al., 2016). Mujica-Mota et al. (2014) suggest that older people perceive less of a decline in quality of life associated with multiple morbidity than do younger people. It seems that age alters the perception of the impact of illness. As older people the participants might expect to be diagnosed with multiple illnesses and therefore the intrusiveness of illness might be less (Liddy et al., 2014). If diagnoses were experienced when younger, at a time when life expectations might be perceived to be markedly affected, then the impact might also be greater.

Although accepting of their diagnoses, Janet and Angela, described intense emotional responses to the fear of becoming critically ill again. Janet (12/9) expressed her fear of hearing "bad" news, aware that it might signal the end of her life. Angela (24/11) remained alert to any "funny feeling" that might indicate that her life was once again threatened. However, at other times they did not report undue unhappiness or psychological distress, as might have been expected from examination of the literature (Walker, 2007). It may be that cultural or generational factors underlie this response and may have impacted the participants' attitude towards revealing any distress, or they may have made sense of their distress in a different way.

The participants expressed an interesting perception of their deteriorating bodies. Most of them commented that they did not consider themselves to be ill despite having a number of diagnoses. It seems that to consider themselves ill they would be in a much worse physical condition and would be able to do much less. Therefore, if they did not consider themselves to be ill, the diagnosis of another illness might have little importance in their thinking. This may be the perception behind their muted response to a further diagnosis.

There has been little research into the concept of resilience in relation to older people, but there seems to have been a common belief that resilience decreases in old age, as physical frailty increases (Perkins, 2013). However, Clark, Burbank, Greene, Owens and Riebe (2011) suggest that older adults have a resilience repertoire that evolves and builds throughout their lives, aiding them when adjusting to the challenges of aging. Some of the participants in this study expressed the view that their ability to adapt in older age had been learned through experiences much earlier in their life. For example, Lilian recalled the impact of life changing damage as a teenager (Lilian, 1/21). It may be that Rutter's (2013) idea of the effect of

inoculation is a component of this. The participants had all experienced unavoidable

difficult events in their lifetime including the death of loved ones, divorce, separation

and war. Having successfully lived through times of stress and continuing with their

lives may have given them the capacity and will to respond in an adaptive way to

events such as serious illness. They all tended to have a positive attitude (Wiles et

al., 2012) that may have helped to sustain their approach.

Adjustment to illness

Rather than considering themselves to be ill the participants regarded themselves as

having problems they needed to cope with, as a consequence of their physical

deterioration. Robert describes his process of adjustment by saying, "You've just got

to think" (Robert, 16/2) and continues to say that he is "sensible about things"

(Robert, 16/4).

It seems that the participants' relationship with illness was one of tolerance and

acceptance. There was the general feeling that they had little choice but to live with

the illnesses they had and simply get on with life. It may be that factors such as

functioning, quality of life and survival (Blom et al., 2015) are more relevant to them

than focusing on their disease. However, it may be that the participants were able to

engage with their experiences with curiosity so that they developed a level of

psychological flexibility that allowed them freedom from distressing thoughts about

their health similar to that described in ACT (Hayes et al., 2012).

Their embodiment seems to have changed the way the participants related to the

world, but did not appear to change the way they regarded themselves. Douglas

described this as "I think I am the same person, just got more problems to cope with,

that's all" (Douglas, 20/18). It seems as though chronic illness somehow permitted

them to retain their sense of who they were (Charmaz, 1999). It may be that chronic illness begins an internal dialogue about identity so that people are more able to define themselves. It may result in being more sure of identity and less affected by social forces.

The participants acknowledged that their bodies were deteriorating and consequently their interaction with the world around them changed. It seems that they were able to find ways to adjust to the physical and emotional challenges presented. Surprisingly, perhaps, they regarded themselves as independent, despite being dependent on others for support (Lilian, 14/16). Some expressed optimism that their independence might improve. They thought of themselves as the same person they had always been, despite the physical changes they had undergone (Charmaz, 1999). It seemed almost as though they were able to detach the self from their deteriorating body. Perhaps, almost like a pre-death adjustment, they had accepted their body would deteriorate and die, but that their sense of themselves continued.

Pain

Pain is generally considered to be an indicator that the body is becoming unwell. Some of the participants commented that pain reminded them of their illness and focused their thoughts on a particular place in their body where illness was located. Two of them described how, if they had no pain, they tended not to think about their diagnosis of disease, so that perhaps they were able to hide their illness from themselves. There has been much written about pain and its possible destructive impact on psychological health (Kroenke et al., 2011; Surah et al., 2014). Kroenke et al. (2011) suggest that there is a causative influence of pain and depression on one another. Among the possible effects of pain is the suggestion that mental health declines as pain increases and the number of activities undertaken decreases

(Gilmour, 2015). Although the participants in this study had moments when they felt down, they did not suggest that this was due to pain. Frank (1999) comments that pain can take over the person so that their life becomes pain, reducing their connectedness with others and increasing their isolation. The participants sometimes experienced pain that may have impacted the way they lived and also their relationships with others, but they had not become isolated. Pain was mentioned, but it did not generally appear to be intrusive. Lilian said that she had a very painful hand on the day of the interview, but she spoke about it apologetically (Lilian, 10/20). Douglas talked about discomfort rather than pain and joked about the "one that hurts the most" (Douglas, 6/8). None of them spoke about sleeplessness resulting from pain (Frank, 1999; Weisbord, 2016).

Self-management

An important aspect of the lives of those with multiple morbidities is the complexity of self-management due to the number of medications and hospital visits (Ritchie, 2014). There may be multiple providers of treatment competing for time and some recommendations may conflict (Janet, 9/28). The participants set their health priorities for each day and made decisions about how to adapt their lives. For some of them, for example Lilian, (25/11) the burden of health-related activities was substantial, requiring significant amounts of time (Islam et al., 2015). Five of the participants seemed to feel that they coped well, although at times both hospital visits and medication were sources of anxiety (Janet, 10/11). On the whole they seemed to cope with the demands by planning, organisation and the co-operation of family members. The participants were older people, who were retired so that they had reduced responsibilities and were able to focus on self-management, which is considered to be beneficial in terms of quality of life (Brazke, 2015).

All of the participants described a reduction in their activities. For example, none of them planned a holiday, and most of them rarely left their home. Some spoke about specific losses of activities they had previously enjoyed, such as driving, being able to tend their garden, or reading the newspaper. However, although sad about their losses, they seemed able to accept them and to go on with their restricted lives. Vaillant (2002) described these as the "small deaths" (p.166) that go with aging. In this case, not just with aging, but also with multiple morbidity.

It seems that all the participants maintained their desired emotional state by not allowing unwanted emotions to dominate their thinking. Although they were able to recognise that they had times when they felt down and questioned the purpose of their lives, they were somehow able to overcome this. The methods they used varied. One strategy was the ability to turn off, or regulate their emotional response so that they did not have prolonged unwanted feelings such as sadness. Their self-perception seemed to be that they were not people who thought negatively and so they denied to themselves that they might feel sad. Perhaps embedded in their thinking was the ability to experience feelings, thoughts and memories whilst continuing to engage with life moment by moment which is an approach taught by ACT (Hayes et al., 2012). Another strategy used was to keep actively engaged in physical activity as this was perceived as improving their mental state. Counselling psychology practice emphasises the well-being and self-actualizing of the individual and so is relevant for those seeking help to maintain a desired emotional state.

The five participants who lived alone managed their day-to-day living including personal care, meals, shopping, their home environment and their health. They were able to recognise when they needed help, ask for it, albeit sometimes reluctantly and accept it with a positive attitude. This seems to be related to internal locus of control (Hundt et al., 2015) suggesting that those who believe that they are in control of

managing their health have lower illness intrusiveness. Further, Coventry et al.

(2014) suggest that meaningful engagement with self-management practices is

present when people felt that they had the capacity, the motivation and take the

responsibility for their management.

The impact of a diagnosis of heart failure

A striking finding was that most of the participants seemed to accept a diagnosis of

advanced heart failure without being significantly distressed by it. Only one participant

mentioned any impact by saying, it "sort of came to light" (Angela, 5/16), which

describes a slow emergence, lacking impact. This was a surprising finding, as

examination of the literature suggests that a new diagnosis, particularly of advanced

heart failure, might be an event that would create some distress in the person

receiving it. Seah et al. (2016) described some people as being overwhelmed by

living with heart failure due to the uncertain trajectory of the disease and its disruptive

impact. Advanced heart failure is frequently associated with social, psychological and

existential distress including depression (Norra et al., 2008; Leeming et al., 2014).

The literature indicates that common responses might be changes in mood, poor

sleep patterns and alterations in relationships (Brown, Gee, Platts, McKenzie &

Javorsky, 2011). In contrast, the multimorbid participants in this study seemed to be

accepting of this serious and life threatening diagnosis. None of them identified it as

a particular source of distress. It seems that somehow the impact was lessened.

Was this perhaps related to the participants already being multimorbid and therefore

having had the experience of receiving a number of diagnoses? There was

awareness, however, that their heart failure did impact their ability to undertake

previously enjoyed activities such as gardening (Angela, 6/18).

Another surprising aspect was that the participants seemed to be unaware of the

seriousness of their heart condition and unsure what its impact might be. Stage 3

heart failure (Appendix A) describes a level of disease that would markedly impair their day-to-day activities. However, two of the participants made no mention of their heart failure at all. One spoke about balancing the medication for heart failure with other medication and the remainder were vague about the diagnosis and the meaning it may have for them. One joked about the number of pills he was taking, but said that he had no idea what effect they had, just referring to them as "various heart pills" (Tony, 13/16). This was in contrast to his shock at having a major heart attack at the age of 88. Lilian's opinion was that her pacemaker was not doing anything and that it was a "waste of time" (Lilian, 11/7). Only Angela spoke specifically about her failing heart. She said that it "occasionally plays up" (Angela, 5/5) although usually it's "very good" (Angela, 5/6) giving the impression that she is not unduly concerned. She showed vagueness about the meaning of heart failure by asking what it is supposed to do to her, or make her feel.

It seems that some of the participants were lacking engagement in what heart failure might mean to them. There may be many issues underlying this. Perhaps, as older people with multiple morbidities, heart failure may have been less disruptive than for a person with a sole diagnosis of heart failure (Seah et al., 2016) and impacted their lives less. Another aspect may be that the participants' response is embedded in their social and physical contexts (Wiles et al., 2012) so that they may feel that they should not complain. They may not actively seek information, but rely on their health professionals to keep them informed. It may also be that their response is related to the historical events they have experienced as well as their personal history. For example, Douglas perceives that he is able to cope with the changing challenges of day-to-day living due to the skills he developed during his 12 years in the Navy (Douglas, 19/4).

The diagnosis of heart failure in this study does not seem to have been a notable event for the participants. It may be that the participants have made their own meaning in the context in which they are living, so that their response to illness was a response to the meaning they made as multimorbid, older people. Younger people with heart failure might be expected to have a lower quality of life (Moser et al., 2013). Moser et al. (2013) suggest that quality of life is related to contentment, being able to carry out desired activities and being with loved ones and friends for people across all age ranges. However, older people reported that their quality of life exceeded their expectations considering their age and the alternative of death. They seemed to accept that their activities would be reduced as they aged and that their expectations of good health were lowered (Ubel, Jankovic, Smith, Langa & Fagerlin, 2005). Further they expressed gratitude for their life. Interestingly they considered that there were many who were worse off than they were.

Moser et al. (2013) also suggest that loss and disappointment were stronger in younger people with heart failure as their expectations were affected negatively by their diagnosis. In this study, Lilian, the youngest participant whose morbidity began as a teenager, was the only person to express loss and disappointment about her life. Most of the participants in this study expressed a view similar to that suggested by the findings of Moser et al. (2013). Janet voiced her feeling, "I'm very content at the moment" (Janet, 21/16), whilst Douglas reported that he had no complaints with his life (Douglas, 2/17). All the participants commented that they had reduced their expectations of the activities they were able to carry out, but that being with people they cared about was very important to them. Most of them expressed the view that life had treated them fairly and that illness was to be expected at their age. Interestingly, gratitude was also expressed by some including Robert who considered himself to be "a very lucky man" (Robert, 19/14). Janet spoke about the "poor devils

who are in bed, being knocked out" as being in a much worse situation than her own (Janet, 24/20).

4.3.2 Overarching Theme 2: Social self - need for others

Discussion in relation to the literature

People are considered social beings with varying need for social connection (Cacioppo & Patrick, 2009) and are part of a social world (Langer, 1989). They are connected with others, have concern for them and are cared for by them (Davis, Tamayo & Fernandez, 2012). This relates to Heidegger's idea of "being-with" (Langdridge, 2007, p.32). The participants spoke about their need for others and the importance of seeing people often. All of them had family with whom they were in frequent contact. The value of being connected with other people for the chronically ill is that not only do they have social contact, but they have a possible source of support if needed. Lindqvist and Hansen (2016) identified the importance of social support in the maintenance of independence and disease management in their study of people with chronic obstructive pulmonary disease (COPD).

Zebhauser et al. (2015) suggest that a stable social network might be an important factor in preventing loneliness and protecting against depression. Each participant had a strong and supportive circle of family and friends on whom they relied for practical day-to-day help as well as emotional support. A study of people with multiple sclerosis (Silverman et al., 2016) suggests that social connection, positive thinking and life meaning are factors supporting resilience. All the participants in this study enjoyed consistent social contacts, thought about themselves and their lives positively and found meaning in their existence.

Loneliness is common in the elderly and those who are ill as they may become isolated by pain (Frank,1999) and disability (Murphy, 1999). All of the participants in this study recognised the importance of a stable network of family and friends, expressing appreciation of this supportive circle. Perhaps this was particularly important because five of the six lived alone. Robert (25/20) commented that he was quite happy, but would probably feel differently if he never saw anybody.

All of the participants expressed trust in some of their medical support, whether it was their consultant, their general practitioner, or specialist nursing staff. The medical personnel who support them are crucial to their continued survival and therefore have a central role in their thinking. Generally, the participants were appreciative of the support they received, particularly the medical professionals who visited them at home and facilitated independent living. Some perceived they had a close relationship with their doctors that they thought was a kind of friendship. This seems to stem from the longevity of the relationship. Most of the participants stated that they felt that the quality of the care they received was high and therefore reliable and beneficial to them. Ritchie (2014) reported similar findings. Further, if professionals are perceived to be understanding, people will seek help so that their quality of life is improved (Shtompel, Whiteman & Ruggiano, 2014). In this study, four of the participants regarded their medical professionals as people they could talk to if needed.

Family relationships seemed to be central to the meaning making in the lives of all the participants. They spoke of love, support, some increased closeness and the value of the contact they had with them. Angela described how visits from her family made her feel "lovely" (Angela, 11/22). The participants implied that they had a role to play within their families and understood their importance to family members, giving their lives meaning. They mattered as parents, grandparents, great grandparents and

siblings. Janet (19/22) expressed her suffering when she was in a hospital too far away for her children to visit frequently. Douglas (31/15) spoke of his plans for family members on a visit to the United Kingdom, something he said that he would not have done for himself. The central importance of family members was indicated by the amount of time the participants talked about them in the interviews and the frequency with which they were mentioned.

Vaillant (2002) describes older people as being "Keeper of the Meaning" (p. 144), when increased experience of life, reduced physical stamina and tolerance enable them to take on the different role as an elder in the family. All of the participants implied that they had value to their families due to their past experiences, knowledge of life and the meaning they had for those close to them.

Participants seemed to feel that family connections had changed little as a consequence of their illness. They expressed the view that they were regarded as the same person they had always been.

4.3.3 Overarching Theme 3: Meaning of time

Discussion in relation to the literature

Lives are lived with the knowledge of the past, an imagined future and the present where we exist in a moment of time. Illness affects the current living and the imagined future. It is suggested that time has an impact on meaning making for those who are ill (Hannum & Rubenstein, 2015) and alters the projections of the person in the future.

The participants expressed the great meaning that past experiences had for them. For some of them, their happy memories were valuable because they seemed able to transport them away from their present. This may appear to be in contrast to their view that they are happy to live in the present and value their current lives.

Four of the participants had experienced the death of their spouses together with the ensuing grief. Lilian described the distress she had felt at the breakdown of her marriage many years before. All had experienced the loss of a loved one, which Janet eloquently described as "a world being wiped out" (Janet, 27/5). They had endured the emotional pain of loss, finding ways to give meaning to their lives following bereavement. Experiencing such loss, and bearing the associated emotions may have helped to provide them with the resources to accept the losses they experience as they become less able and their living more limited.

All of them seemed proud of the families they had produced. Much of the content of the interviews concerned talking about the past, not only in terms of the development of morbidities, but also about families, holidays, gardening, business and all the expected aspects of family life. All of the participants showed me photographs of family members that surrounded them.

Vaillant (2002) wrote about the personality in advancing age becoming more sharply defined, as a result of life choices. Most of the participants described the clear choices they had made about the way they lived their lives. Douglas expressed this as, "I've lived my life as I wanted to…I wouldn't change anything" (Douglas, 9/13).

Hope for the future in some form was expressed by all the participants, despite the proximity of death. Hope appears to be closely bound up with suffering as death approaches and is regarded as a coping mechanism (Broadhurst & Harrington,

2016). All the participants expressed hope for a limited future, but at the same time most of them acknowledged the clear possibility of imminent death. Most of the participants were looking for signs that their condition might be improving. Some set goals for themselves, such as walking to the end of the road. Their hope appeared to be that they might rehabilitate themselves to some extent indicating their belief that their situation might improve (Hermanns & Haas, 2014).

All of the participants were acutely aware of their own mortality. They recognised that their lives were limited due to age and illness. There was an undercurrent of sustained uncertainty of continued living for all the participants, which varied according to the trajectory of their illnesses. Despite this, or perhaps because of it, they mostly appeared to live each day as meaningfully as they could, gaining as much value as they could from the life that remained (Sheilds et al., 2015). Their engagement with life seemed to enable them to be in touch with the social, physical and psychological present. It would appear that they had developed psychological flexibility so that they were largely able to enjoy their life with its limitations, which is resonant of the processes taught by ACT (Hayes et al., 2012).

All of the participants, except for Robert, expressed a clear wish to go on living. Two of them spoke about preferring to die in their sleep, implying a peaceful, uninvolved and passive end to their lives. Tony and Janet were clear that they did not want to die. Tony expressed anger that he had a DNR in hospital and Janet was very afraid that she might die when she was " really poorly" (Janet, 20/18). Conversely, Lilian (28/12) said that she was unafraid of death, but then distanced the possibility by saying that it might not be for years.

Discussion in relation to theory

<u>Adaptive coping</u>

The participants in this study seemed to find ways to accept diagnoses, adapt to deteriorating health, cope with psychological difficulties and live through periods of trauma and loss so that they continued to live their lives. What is it about their approach that enabled them to continue to adapt to the challenge of successive diagnoses? The data indicate the emergence of several features. These are acceptance of life's changing circumstances, a stable social network, emotional balance, willingness to problem-solve and the capacity to self-manage. However, two features seem to be common to most of the participants and these are emotional balance, or regulation and the capacity to adapt to their changing capabilities.

 The participants described the different ways in which they maintained their emotional balance. Five of them described how they were able to rebalance their emotions if they were feeling that they were not as they desired. They seemed to have developed techniques to do this similar to those described in the psychological literature. To illustrate this, Janet used distraction to control her anxiety saying, "the more I do, the better I feel" (Janet, 23/20). Stallard (2005) suggests absorbing activity as a way of controlling anxiety resulting in increased relaxation. McKay, Wood and Brantley (2007) consider that distraction skills are important because they can stop distressing thoughts and give time to work out an appropriate coping response.

Robert (22/18) described how he acknowledged his emotions, but was able to let them go. This is a kind of emotional regulation where the emotion is recognised and the feelings modulated (McKay et al., 2007). Angela (11/2) and Tony (3/8) acknowledged their unwanted emotions, but felt these were unacceptable and seemed to use self-regulation to turn them off.

Robert (22/25) treated himself to a little white Italian wine, a habit he had developed

during his time in Italy after the War. He remembered this time fondly (Robert 23/2),

so perhaps he was invoking emotions of contentment by taking himself, in his

thoughts, to a place where he was happy (Harris, 2007).

Each day seemed to have value because the participants were life limited, so it

appeared as though they were living a kind of mindful existence where they were able

to live in the moment (Harris, 2007).

Mindfulness is used to help people to pay attention to their thoughts and feelings

throughout different experiences (Hayes, Strosahl & Wilson, 2012) so that they may

become more able to accept how they feel and better able to manage their emotions.

By accepting difficulty and setting value-based goals, it may be possible to adapt to

their new circumstances. The process involves understanding the aspects of life that

are important to the individual, adjusting their goals and living their life accordingly.

The participants in this study seemed to have this approach. Angela (25/17) spoke

about how she is able to ignore her housework on some days when she feels

lethargic, by saying "Oh well, bugger it". She does not push herself or make herself

feel uncomfortable, but accepts the way she is. Robert (15/12) expressed similar

ideas when he said, "You adjust yourself for what you can do". They also seem to

show a level of self-compassion. This is a notion about treating oneself kindly with

the care and concern that might be given to a good friend (Neff, 2011) and seems to

be associated with acceptance of weakness and limitation, similar to mindfulness and

ACT (Hayes et al., 2012).

Charmaz (1991) describes how people with chronic illness simplify their lives by

giving up some activities or the ways in which they do things. By this means they

adapt. They pace themselves and juggle what they do to make their lives more

manageable. If they become more ill and less capable, then this process is repeated.

She also discusses the way in which seriously ill people live one day at a time which

allows them to focus on today and gives some sense of control. A focus on the

present allows avoidance or minimising the possibility of further illness or death.

Embodiment

Merleau-Ponty (Langer, 1989) wrote that people are connected to the world through

embodied consciousness. The world has meaning through each person's perception

of it. People are embodied and therefore think and speak from within a body and are

intrinsically interlinked with the world through the body. Therefore, when the body

changes, the interaction with the world might also change. These ideas are in

contrast to Descartes' dualism which advances the idea that minds and bodies are

distinct entities, but are closely bound in humans (Heil, 2013). Descartes' approach

to the mind was that there is a difference between mental and material states.

Material objects occupy space, have shape and dimensions. Mental objects, i.e.

thoughts and sensations, do not. Descartes asserted that they are different kinds of

substance with totally different properties (Heil, 2013).

Some of the participants seemed to show a dualist perspective at times, because

they felt that their sense of self was unaffected by their physical deterioration.

Angela's comment about her heart, "Occasionally it plays up…but just lately it's been

very good" (Angela, 5/5) suggests that she perceives her failing heart as being

separate from herself, which may indicate a dualist perspective. On another occasion

she spoke about being "dead scared"(Angela, 24/11) when she was critically ill,

suggesting that her emotions were affected by her embodied self. This might be

described as a more monist view where mind and body are the considered as same

thing. It seems that both perspectives may have been apparent at different times in

the same individual.

The way in which Robert described himself and his body seemed to present a monist perspective. When told he had cancer he commented, "It's got worse…I am what I am and that's it" (Robert, 3/16). Although the participants may have felt that they were unchanged as a person by their illness, it seems that awareness of their physical state did impact their emotions at times.

Despite their serious chronic illness and deterioration in their capabilities all the participants seemed to show reappraisal of their new situation leading to adjustment in their way of living. Charmaz (1995) describes how people are able to adapt to serious chronic illness by changing their lives and themselves to accommodate physical decline. After initial struggle they may reconcile themselves to illness and flow with it. Further deterioration in health brings about further adaptation as it has done for the participants in this study. Charmaz (1995) further suggests that chronic illness brings about changes in the perception of the person by others so that they may be identified by their physical impairment. Disunity may exist between the body and the self. With each subsequent bodily impairment, which may be marked by a diagnosis, there is further loss of unity. Charmaz (1995) describes the way in which chronically ill people surrender to their impaired body when they stop trying to fight their illness and they become willing to accept the way they are. Part of this is acknowledging that the person is constrained within an ailing body. She argues that this is not giving up, but going with the flow of illness. She further argues that adapting to impairment facilitates a deepening understanding of the self.

Existential issues

All of the participants have life limiting illnesses, which, to a greater or lesser extent, will affect their future in terms of how long they live and the quality of their living. One of the fundamentals of existentialism is that the struggle for freedom is an essential

part of the human condition (Langdridge, 2007). The suggestion is that people strive to live as they choose so that they attain a state where they are free of the expectations of others. Perhaps it is the case that these participants, who have lived for many years, have reached this point so that, despite the constraints of illness, they are able to live their own lives freely in the way they have chosen. To some extent they show rebelliousness in that they are not willing to be the person others expect. For example, subjectively they do not consider themselves to be ill, but objectively the world might regard them as such. When Douglas makes the observation, "It's making your job rather useless though, isn't it?" (Douglas, 18/12) he is referring to what he perceives the researcher's view to be. His view of himself is that he is very independent and capable, but it seems that he expected to be seen differently as someone experiencing difficulties that he was struggling to overcome.

Heidegger developed the concept of *Dasein* (existence) to describe the person's being in the world, which he saw as a uniquely human feature (Langdridge, 2007). *Dasein* is used instead of man, person or subject to focus on the meaning of existence. Within the existentialist tradition there are a number of key features that are fundamental to being in the world as a human. These are time, mood, limitations on our ways of being (facticity), being-towards death, care, authenticity, relationships with others and discourse (Langdridge, 2007). All are pertinent to the participants as they described their lived experience and the meaning of their existence.

Frankl (2000; 2004) also expresses ideas about finding ways to fulfilment and meaning. He describes the response of humans in situations that cannot be changed; where existence is threatened so that only the response of the self can be altered. Many people are able to find meaning to their lives in such challenging situations. For the participants in this study perhaps it is being at a time when their life is drawing to an end that enables them to find meaning.

Time, as described by Heidegger (Langdridge, 2007), is always at the heart of what it means to exist. The understanding of the present is thought of in relation to the past and the future. People are generally focused on future possibilities. In this study the futures of all the participants have been affected by illness in terms of limited life expectancy or quality of life. However, they all seemed to have maintained hope for things to come.

Heidegger (Langdridge, 2007) considered mood to be a pre-reflective way of experiencing the world and that depression is not merely the result of negative life events, but rather awareness that existence is nothing. The people in this study occasionally had depressive times, but they passed. Perhaps, sometimes, they felt that their existence was questionable. Robert (22/16) commented "What's it all about? If this is life, what is it?" More usually, however, it seemed that the paucity of a future seemed to increase the value of the present.

Existence as humans ends in death, at which point future life in the world ends. People do not chose their moment of birth, or, generally, their moment of death. As life progresses the likelihood of imminent death increases. For people with serious life limiting illnesses, imminent death is likely. When people are younger, the prospect of death can be ignored, but when they are older and seriously ill, the possibility of death becomes a more imminent possibility and is not so easily hidden (Langdridge, 2007). The participants acknowledged the nearness of death and for those who talked about an afterlife there was the hope that they would be reunited with those they loved.

In summary, Frankl (2004) wrote that there are three ways to find fulfilment and meaning and so reduce the possibility of mental distress. The first is by doing something, the second by experiencing something or someone and the third by facing

a fate that cannot be changed. The experience of someone is described as loving another person. All of the participants seemed to find meaning in their lives. They busied themselves each day doing what they could when they could manage it, sometimes even setting targets for themselves. They valued their connection with other people and enjoyed loving relationships. They faced the challenges of their life-limited existence by adjusting to their circumstances and finding hope in their situation. There are clear links with counselling psychology theory and practice, where approaches may be individual or systemic, seeing the person in context and focusing on all areas of psychological functioning, such as feeling and thinking, personal issues and recreational activity. Approaches such as ACT may be able to teach the individual self-awareness so that they are able to attend to the present moment in a flexible fashion (Hayes, et al., 2012). Such awareness seems to be closely associated with healthy psychology.

4.4 In conclusion

The findings were surprising in that the participants interviewed were all focused on living despite acknowledging that they did experience distress at times. The only participant who seemed to be looking forward to death was the 93-year-old man, who believed in an afterlife and so was anticipating a time when he would be reunited with family members. However, in the meantime, rather than giving up on life, he continued to live with dignity, independently and managing his own affairs. He did not retreat from life despite his physical frailty. I experienced surprise at each interview as the participants told me that they accepted their diagnoses and illnesses, found meaning in their lives and adjusted to their reduced capability.

4.5 Evaluation of the work

The research achieved its aim, which was to examine the lived experience of people with multiple morbidity as they received successive diagnoses. The findings develop further the existing body of knowledge as there is a paucity of research in the area. Perhaps surprisingly, the analysis suggests that the participants were more focused on the way in which they live their lives, rather than on the time when they received the diagnosis of another serious illness. Although most of the data provided by the participants did not relate to the time of diagnosis, many of the ideas they expressed described the way that they lived with their illnesses subsequently. Giorgi and Giorgi (2008) commented that generally people have the capability to live through events rather than knowing what they are doing, or why they are doing it.

4.5.1 Credibility of the research process

I used IPA as the methodology because I wanted to explore the lived experience of people with multiple morbidities as they received successive diagnoses. Using this approach I was able, to some extent, to gain understanding of the perceptions of the people interviewed and the way they lived their lives and interacted with others, while at the same time seeking to gain insight into their subjective experience of being multiply diagnosed. I enjoyed the interview experience and felt that I was able to engage well with the participants so that I gained some understanding into their perceived experience. There were limitations to this study because I could only gain limited insight into the participants' worlds. They spoke about their experiences receiving several diagnoses for a limited length of time on one day. It may be that further interviews might have elicited more information.

The participants were introduced to the study by their heart failure nurse and I have no direct knowledge of how this was done, although clearly this may have impacted the way the participants approached the interview. My assumption is that they explained the study as being one that would address the research question seeking insight into the phenomenon of receiving successive diagnoses. Interestingly, the first participant produced a list of all his diagnoses and treatments (written by his nurse) that would seem to indicate that the focus of the research may have been clearly explained to him.

Although there was no intention to exclude those with mental illness, none of the participants identified mental ill health as one of their morbidities. It may be that the nurses had included only those with physical illnesses as they may have believed that it was people with diagnoses of physical illness who were being sought. This was not the case and is a limitation of the research. Any future research would need to make reference to more explicit criteria about the nature of the morbidities included.

There are, however, limitations to the IPA process. Willig (2008) identified such areas, including "the role of language", "the suitability of accounts" and "explanation versus description" (pp. 67-68). Firstly, language is used by interviewees to communicate their experiences to the researcher and so is reliant on the representational validity of the language used. In other words, what people say accurately represents their experiences. The same experience may be described in many ways, so that words can never give direct access to it. The transcript gives information about the way in which a participant talks about an event, but does not give access to the experience itself. Each interview was a conversation in which each interviewee was using language in their own particular way. It is not my intention to look at the role played by conversation, but merely to say that the conceptualisation of language can be criticised for not engaging sufficiently with its

stated purpose, i.e. looking at the meaning that participants give to their experiences. Perhaps this is the reason I found engagement with some of Tony's transcript difficult. He described white marble statues "moving towards me" (Tony, 2/24) when he was very ill in hospital. I assumed that he was so ill that he was not making sense of his surroundings, however he may have been talking about something meaningful that I have missed.

"The suitability of accounts" (Willig, 2008, p.67) is about exploring the quality of certain experiences to help with understanding of a particular phenomenon. This is dependent on the participants being able to use language to express their thoughts, feelings and perceptions in words that are suitable for analysis. A lack of ability to articulate them adequately limits the usefulness of the method. I think that this is evident in Lilian's transcript. Her head injury when a teenager resulted in slow and deliberate speech, perhaps indicative of word finding difficulties and a lack of sophistication in the language used. However, this does not render her narrative without value. She was able to express herself so that hopefully, I have been able to understand and represent her perceptions to some extent. Finally, IPA attempts to describe and document the lived experience of those taking part. It does not try to explain, or seek causes (Willig, 2008).

The transcripts were analysed to produce data with a multitude of themes. Throughout the analysis, my attention turned from the individual account to an overview of the whole of the data. As a first time researcher using IPA I sought to stay as close as possible to the process detailed by Smith et al. (2009). I also sought to remain consistent with the ideological commitment of IPA, looking at the individual in their own context in detail and seeking to explore their perspectives, prior to moving on to looking at other cases and the possibility of more general claims.

During the analysis I undertook a painstakingly detailed examination of the data of each case, prior to moving on. My concern to carry out the process meaningfully and in accordance with the process led me to analyse the data three times. I hesitated to move on to cross case analysis to be as sure as I could that I had carried out the analysis process effectively. Each time, although I developed different names for the themes and groups of themes, there was a remarkable similarity when the overarching themes were developed using an examination of similarities and differences across the cases. During the analysis phase, I was concerned to move beyond the participants' words to an interpretation of their meaning.

Throughout the process I remained committed to rigour and quality. This was raised as a focus at the proposal stage, as the NHS Research Ethics Committee I attended enquired about the possible use of cross validation to validate the thematic analysis. Cross validation in the usual sense is not pertinent to IPA studies, because each interview has validity and stands as an experience in its own right. It would not be appropriate to use focus groups, because they are different people with different experiences, or to feed my interpretation back to the participants to gain their opinion. However, there are core principles for evaluating the validity of qualitative psychology. Yardley (2008) identified these as "sensitivity to context", "commitment and rigour", "coherence and transparency" and "impact and importance" (pp. 243-244).

This study clarifies what is already known from theory and research and formulates a novel question about the experiences of a particular group of people and so is sensitive to what is already known. Sensitivity to the perspective and position of the participants was provided by interviewing them in their own homes, maximising privacy, security and accessibility. I, as an older researcher, interviewed the

participants who were my age or older which, hopefully, engendered a feeling of comfort that I may have some understanding of their lived experience.

I attempted to bracket off my knowledge of the subject when I analysed the transcripts (Smith et al., 2009). I focused on the material being analysed, without reference to theory or literature, except for those I had already researched for the research proposal, which I attempted to put to one side. Hopefully looking at the transcripts with little reference to prior knowledge enabled me to remain focused on the information being analysed without introducing other ideas, so that the possibility of being skewed or affected was minimised. Realistically, it is not possible to bracket off completely, but the effort was made to do this so that I remained sensitive to the data. Additionally, when analysing the transcripts, I considered in some depth the exact meaning of the words used, as I understood them, so that representative themes could be constructed which sensitively interpreted the participants' transcripts.

During analysis of the transcripts I paid due regard to Ricoeur's ideas of empathy and suspicion (Langdridge, 2007). On the one hand engaging with the participant empathetically in order to identify meanings where there is understanding of each other's worlds. This involves bringing my "pre-understandings" (Langdridge, 2007, p.49) or my way of viewing the world into play. On the other hand, there is the act of suspicion, where I looked for the meaning below the surface of the words spoken to search for the underlying meaning of the discourse. The analysis is my interpretation of what I understood the participants to be telling me. So, for example, when Robert (15/22) laughs as he talks about not being able to live as he used to do, I interpret this as feeling the losses he finds uncomfortable to discuss.

My commitment to the topic is shown by my long-term interest in the experiences of those who are life limited, more recently through my firsthand experience of working as a placement trainee counselling psychologist in a community palliative care service with patients with advanced heart failure. The study has been ongoing for over two years during which time I have spent many months immersed in, and reviewing the data. The interviews were as thorough as could be achieved in a minimum of an hour's conversation with participants who were very ill. They were, however, very willing to give their time to talk to me and seemed to answer my questions candidly. The data was analysed rigorously and the process discussed with my research supervisor, as well as my peers in an IPA group, to ensure that it was of a high standard and in line with the accepted principles and process. I sought advice from them about ending the analysis as it seemed that it might become an interminable process. Attending an IPA peer group provided me with a valuable opportunity to discuss and explore the themes emerging from my research as well as recognising and naming those themes.

Purposive sampling provided commitment and rigour in the recruitment of the participants. Chapter Three provides specific details of coding and the development of themes. The section on reflexivity details the ways in which I feel that I may have influenced the study.

I have attempted throughout the research report to be transparent by providing honest, detailed descriptions of my methods and the research process, as well as commenting on my personal views in the reflexivity section. The paper trail is transparent and runs from the transcript through to the development of overarching themes.

4.5.2 Sample size and recruitment

The sample size of six participants was considered sufficient for an IPA study at doctoral level (Smith et al., 2009).

The participants were purposively sampled (Yardley, 2008) to include those diagnosed with multiple morbidities needing regular treatment or medication, which also included those with a diagnosis of stage 3 heart failure. The group was homogenous in so far as they participants were limited to people with three or more diagnoses, one of which was stage 3 heart failure (Appendix A). This limitation on recruitment produced far fewer participants than I had anticipated. At one point I had only four participants and so discussed solutions to this difficulty with my research supervisor. It was decided to change the criteria to include stage 2 and 3 heart failure, if there were no further volunteers. However, two more participants fulfilling the original criteria were recruited shortly after. I had some concerns about the inclusion of stage 2 as the impact of heart failure on the participants' everyday lives would have been substantially less in terms of physical capability, than those at stage 3. Another concern would be about whether I would interview all the volunteers if a large number of people volunteered. I felt that, ethically, I should interview all who volunteered and that they should not be rejected simply due to their number. In any case, if I were not to interview them all, how would I select those I might choose?

The participants were selected by introduction to the research by a heart failure nurse, who gave prospective interviewees a pack of information. I prepared 50 packs so, if they were all distributed, that would be a very low rate of volunteering among that population. No inducement was offered. The participants commented that they volunteered because they would like their experiences to be of use to others, that is that they participated for altruistic reasons. Perhaps there might have been more volunteers if I had offered inducements, but I was concerned that these very sick

people should not feel compelled to take part in a study if they felt too unwell. The participants were volunteers who did so willingly and engaged well in the interview.

4.5.3 Reflexivity

Throughout the research process I have been very mindful of the possible impact that I, as researcher, may have had on the process and the findings. According to Willig (2008) reflexivity requires the researcher to be aware of the construction of meanings and that it is impossible to remain outside of the subject matter. My analysis of the data reflects my point of view of the world, and the constructions of meaning that I may have contributed. It may be that my viewpoint led me to interpret data in line with my own thinking and experience, so that I may have ignored the importance of data that contradicted my own understandings. With another researcher another set of themes may have emerged.

I consider myself to be a person-centred psychologist, so that the relationship with the interviewees has been important to me throughout. Although I met them for only a short time, up to two hours overall, depending on their ability to participate, there was an openness to meet them at some relational depth. I recognise that these were not therapeutic interactions, rather research interviews, but the tendency, at least initially, was to apply my natural therapeutic stance. I, therefore, tried to guard against this, particularly with regard to empathy, as I was concerned that an over-empathic approach might skew the participants' responses. The non-judgemental approach (Unconditional Positive Regard) was useful in trying to hold at bay prior understandings and knowledge and in maintaining a phenomenological attitude. Finlay (2011) encourages the humanistic values of empathy and openness to being surprised.

This research grew out of my experiences and beliefs. As an older person, I have a particular perspective about the future and my own mortality. I find the aging process an undesirable one particularly when I witness the lives of others that I perceive to have increasing suffering and limitation. This study has given me a fresh perspective on the future, which I now consider that I may enjoy more than I had previously imagined. As a child I was very ill with a single morbidity that rendered me isolated due to lack of mobility. This is an experience I had chosen to forget, probably because it was a very difficult time, but this research has put this at the front of my thinking. I have now been able to process the past and see its relevance to my perceived future. The experiences I had at that time may have impacted my understanding of the participants' worlds in terms of losses of desired activities and the need for others.

I had believed that the participants would view life as becoming increasingly difficult and that the loss of capability might lead to emotional distress. The approach displayed by the participants surprised me. They used strategies to manage and live their altered lives. Although vulnerable, they continued to accept aging and have meaning in their lives. This has helped me to appreciate further the differences that exist between people and their approaches to life, particularly when life is limited. I have reminded myself that older people often have a story to tell about their past that is frequently fascinating.

During the research I referred to an autobiographical questionnaire (Chenail, 1996) to assist me in examining the beliefs I have developed over a lifetime. It helped to facilitate thought about issues that I may otherwise have pushed to one side and helped me to think about the way I may have changed or remained the same with particular regard to the research.

4.5.4 Reflections on design and future research

One obvious limitation of this study is its small scale, with only six participants. Nevertheless, it is suggested that rich data was collected due to the openness and willingness of the participants. The in-depth analysis of every transcript produced a range of quality data. Many more participants were invited to join the study, but they did not engage. This might have been for many reasons, not least because they are very ill people who might have felt that they would have difficulty with sustaining the interview. It might also have been because they felt that they did not have a valuable story to tell. Whatever the reason, they did not volunteer and so I do not have access to their perspective and meaning making.

The participants were recruited through an NHS heart failure team. They had all been diagnosed with physical illnesses. None of the participants said that they had been diagnosed with a mental illness. This was an accidental omission and was to some extent the result of a lack of clarity about the nature of diagnoses included. Future research of this nature would need to make specific reference to the diagnosis of all types of illness in the inclusion criteria.

It may be that different teams, with different staff and different protocols might have produced other experiences. A broader study of this kind might be useful for gaining a wider perspective. However, it was not the intention of this study to generalise in any way about the experiences of multimorbid patients across areas.

Smith et al. (2009) stress the importance of purposive homogenous samples. In this study the sample was homogenous because each participant had experience of the diagnosis of three or more morbidities, including advanced heart failure. However, they were also heterogeneous because serious illnesses for which they were having ongoing treatment varied greatly. Also the number of morbidities was not limited to

three, nor was the duration of a morbidity restricted. For example, one participant

had experienced morbidity for 50 years, which she felt had curbed her living during

that time significantly. Other peoples' illnesses developed later in life and felt that

they had been very lucky. If it were possible, it would have been useful to look at

groups whose characteristics were more similar so that a comparison might be made

of their perceptions and meaning making for their different circumstances. It is not

clear from the data obtained whether the impact of morbidity is greater or less when it

has been in existence for a longer time. Therefore an area for further research might

be listening to the voices of others as they live with this experience. I wonder also,

whether different cohorts in 10, 20 or 30 years time would have similar experiences.

I found the interview process engaging and I believe that it was a satisfactory method

for the collection of data. I valued being able to meet the participants and to hear

firsthand about their experiences. The study produced information about the

phenomenon of the participants' subjective experiences through my own subjective

experience. Meeting with the participants in their own homes enabled me to add

detail to the data and analysis. Being with the interviewees as an embodied person

assisted in gaining insight into their physical existence, which was an integral part of

this study. However, despite carefully constructing the interview schedule it was

amended in the light of experience after the first interview, due to a perceived need to

improve the focus on the research question. There was also a focus on ensuring that

the participants felt free to respond as they would like. I had a general conversation

with each participant prior to the interview both to ensure that they had understood

what would happen, were aware of the focus of the research question and also to

begin to build an understanding. This helped to create a situation in which the

participant was encouraged to respond freely (Arskey & Knight, 1999). The language

used could also be adjusted so that understanding by the participant of their part was

maximised. The interview that followed became a kind of guided conversation in which the language was led by the participant and not imposed by the researcher.

The interview schedule was focused on the research question and was introduced prior to the interview so that participants were aware that my research was about their experiences of receiving successive diagnoses. The initial three questions were directly focused on diagnoses to elicit more general responses about the phenomenon. Subsequent questions invited comments about the psychological, emotional and physical impact of receiving successive diagnoses. The intention was to engage the participant in a dialogue about what it was like to live in their world where they had been successively diagnosed with serious illnesses. The resulting data obtained was focused on their diagnoses and the impact of them.

However, there are any number of factors that may have affected the participants' responses. It is possible that my age, gender, experience and manner may have had an impact. As an inexperienced interviewer, I may, at times, not have sought the clarity that I might have about the participants' worlds. Throughout I was mindful that there is a narrow line between eliciting their experiences and probing too directly, or responding in a way that influences the participants' responses. Wherever possible I allowed the participant to talk, only questioning further about specific areas when interview questions were not covered. My confidence had grown through the experience of interviewing resulting in less intervention in the later interviews, allowing participants to talk more freely so that the questions might have a reduced impact on their expression of the issues that they felt important. The first interview may have been affected by my anxiety that they might produce data that would not contribute to understanding of the research question. My supervisors provided reassurance that allowing the participants to talk would provide relevant data and the experience of interviewing confirmed this. My lack of confidence and anxiety in the

first interview may have resulted in my giving insufficient time for the participant to give a considered answer and so the data may have lacked richness. I feel that I may not have asked the supplementary questions so confidently which may have resulted in a lack of probing meaning.

In the light of the findings, there are a number of areas for potential further research, which I am strongly motivated to undertake. Firstly, it might be useful to extend the study to thinking about whether it might be possible to undertake some kind of longitudinal study, looking at different cohorts over time. Perhaps a study of different age groups may reveal differences in their lived experiences. Would those who are younger and whose childhood and early adulthood were spent in different times have developed a more or less resilient approach?

It might also be interesting to look at whether there is a tipping point when resilience diminishes and the person becomes more dependent and resigned to a future of dependency and death.

Another study might be focused on working with people who are experiencing significant distress when receiving successive diagnoses. Perhaps a difference might be discerned between those who experience different levels of distress.

It may be that further research might suggest the factors that build and protect the coping strategies of very sick people. Linking with current research, it might be interesting to look at whether the ability to cope might be predicted. However, this would probably be a large-scale quantitative study. It may be that adaptive coping approaches, similar to ACT, can be taught so that people are less susceptible to distress.

4.5 Implications for professional practice

The importance of this research to the discipline of counselling psychology is that it adds to the body of knowledge about the experience of multiple morbidity and aging. This research suggests that some people do not experience undue distress, but are able to maintain a focus on adjusting their lives in accordance with their capabilities. However, it may be that others experience significant distress. Counselling psychology has the objective of helping individuals to live more effective and fulfilled lives (Nelson-Jones,1982), whatever their circumstances. It does not pathologise the individual, but regards each one holistically and as unique. For those who experience distress, it may be valuable to focus therapy not only on emotional distress, but also on steps that the person might take to achieve personal goals that may give their lives meaning. Counselling psychologists frequently work in health settings where the approach may be humanistic or one that targets behaviours, such as CBT. Techniques such as ACT and mindfulness might also be offered, teaching the individual six processes to improve psychological flexibility and so enable adaptation to changing and challenging life circumstances (Hayes et al., 2012).

Resilience, which has some similarity with the adaptive coping behaviours of people in this study, has some current popularity with research examining the lives of people of all ages. There is a particular focus on teaching awareness of resilience and resilient responses in schools. It has been suggested that resilience is an ordinary response in children (Masten, 2001; Prince-Embury, 2008). However, there is currently very little written about resilience in older people, although it is increasingly becoming an area of focus and is relevant to the practice of counselling psychology. The findings of this study seem to indicate that adaptive coping strategies, which might be considered to be aspects of resilience, are used by some people to give their lives meaning and to adjust to changing circumstances. The identification of

coping strategies and addressing them in therapy, such as the use of ACT, may be an approach that counselling psychologists might use.

Additionally, I would hope that the findings might inform those within the broader therapeutic community and beyond about the experiences of older people with multiple morbidities and the role played by adaptive coping strategies in continuing on their life trajectory.

Perhaps also the role of adaptive coping when faced with life changes might provide some background to its importance to people of all ages. The work of counselling psychologists as therapists goes beyond work with the individual to influence the needs of society in general. This wider role might encompass schools, health services, social services or any setting where the understanding of different types of adaptive coping might be an appropriate means of developing strategies and so alleviate distress. This might also be applicable to parents who would be interested in possible ways to try to develop such strategies in their own children. Resilience in its various guises can therefore be seen to be relevant to many areas of society.

Chapter 5 Conclusion

The main aim of this research was to explore the experience of receiving successive diagnoses for those with multiple chronic health conditions including heart failure. I hope that this research goes some way to promote curiosity about the way in which some of the increasing number of people diagnosed with multiple chronic illnesses experience their lives. Perhaps it will also lead to more research into the lived experience of those who receive successive diagnoses and how they respond, as it has been the focus of little enquiry so far.

The participants' skills in adjusting to their changing physical capabilities and coping with mental distress was a striking finding and one that perhaps might be explored further, so that greater depth of understanding of their coping strategies might be gained. Throughout their living, the participants have a particular focus on connection with other people that may be a crucial factor in their adjustment to their changing circumstances. It may be useful for all of those involved with the chronically ill to be aware of the importance of the different aspects of life that gives it meaning for them.

References

Arskey, H. & Knight, P. (1999). *Interviewing for social scientists: An introductory resource with examples.* London: SAGE Publications Ltd.

Banham, D., Hawthorne, G., Goldney, R., & Ratcliffe, J. (2014). Health-related quality of life (HRQoL) changes in South Australia: Comparison of burden of disease morbidity and survey-based health utility estimates. *Health and Quality of Life Outcomes 12*(1), 113-123.

Barlow, M.A., Liu, S.Y., & Wrosch, C. (2015). Chronic illness and loneliness in older adulthood: The role of self-protective control strategies. *Health Psychology, 34*(8), 870-879. http://dx.doi.org/10.1037/hea0000182

Bayliss, E.A., Edwards, A.E., Steiner, J.F., & Main, D.S. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice,* 25(4), 287-293.

Bayliss, E.A., Balasubramianian, B.A., Gill, J.M., & Stange, K.C. (2014a). Perspectives in primary care: Implementing patient-centred care co-ordination for individuals with multiple chronic health conditions. *The Annals of Family Medicine, 12*(6), 500-503. doi: 10.1370/afm.1725.

Bayliss, E.A., Bonds, D.E., Boyd, C.M., Davis, M.M., Finke, B., Fox, R.E.,…Stange, K.C. (2014b). Understanding the context of health for persons with multiple chronic conditions: Moving from what is the matter to what matters. *The Annals of Family Medicine,12*(3), 260-269. doi: 10.1370/afm.1643

Bekelman, D.B., Havranek, E.P., Becker, D.M., Kutner, J.S., Peterson, P.N., Wittstein, I.S., ... Dy, S.M. (2007). Symptoms, depression, and quality of life in patients with heart failure. *Journal of Cardiac Failure, 13*(8), 643-649.

Beker, J., Belachew, T., Mekonin, A., & Hailu, E. (2014). Predictors of adherence to self-care behaviour among patients with chronic heart failure attending Jimma University Specialized Hospital chronic follow up clinic, South West Ethiopia. *Journal of Cardiovascular Diseases and Diagnosis. 2*(6). Retrieved from http://dx.doi.org/10.4172/2329-9517.1000180

Bhattarai, N., Charlton, J., Rudisill, C., & Gulliiford, M.C. (2013). Prevalence of depression and utilization of health care in single and multiple morbidity: A population-based cohort study. *Psychological Medicine, 43*(7), 1423-1431.

Blom, J.W., El Azzi, M.E., Wopereis, D.M., Glynn, L., Muth, C., & van Driel, M.L. (2015). Reporting of patient-centred outcomes in heart failure trials: Are patient preferences being ignored? *Heart Failure Reviews, 20*(4), 385-392.

Braden, G. (2015). *Resilience from the Heart.* London: Hay House.

Bratzke, L.C., Muehrer, R.J., Kehl, K.A., Lee, K.S., Ward. E.C., & Kwekkeboom, K.L. (2015). Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature. *International Journal of Nursing Studies. 52*(3), 744-755.

British Psychological Society. (2009). *Code of Ethics and Conduct. Guidance published by the Ethics Committee of the British Psychological Society.* Leicester: The British Psychological Society.

British Psychological Society. (2010). *Code of Human Research Ethics*. Leicester: The British Psychological Society.

Broadhurst, K. & Harrington, A. (2016). A mixed method thematic review: The importance of hope to the dying patient. *The Journal of Advanced Nursing, 72*(1), 18-32.

Brown, M., Gee, H., Platts, D., McKenzie, S. & Javorsky, G. (2011). Psychosocial impact of heart failure diagnosis in the age group 40-67 Years. *Heart, Lung and Circulation, 20*(Supplement 2)*,* 244.

Bunker, J.P. (2001). The role of medical care in contributing to health improvements within societies. *International Journal of Epidemiology 30*(6)*,*1260-1263.

Cacioppo, J.T & Patrick, W. (2008). *Loneliness. Human Nature and the Need for Social Connection.* New York: Norton.

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time.* New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly, 36*(4), 657-680.

Charmaz, K. (1999). 'Discoveries of self in illness'. In K. Charmaz & D.A. Paterniti (Eds.), *Health, illness and healing. Society, social context and self: An Anthology* (pp. 72-82). Oxford: Oxford University Press.

Chenail, R.J. (1996). Questionnaire for an autobiographical portrait of a practicing

therapist and researcher. *The Qualitative Report, 2*(4), 1-5.

Clark, P.G., Burbank, P.M., Greene, G., Owens, N., & Riebe, D. (2011). What do we

know about resilience in older adults? An explanation of some facts, factors and

facets. In B. Resnick, L.P. Gwyther & K. Roberto (Eds.), *Resilience in aging:*

Concepts, research and outcomes (pp. 51-56)*.* New York: Springer.

Conrad, P. (1987). The experience of illness: Recent and new directions. *Research*

in the Sociology of Health Care, 6,1-31.

Coventry, P.A., Fisher, L., Kenning, C., Bee, P., & Bower, P. (2014). Capacity,

responsibility, and motivation: a critical qualitative evaluation of patient and

practitioner views about barriers to self-management in people with multimorbidity.

BMC Health Services Research 14, 536. Retrieved from

http://bmchealthservices.biomedcentral.com/articles/10.1186/s12913-014-0536-y.

Davis, E., Tamayo, A., & Fernandez, A. (2012). "Because somebody cared about me.

That's how it changed things" : Homeless, chronically ill patients' perspectives on

case management. *PloS ONE, 7*(9) e45980. Retrieved from

http://dx.doi.org/10.1371/journal.pone.0045980

Department of Health (2014). The NHS Outcomes Framework 2015/16. Retrieved

from

government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_F

ramework.pdf https://www.gov.uk/

Donovan, K.A., Grassi, L., McGinty, H.L., & Jacobsen, P.B. (2013). Validation of the distress thermometer worldwide: State of the science. *Psycho-Oncology, 23*, 241-250. doi: 10.1002/pon.3430

Doos, L., Roberts, E.O., Corp, N., & Kadam, U.T. (2014). Multi-drug therapy in chronic condition multimorbidity: A systematic review. *Family Practice,* 31(6), 654-663. doi: 10.1093/fampra/cmu056

Duguay, C., Gallagher, F., & Fortin, M. (2014). The experience of adults with multimorbidity: a qualitative study. *Journal of Comorbidity, 4*(1)*,* 11-21.

Egede, L.E. (2005). Effect of comorbid chronic diseases on prevalence and odds of depression in adults with diabetes. *Psychosomatic Medicine, 67*(1), 46-51.

Ehret, A.M., A.M., Joormann, J., & Berking, M. (2014). Examining risk and resilience factors for depression: The role of self-criticism and self-compassion. *Cognition and Emotion, 29*(8), 1496-1504. doi: 10.1080/02699931.2014.992394

Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world.* Chichester: Wiley-Blackwell.

Frank, A.W. (1999). Seeing through pain. In K. Charmaz & D.A. Paterniti (Eds.), *Health, illness and healing. Society, social context and self. An Anthology* (pp.52-55). Oxford: Oxford University Press.

Frankl, V.E. (2000). *Man's search for ultimate meaning.* Rider: London.

Frankl, V. E. (2004). *Man's search for meaning.* Rider: London.

Fried, T.R., McGraw, S., Agostini, J.V., & TInetti, M.E. (2008). Views of older persons with multiple morbidities on competing outcomes and clinical decision-making. *Journal of the American Geriatrics Society, 56*(10), 1839-1844.

General Medical Council (2013). *Shape of Training: Securing the future of excellent patient care.* London: General Medical Council.

Gilmour, H. (2015). Chronic pain, activity restriction and flourishing mental health. *Health Reports 26*(1), 15-22.

Gilgun. J.F. (2005). "Grab" and good science: Writing up the results of qualitative research. *Qualitative Health Research, 15*(2), 256-262.

Giorgi, A. & Giorgi, B. (2008). Phenomenology. In J.A.Smith, (Ed.), *Qualitative psychology: A practical guide to research methods (*2nd ed., pp. 26-52). London: Sage.

Glass, G.V. (1976). Primary, secondary and meta-analysis of Research. *Educational Researcher, 5*(10), 3-8.

Graven, L.J., Grant, J.S., Vance, D.E., Pryor, E.R., Grubbs,L, & Karioth, S. (2014). Coping styles associated with heart failure outcomes: A systematic review. *Journal of Nursing Education and Practice, 4*(2), 227-242. Retrieved from http://dx.doi.org/10.5430/jnep.v4n2p227

Griffiths, P. (2012). Addressing depression for people with a chronic physical health problem. *Healthcare Counselling and Psychotherapy Journal, 12*(3), 8-13.*

Gunn, J.M., Ayton, D.R., Densley, K., Pallant, J.F., Chondros, P., Herrman, H.E., & Dowrick, C.F. (2012). The association between chronic illness, multimorbidity and depressive symptoms in an Australian primary care cohort. *Social Psychiatry and Psychiatric Epidemiology, 47*(2), 175-184.

Hannum, S.M. & Rubinstein, R.L. (2015). The meaningfulness of time; Narratives of cancer among chronically ill older adults. *Journal of Aging Studies, 36,* 17-25. doi:10.1016/j.jaging.2015.12.006

Harris, R. (2007). *The Happiness Trap.* London: Constable and Robinson.

Hayes, S.C., Strosahl, K.D., & Wilson, K.G. (2012). *Acceptance and Commitment Therapy: The Process and Practice of Mindful Change.* New York: The Guilford Press.

Heil, J. (2013) *Philosophy of mind. A contemporary introduction* (3rd ed.). New York: Routledge.

Hermanns, M., & Haas, B.K. (2014). One step at a time: A journey of hope, inspiration, and determination. *The Qualitative Report, 19*(14), 1-9. Retrieved from http://www.nova.edu/ssss/QR/QR19/hermanns14.pdf

Hundt, N.E., Bensadon, B.A., Stanley, M.A., Petersen, N.J., Kunik, M.E., Kauth, M.R., & Cully, J.A. (2015). Coping mediates the relationship between disease severity and illness intrusiveness among chronically ill patients. *Journal of Health Psychology, 20*(9), 1186-1195.

Islam, M.M., McRae, I.S., Yen, L., Jowsey, T., & Valderas, J.M. (2015). Time spent on health-related activities by senior Australians with chronic diseases: What is the role of multimorbidity and comorbidity? *Australian and New Zealand Journal of Public Health, 39*(3), 277-283.

Jaarsma, T., Lesman, I., & van Veldhuisen, D.J. (2008). Psychology and cardiology: Do not forget the heart failure patient. *European Heart Journal, 29*(9), 1208-1209.

Jacobsen, P.B., Donovan, K.A., Trask, P.C., Fleishman, S.B., Zabora, J., Baker, F., & Holland, J.C. (2005). Screening for psychological distress in ambulatory cancer patients: A multicenter evaluation of the distress thermometer. *Cancer, 103*(7), 1494-1502.

Koné Pefoyo, A.J., Bronskill, S.E., Grunier, A., Calzavara, A., Thavorn, K. Petrosyan, Y.,… & Wodchis, W.P. (2015). The increasing burden and complexity of multimorbidity. *BMC Public Health, 15,* 415-426.
doi 10.1186/s12889-015-1733-2

Kroenke, K., Wu, J., Blair, M.,J., Krebs, E.E., Damush, T.M. & Tu, W. (2011). Reciprocal relationship between pain and depression: A 12-month longitudinal analysis in primary care. *Journal of Pain, 12*(9), 964-973.

Langer, M.M. (1989). *Merleau-Ponty's phenomenology of perception.* London: The Macmillan Press.

Langdridge, D. (2007). *Phenomenological psychology*: *Theory, research and method.* Harlow: Pearson Education.

Leeming, A., Murray, S.A., & Kendall, M. (2014). The impact of advanced heart failure on social, psychological and existential aspects and personhood. *European Journal of Cardiovascular Nursing, 13(2),* 162-167.

Liddy, C., Blazkho, V., & Mill, K. (2014). Challenges of self-management when living with multiple chronic conditions. Systematic review of the qualitative literature. *Canadian Family Physician, 60*(12), 1123-1133.

Linden, W., Phillips, M.J., & Leclerc. J. (2007). Psychological treatment in cardiac patients: A meta-analysis. *European Heart Journal, 28*(24), 2972-2984.

Linden, W., Phillips, M.J., & Leclerc, J. (2008). Psychology and cardiology: Do not forget the heart failure patient: reply. *European Heart Journal, 29*(9), 1208-1209.

Lindqvist, G.E., & Hanson, E. (2016). Conceptions of everyday life among people living alone with chronic obstructive pulmonary disease. *Clinical Nursing Studies, 4*(2), 8-20. Retrieved from http://dx.doi.org/10.5430/jcns.v4n2p8

Longevity Science Advisory Panel (2012). Life expectancy: Past and future variations by gender in England and Wales. Retrieved from http://www.longevitypanel.co.uk/index.html.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., Meinow, B., & Fratiglioni, L. (2011). Aging with multimorbidity: A systematic review of the literature. *Aging Research Reviews, 10*(4), 430-439.

Marks, A. (2013). Health research: The future of health and wellness. Retrieved from http://www.therivergroup.co.uk/what-we-think/health-research-future-health-wellness/

Mason, B., Nanton, V., Epiphaniou, E., Murray, S.A., Donaldson, A., Shipman, C., Daveson, B.A., Harding, R., … & Boyd. K. (2016) 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: Serial interviews with patients and carers. *BMJ Supportive and Palliative Care, 6*(1), 60-65. doi:10.1136/bmjspcare-2013-000639

Masten, A.S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist, 56*(3), 227-238.

McKay, M., Wood, J.C. & Brantley, J. (2007). *The dialectical behavior therapy skills workbook: Practical DBT exercises for learning mindfulness, interpersonal effectiveness, emotional regulation and distress tolerance.* Oakland: New Harbinger Publications.

McKenzie, K.J., Pierce, D., & Gunn, J.M. (2015). A systematic review of motivational interviewing in healthcare: The potential of motivational interviewing to address the lifestyle factors relevant to multimorbidity. *Journal of Comorbidity, 5*(1), 162-174.

McKie, J. & Richardson, J. (2003). The rule of rescue. *Social Science and Medicine, 56*(12), 2407-2419. doi: 10.1016/S0277-9536(02)00244-7

Meranius, M.S., & Hammar, L.M. (2016). How does the healthcare system affect medication self-management among older adults with multimorbidity? *Scandinavian Journal of Caring Sciences. 30*(1), 91-98.

Moser, D.K., Heo, S., Lee, K.S., Hammash, M., Riegel, B., Lennie, T.A., Arslanian-Engoren, C., Mudd-Martin,G., Albert, N. & Watkins, J. (2013). 'It could be

worse…lot's worse!' Why health-related quality of life is better in older compared with younger individuals with heart failure. *Age and Ageing, 42*(5), 626-632.

Mujica-Mota, R.E., Roberts, M., Abel, G., Elliott, M., Lyratzopoulos, G., Roland, M. & Campbell, J. (2014). Common patterns of morbidity and multi-morbidity and their impact on health-related quality of life: evidence from a national survey. *Quality of Life Research, 24*(4), 909-918. doi:10.1007/s11136-014-0820-7

Mulhall, S. (2013). *The Routledge guidebook to Heidegger's being and time.* London: Routledge.

Murberg, T.A., Bru, E., Svebak, S., Tveterås, R., & Aarsland, T. (1999). Depressed mood and subjective health symptoms as predictors of mortality in patients with congestive health failure: A two-years follow-up study. *The International Journal of Psychiatry in Medicine, 29*(3), 311-326.

Murberg, T.A., & Bru, E. (2001). Social relationships and mortality in patients with congestive heart failure. *Journal of Psychosomatic Research, 51*(3), 521-527.

Murphy, R.F. (1999). The damaged self. In K. Charmaz & D.A. Paterniti (Eds.), *Health, illness and healing; Society, social context and self: An anthology* (pp.62-71). Oxford: Oxford University Press.

NICE (2009). *Depression in adults with a long-term physical health problem: treatment and management.* National Clinical Guidelines CG91- London: NICE

Neff, K. (2011). *Self Compassion: Stop beating yourself up and leave insecurity behind.* New York: HarperCollins.

Nelson-Jones, R. (1982). *The theory and practice of counselling psychology* . London: Cassell.

Nelson-Jones, R. (2015). *Theory and Practice of Counselling and Psychotherapy (6*[th] *ed.)*. London: Sage.

Newman, R. (2005). APA's Resilience Initiative. *Professional Psychology: Research and Practice, 36,* 227-229.

Norra, C., Skobel, E.C., Arndt, M., & Schauerte, P. (2008). High impact of depression in heart failure: Early diagnosis and treatment options. *International Journal of Cardiology, 125(2),* 220-231.

Obieglo, M., Uchmanowicz,I., Wleklik, M., Jankowska-Polańska, B., & Kuśmierz, M. (2015). The effect of acceptance of illness on the quality of life in patients with chronic heart failure. *European Journal of Cardiovascular Nursing. doi:* 10.1177/1474515114564929.

OECD (2011a). *Health reform: Meeting the challenge of aging and multiple morbidities.* OECD Publishing. Retrieved from http://dx.doi.org/10.1787/9789264122314-en

OECD (2011b). *Health at a glance 2011: OECD Indicators.* OECD Publishing.

Parekh, A.K., & Goodman, R.A. (2013). The HHS Strategic Framework on multiple chronic conditions: genesis and focus on research. *Journal of Comorbidity, 3*(2)*,* 22-29.

Pelle, A.J.A., Gidron, Y.Y., Szabó, B.M. & Denollet, J. (2008). Psychological predictors of prognosis in chronic heart failure. *Journal of Cardiac Failure, 14*(4), 341-350.

Perkins, M.M. (2013). Resilience in later life: Emerging trends and future directions.*The Gerontologist, doi:10.1093/geront/gnt159*

Pettite, T., Mallow, J., Barnes, E., Petrone, A. Barr, T., & Theeke, L. (2015). A systematic review of loneliness and common chronic physical conditions in adults. *The Open Psychology Journal. 8,*(Suppl. 2), 113-132.

Pew Research Center (2013). Living to 120 and beyond: Americans' views on aging, medical advances and radical life extension. Retrieved from www.pewforum.org/2013/08/06/living-to-120-and-beyond-american-views-on-aging-medical-advances-and-radical-life-extension/

PhRMA (2016). Medicines in development. Retrieved from www.phrma.org/innovation/meds-in-developement

Prince-Embury, S. (2008). Translating resiliency theory for assessment and application in schools. *Canadian Journal of School Psychology, 23*(1), 4-10.

Rafferty, K.A., Billig, A.K., & Mosack, K.E. (2015). Spirituality, religion, and health: The role of communication, appraisals, and coping for individuals living with chronic illness. *Journal of Religion and Health, 54*(5), 1870-1885.

Reeve, J. & Cooper, L. (2016). Rethinking how we understand individual health care needs for people living with long-term conditions: A qualitative study. *Health & Social Care in the Community,* 24(1), 27-38. doi: 10.1111/hsc.12175.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20-23.

Resnick, B.A., & Inguito, P.L. (2011). The resilience scale: Psychometric properties and clinical applicability in older adults. *Archives of Psychiatric Nursing, 25(1),* 11-20.

Ritchie, L.H. (2014). *'I'm not a pill-taker': Medication and meaning for older people.* (Thesis, Doctor of Philosophy). University of Otago. Retrieved from http://hdl.handle.net/10523/5016

Röing, M., & Sanner, M. (2015). A meta-ethnographic synthesis on phenomenological studies of patients' experiences of chronic illness. *International Journal of Qualitative Studies on Health and Well-being,* 10. Retrieved from www.ijqhw.net/index.php/qhw/article/view/26279

Ruggiano, N., Shtompel, N., Whiteman, K., & Sias, K. (2015). Influences of transportation on health decision-making and self-management behaviours among older adults with chronic conditions. *Behavioural Medicine.* doi: 10.1080/08964289.2015.1065788

Rutter, M. (2013). Annual research review: Resilience – clinical implications. *Journal of Child Psychology and Psychiatry, 54*(4)*,* 474-487.

Salive, M. E. (2013). Multimorbidity in older adults. *Epidemiologic Reviews, 35,* 75-83.

Satariano, W.A., & Boyd, C.M. (2013). Improving the evidence base on multimorbidities through better research: A commentary on the U.S. HHS initiative, multiple chronic conditions: A strategic framework. *Journal of Comorbidit*y, *3*(2),18-21.

Schoenberg, N.E., Leach, C., & Edwards, W. (2009). "It's a toss up between my hearing, my heart and my hip" : Prioritizing and accommodating multiple morbidities by vulnerable older adults. *Journal of Health Care for the Poor and Undeserved, 20*(1), 134-151.

Seah, A.C.W., Tan, K.K., Huang Gan, J.C., & Wang, W. (2016). Experiences of patients living with heart failure: A descriptive qualitative study. *Journal of Transcultural Nursing, 27*(4), 392-399*.* doi:10.1177/1043659615573840

Sheilds, L., Molzahn, A, Bruce, A., Schick Makaroff, K., Stajduhar, K. Beuthin, R., & Shermak , S. (2015). Contrasting stories of life-threatening illness: A narrative inquiry. *International Journal of Nursing Studies, 52*(1), 207-215.

Shiner, A., Steel, N., & Howe, A. (2014). Multimorbidity: What's the problem? *Quality in Primary Care, 22*(3),115-119.

Shtompel, N., Whiteman, K., & Ruggiano, N. (2014). Negative feelings and help seeking among older adults with chronic conditions. *Journal of Gerontological Social Work, 57*(8), 810-824.

Silverman, A.M., Verrall, A.M., Alschuler, K.N., Smith, A.E., & Ehde, D.M. (2016). Bouncing back again, and again: A qualitative study of resilience in people with multiple sclerosis. *Disability and Rehabilitation.* doi:10.3109/09638288.2016.1138556

Sirois, F.M., Molnar, D.S., & Hirsch, J.K. (2015). Self-compassion, stress, and coping in the context of chronic illness. *Self and Identity,14*(3), 334-347. doi:10.1080/15298868.2014.996249

Smith, J.A. (Ed.) (2008). *Qualitative psychology: A practical guide to research methods.* London: Sage.

Smith, J.A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons and A. Coyle, (Eds), *Analysing qualitative data in psychology,* pp. 53-80)*.* London: Sage.

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis. Theory, method and research.* London: Sage.

Smith, J.A., & Osborn, M. (2008) Interpretative phenomenological analysis. In J.A. Smith, (Ed.), *Qualitative psychology: A practical guide to research methods.* London: Sage.

Stallard, P. (2005). *A clinician's guide to think good – feel good. Using CBT with children and young people.* Chichester: John Wiley & Sons Ltd.

Stanners, M.N., Barton, C.A., Shakib, S., & Winefield, H.R. (2014). Depression diagnosis and treatment amongst multimorbid patients: A thematic analysis. *BMC Family Practice, 15*, 124.

Retreived from http://www.biomedcentral.com/1471-2296/15/124

Surah, A., Baranidharan, G., & Morley, S. (2014). Chronic pain and depression. *Continuing Education in Anaesthesia, Critical Care and Pain, 14*(2), 85-89.

Swartz, J.A., & Jantz, I. (2014). Association between nonspecific severe psychological distress as an indicator of serious mental illness and increasing levels of medical morbidity. *American Public Health Association, 104*(12), 2350-2358.

Tannenbaum, C. (2013). How to treat the frail elderly: The challenge of multimorbidity and polypharmacy. *Canadian Urological Association Journal, 7*(9-10)(Suppl. 4),183-185. Retrieved from http://dx.doi.org10.5489/cuaj.1619

The King's Fund. (2016). *Life expectancy.* Retrieved from http://www.kingsfund.org.uk/time-to-think-differently/trends/demography/life-expectancy.

The Statistics Portal (2016). *Market value of health and wellness in the United Kingdom from 2011 to 2016.* Retrieved from http://www.statista.com/statistics/491348/health-and-wellness-united-kingdom-uk-market-value/

Townsend, A., Wyke, S., & Hunt, K. (2006). Self-managing and managing self: Practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness, 2*(3), 185-194.

Tudball, J., Smith, L., Ryan, K., Williamson, M., & Manias, E. (2015). Challenge to consumers travelling with multiple medicines. *Journal of Pharmaceutical Health Services Research, 6*(3), 127-132. doi: 10.1111/jphs.12097

Ubel, P.A., Jankovic, A., Smith, D., Langa, K.M., & Fagerlin, A. (2005). What is perfect health to an 85-year-old?: Evidence for scale recalibration in subjective health ratings. *Medical Care 43*(10), 1054-1057.

Underwood, N. (2001) Cheating time. *Maclean's, 114*(28), 14.

U.S. Department of Health and Human Services (2010). *Multiple chronic conditions: A strategic framework. Optimum health and quality of life for individuals with multiple chronic conditions.* Washington, DC: USDHHS.

Vaccarino, V., Kasl, S.V., Abramson, J., & Krumholz, H.M. (2001). Depressive symptoms and risk of functional decline and death in patients with heart failure. *Journal of the American College of Cardiology, 38*(1), 199-205.

VanHoose, L., Black, L.L., Doty, K., Sabata, D., Twumasi-Ankrah, P., Taylor, S., & Johnson, R. (2015). An analysis of the distress thermometer problem list and distress in patients with cancer. *Support Care Cancer, 23,* 1225-1232.

Vaillant, G.E. (2002). *Aging Well.* New York: Little, Brown and Company.

Vos, R., van den Akker, M., Boesten, J., Robertson, C., & Metsemakers, J. (2015). Trajectories of multimorbidity: Exploring patterns of multimorbidity in patients with more than ten chronic health problems in life course. *BMC Family Practice* 16, 2. doi:10.1186/s12875-014-0213-6

Vyas, A., Pan, X.L., & Sambamoorthi, U. (2012). PHP26 multimorbidity and polypharmacy. *Value in Health,15*(4), A17-A18. doi: 10.1016/j.jval.2012.03.103

Walker, E.A. (2007). Multiple chronic diseases and quality of life: Patterns emerging from a large national sample, Australia. *Chronic Illness 3*(3)*,* 202-218.

Warren, N., & Ayton, D. (2014). Loneliness as social suffering: Social participation, quality of life, and chronic stroke. *World Suffering and Quality of Life,* Vol 56 of the series Social Indicators Research Series,159-170.

Wehling, M. (2009). Multimorbidity and polypharmacy: How to reduce the harmful drug load and yet add needed drugs in the elderly? Proposal of a new drug classification: Fit for the aged. *Journal of American Geriatrics Society, 57*(3), 560-561.

Weisbord, S.D. (2016). Patient-centred dialysis care: Depression, pain and quality of life. *Seminars in Dialysis, 29*(2), 158-164. doi: 10.1111/sdi.12464

Westlake, C., Dracup, K., Fonarow, G. & Hamilton, M. (2005). Depression in patients with heart failure. *Journal of Cardiac Failure, 11*(1), 30-35.

White, C., Lentin, P. & Farnworth, L. (2016). Multimorbidity and the process of living with ongoing illness. *Chronic Illness, 12*(2), 83-97.

Wiles, J.L., Wild, K., Kerse, N. & Allen, R.E. (2012). Resilience from the point of view of older people: 'There's still life beyond a funny knee'. *Social Science and Medicine, 74*(3), 416-424.

Willig, C. (2008) *Introducing qualitative research methods in psychology* (2nd ed.). Maidenhead: McGraw Hill Open University Press.

Willig, C. (2012). *Qualitative interpretation and analysis in psychology.* Maidenhead: McGraw Hill Open University Press.

Yalom, I.D. (1980). *Existential psychotherapy.* New York: Basic Books.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.),*Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 235-251). London: Sage.

Zebhauser, A., Baumert, J., Emeny, R.T. Ronel, J., Peters, A., & Ladwig, K.H. (2015). What prevents old people living alone from feeling lonely? Findings from the KORA-Age-Study. *Aging and Mental Health,19*(9), 773-780.

Section B: An Extended Client Study using the Person-Centred Approach

The client study has been withheld to protect the welfare and confidentiality of the client.

Section C: Paper for Publication

This section is the journal article prepared for submission to Journal of Health Psychology for publication. The reason I chose this journal was because its focus is to support research into aspects of health psychology and accepts papers with a qualitative approach including interpretative phenomenological analysis. A particular area of interest is the contexts in which psychological processes are embedded, which is clearly relevant to this study.

'It's just another thing': A qualitative study of the experience of receiving successive diagnoses including stage 3 heart failure.

Sue Taylor

Department of Psychology, City, University of London, UK

Abstract

Interpretative Phenomenological Analysis (IPA) was used to explore the experience of receiving successive diagnoses for people with stage 3 heart failure (NYHA) and at least two other chronic health conditions. Six people (three male, three female) were interviewed using a semi-structured questionnaire. Three overarching themes emerged relating to the acceptance of diagnoses, the importance of relationships and the meaning of time. The subthemes were related to adapting both physically and emotionally to progressive deterioration.

Introduction

The King's Fund (2016) details the estimate of a healthy life span. It suggests that males are likely to have about 10 years of healthy life expectancy after 65, whilst females have slightly more at about 12 years. Therefore for most people, death will be preceded by several years of ill-health that may involve several diseases. It is suggested that multiple morbidity affects more than half of the elderly population (Marengoni et al., 2011). It is common in older people, but by no means exclusively.

Multiple morbidity is considered to be the co-occurrence of two or more diseases in the same individual (McKenzie et al., 2015). It is associated with higher rates of disability and significantly lower quality of life (Banham et al., 2014). There are studies about receiving one diagnosis (Schofield et al., 2003; Hughes et al., 2006; Leeming et al., 2014;), but little about the experience of receiving successive diagnoses.

The National Institute for Health and Care Excellence (2009) proposes that there are increasing mental health issues when people have multiple chronic illnesses. Egede (2005) suggest that depression is more prevalent in the presence of multiple morbidities. Further, Bhattarai et al. (2013) suggest that it is the number of morbidities, rather than the nature of the diagnoses that has an impact on mental health. Duguay et al. (2014) suggest that people living with multiple morbidities felt that they were aging more rapidly than others of their age, perhaps due to their increasing physical limitations.

Additionally, a diagnosis of heart failure is suggested to have a negative impact on mental health (Vaccarino et al, 2001). Seah et al. (2015) suggest that the uncertainty of the trajectory of their illness can overwhelm the individual. A diagnosis of a single life threatening disease, such as cancer, chronic kidney disease and HIV/AIDS may be accompanied by an increase in awareness of mortality as the uncertainty of the future becomes part of living (Sheilds et al., 2015).

It is suggested that increased morbidity including heart failure may lead to reduced social connections and loneliness (Pettite et al., 2015). Linked to this is the issue of isolation, which is sometimes a consequence of chronic illness, but also increases as people become older (Barlow et al., 2015).

The aim of this research was to gain insight into the experience of receiving successive diagnoses for people with several chronic illnesses. It was hoped to learn more about this, so that the knowledge gained might provide some insight into the perspective of multimorbid individuals and the ways in which they cope with their situation.

The research project was done as part of the fulfillment of the requirement of the degree of Doctor of Psychology at City, University of London.

Methodology:

Design

This qualitative study used one-to-one semi-structured interviews with six participants. Interpretative phenomenological analysis (IPA) was used to identify the lived experience of those receiving successive diagnoses. Smith, Flowers and Larkin (2009) describe IPA as an approach that is focused on personal meaning and sense making for people who share a common experience.

Ethical approval was obtained initially from City University London and subsequently from the local centralised National Health Service (NHS) Ethics committee.

Participants

NHS Heart Failure Community Specialist Nurses (CNS) identified possible participants through their knowledge of their caseload. The inclusion criteria were that they should have at least three morbidities for which they were receiving regular treatment, one of which was stage 3 heart failure of at least six months duration. There were only six participants, three of each gender, aged between 64 and 93 years. Five of the six lived alone. All were not working. None of them scored more than seven on the Distress Thermometer (a device used by the heart failure team to assess emotional and psychological distress) and so were not considered to be experiencing a significant level of distress at the time of the interview. This produced a more homogenous sample.

Procedure

Initial discussion was held between the CNS and the prospective participant to introduce the study. If interest was shown, the researcher telephoned to discuss the process further. All interviews were conducted in the participants' homes, as it would have been difficult for them to travel to another venue. The process was reviewed before the consent form was signed by the participant, ensuring fully informed consent was obtained. The interviews lasted from 55 to 90 minutes, depending on whether the participant felt able to continue. The interview schedule consisted of open-ended questions about the participant's experience of having had a number of diagnoses, such as 'Could you describe in your own words how you felt when you got each diagnosis?' and 'How do you feel now that you are living with these illnesses?'

A debrief followed to gain the participant's reactions. Interviews were held in the morning so that appropriate staff might be available if the participant needed support. Interviews were digitally recorded and transcribed by the researcher. Transcriptions included all spoken words, pauses, false starts and laughter. Reflexivity was used to inform the researcher about the ways in which personal involvement impinged on the research, including the data collection and analysis.

Data Analysis

The researcher analysed the transcribed interviews using IPA. This is a process in which description moves to the interpretative and the particular to the shared (Smith et al. 2009). It is underpinned by principles of commitment to understanding the individual's point of view and focusing on meaning-making. Smith et al. (2009) described the process as an iterative and inductive cycle. The six stages of analysis described by Smith et al (2009) were used.

Analysis and Discussion

The analysis produced three overarching themes and subthemes

1. Acceptance of successive diagnoses
   - The relationship with illness
   - Adjusting to life with illness
   - Impact of diagnoses
   - Managing emotional responses

2. Importance of others
   - Social self – the need for others
   - Dependence on professional support

- Relationships with family

3. Meaning of time (Temporality)

- Importance of the past

- Hope for the future

- Focus on death

This section will provide further detail on these themes illustrated by the participant's words where appropriate.

Acceptance of successive diagnoses

Surprisingly, perhaps, the participants rarely dwelt on the moment or time when they received another diagnosis, but rather seemed to show a marked acceptance of these events, as though they were to be expected. Lilian explains her feelings of acceptance, or perhaps it is tolerance, when she received a recent diagnosis:

> Because when they said to me that these were cancerous. Oh well, it's just something else to add to everything else that I've got wrong with me. And I've never been afraid of dying. (Lilian, 27/17)

A diagnosis of cancer may pose an existential threat that may be expected to be greeted with some distress. However, Lilian does not appear to be distressed, but rather seems to be accepting of it. Although she says that she is unafraid of death, she does not anticipate that this will be soon, thus distancing herself from the possibility '…because I don't know when my time's up. It probably won't be for years…' (Lilian, 28/12)

Perhaps this might be interpreted as a protective strategy. There seemed to be other protective strategies apparent. For example, it was interesting to note that, although the participants recognised that they had a number of diagnoses, they did not consider themselves to be ill:

> I suppose whatever I've had go wrong with me has not made me what I consider ill. I've still been able to walk around and do things. I think of really ill when you see some of these poor devils who are lying in bed, being knocked out and God know what else. To me, that's ill. I mean, I know I'm ill and deep down I've got a lot wrong with me and things like that, but when you've got no pain or discomfort or anything from that particular thing, you don't think about it do you? (Janet, 24/17)

Janet appears to use another protective strategy. By comparing herself with others she considers are worse off than herself, she may be able to feel that her own situation is not so serious. All of the participants except Lilian, the youngest, had the perception that they were not ill. Douglas also considered himself to be 'not ill' just as having medical problems he needed to solve. 'No, I see myself as medical problems, but not ill' (Douglas, 28/14). Although denying that he is ill, Douglas aligns his sense of self as very much entwined with his health issues.

By feeling they are not ill, they may protect themselves from understanding the seriousness of their condition. Further, if they consider themselves to be not ill having received diagnoses, the diagnosis of another illness may have little importance in their thinking.

The participants' central concern appeared to be a continuation of living with their changing capabilities and finding ways to maintain their independence. Surprisingly,

perhaps, they regarded themselves as independent, despite being dependent on others for support, 'Yes, well, I mean I'm still independent even though I can't do things for myself' (Lilian, 14/16).

It would seem that the self-perception of independence is unrelated to physical dependency in the participants' thinking.

The participants described how they have developed strategies for adjusting to their increasingly limited capabilities as well as any mental distress they may experience. Robert describes his process of adjustment to his changing capabilities by saying:

> You adjust for what you can do. You know you're limited of what you can do and you, you've got to live with it. (Robert, 15/12)
> I think it's to do with your heart and your balance. It's all to do, you've got to learn to do things slowly, not think what you used to do. (Robert, 14/24)

He continues by saying 'you've just got to think' (Robert, 16/2) and that he is 'sensible about things' (Robert, 16/4). He talks about doing things in a different way, illustrating flexibility of thinking and an ability to adapt. He also appears to show some self-compassion by accepting his deterioration and adjusting to it. Angela too, seems to have self-compassion when she explains how she paces herself when doing housework, or allows herself to leave it if unable to cope:

> If I need to do something and it's hard work, I'll do it in bits and pieces. I'll sit down a while and then I'll go and do a bit more. I mean, I can go cleaning all around the house, can take me a whole day. I'll do a bit here and a bit there.
> (Angela, 18/22)

I mean some days I haven't got the energy to pull the vacuum cleaner about, then I think, oh well, bugger it, whoever doesn't like it, they can come and do it. (Angela, 25/16)

Despite having to adjust to their changing capabilities, the participants did not appear to change the way they regarded themselves. Douglas described this as 'I think I am the same person, just got more problems to cope with, that's all (Douglas, 20/18).

Although the participants sometimes experienced emotional distress, they seemed able to maintain their desired emotional state by not allowing unwanted emotions to dominate their thinking:

Well I suddenly think, what's it all about? What am I living for? If this is your life, what is it? What are you doing? You know, and I don't think like that and then I, then I let it go and I'm, then I'm all right again then. (Robert, 22/15)

Robert appears to be able to regulate his emotional response. The participants' self-perception seemed to be that they were not people who thought negatively and so they denied that they might feel sad. Another strategy was to keep actively engaged in physical activity so as this was perceived to improve their mental state. 'I do try to do as much for myself as I can, you know, the more I do, the better I feel' (Janet, 23/19).

This was a striking aspect of the analysis that seems to indicate that the participants displayed some level of resilience by adapting to changing physical capability and regulating their emotions when events became challenging.

Despite their acceptance of diagnoses, two of the participants expressed fear of becoming critically ill again:

> …they've only got to say one little thing that sounds, shall we say, to me, slightly bad, shall we say, and I don't hear any more. My, I seem to blank off, you know, I'm aware of it, you hear it, but from a distance. All you're thinking about is that, oh my God, you know. (Janet 11/6)

Janet described how she fears that she might hear bad news and her panic at her awareness that it might signal the end of her life. She appears to dissociate and shut down when she fears hearing bad news, which would seem to be a protective strategy. She does not appear to be talking about a new diagnosis, but rather of deterioration in one of her existing medical conditions. Similarly, Angela described her terror at a time when she was close to death:

> I was dead frightened. I was dead scared. And I really, I'm not, I'm not over that. As soon as I get a funny feeling in here …It's ridiculous really when I think about it. (Angela, 24/11)

Angela remained alert to any feeling that might indicate that her life was once again threatened. However, at other times the participants did not report undue unhappiness, or psychological distress. Generally, they seemed to be thankful for the lives they had led and happy with their present. Robert described himself as a very lucky man (Robert, 19/14). Despite her concern about being alone, Janet described herself as 'very content at the moment' (Janet, 21/16).

The participants seemed to use a range of protective strategies for coping with their diagnoses. They had received and survived diagnoses previously and so seemed to expect to survive and cope with any further diagnoses.

All the participants had been diagnosed with a significant level of heart disease. However, they did not appear to experience the level of social, psychological and existential distress that might be expected to accompany this diagnosis. Only one participant described any impact by saying that it 'sort of came to light' (Angela, 5/16) which describes a slow emergence, lacking impact. The remainder made no comment. This is surprising and in contrast to the literature that suggests that a diagnosis of advanced heart failure might cause some distress in the person receiving it.

Another surprising aspect was that the participants seemed to be unaware of the seriousness of their heart condition and unsure what its impact might be. Two of the participants made no mention of their heart failure at all. One spoke about balancing the medication for heart failure with other medication and the remainder were vague about the diagnosis and the meaning it may have for them. Only Angela spoke specifically about her failing heart. When asked she commented:

> Well I can't really complain about my heart. Occasionally it plays up and it does a few funny jumps, but, just lately, it's been very good. (Angela, 5/5)

It would appear that Angela did not feel concerned. Perhaps the participants were lacking engagement in what heart failure might mean to them to protect themselves.

When asked about his heart, Tony's comment implies an unconcerned attitude when he said, 'The heart is not too bad as far as I know' (Tony, 13/1).

He went on to talk about taking 'various heart pills' (Tony,13/16) and the 'hilarious game' (Tony,13/23) he plays with his wife when taking them. He seemed to be unconcerned about his heart and lacking curiosity about what it may mean. Playing a game with his medication may be a way of minimising its importance and significance to him.

When Angela spoke about her diagnosis of heart failure she implied that it might have been there for years without her knowing:

> I know this heart failure only sort of came to light before Christmas. Oh yes, I haven't lived that long with it. Well, I must have, but not knowing. (Angela, 5/16)

Angela acknowledges that she may have had heart failure for some time but, if so, it seems its impact has been unremarkable. The participants generally seem unconcerned about having a serious level of heart failure and seem uncertain about the meaning it might have for them.

Importance of others
Each of the participants strongly expresses the need for contact with other people for their company as well as the support they provided. All of the participants, except for Tony, lived alone. There was variation in the amount of support each of them received, but they were all dependent on other people to maintain their independent living. Some of the participants spoke about the value that connecting with others had for them, whilst others talked about the special nature of their relationship with medical professionals. This is particularly pertinent considering their dependency on medical support for their continued existence.

The importance of others is apparent when Robert, now housebound, comments about those who support him:

> I feel happier at home. No, no, I'm quite happy with my lot really. As I say, if I was all on my own and I never saw anybody, I would probably have a different outlook. But I'm so well looked after by everybody and everybody is so concerned and kind, that's, that's what, that's what I like. (Robert, 25/20)

The participants frequently described the comfort, care and support provided by family members and medical staff. All of the participants spoke about the importance of their family relationships. They spoke about their central role in providing practical help and much appreciated emotional support. Loving relationships were apparent, 'They just love me. They always tell me they love me' (Angela, 15/23).
Tony described the value that social contact with family members has for him:

> …that part of the day when I've got my wife, or my daughter, or my grandson, but it's the first two that I see the most, in the room, one can almost forget oneself, almost. (Tony, 24/6)

Having other people with him appears to distract him so that he is able to forget his ailing self.

Douglas spoke movingly about the emotional connection he has with his family. He was surrounded by family photographs and keen to explain his relationships. He commented on the increased closeness he feels with his family, 'I think sometimes that we are closer than what we were. More or less, because they think they've got to help me and all that, I suppose' (Douglas, 24/14).

Janet also expressed her need for others to help her through the panic and anxiety she experiences as a result of her physical symptoms. She illustrated this by talking about a trip to the supermarket with a family member:

> …because I am wondering round there thinking of what I'm going to get, you don't think of what's going on in there [indicating body] and when you get back in the car and you start being…because you don't think about it. People keep saying to you well try and think about something else and not think about your breathing. And it is better if you can do that, but it's surprising how difficult that can be, especially when you're on your own. If you're with somebody, you've got somebody else to take it off, but when you're on your own, you can dwell on these things and that doesn't help. (Janet, 16/12)

Janet eloquently describes her feelings and how she uses the distraction of being with others to control her concern.

The importance of relationships of the participants with medical staff was apparent, as they rely on them to continue their living. Janet's relationship appears to be not only close, but also protective. She expressed her perception of a close relationship with a hospital doctor:

> …it was a bit like being taken under her wing. And she's been really very good and looked after me ever since and we've had, it's a bit of, a bit like a bond in a way, because every time I go up there to see her, she always says "Hi [participant's name]", you know. We've become almost like friends, you know. (Janet, 4/19)

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Angela describes her long term relationship with her doctors as one in which her emotional state is improved by contact with them:

> I have to go to the liver doctor on Friday, him and I have a little laugh and little smile and I have all these doctors that I've had for so long and they are all so lovely and they make you feel better. (Angela, 20/22)

Interestingly her comments make no mention of the medical treatment she receives, but focus on the personal value of the relationships.

Conversely, Tony readily expressed his opinion about the competency of medical staff, which is so vital for his continued existence. He spoke angrily about his perception that medical staff at a certain hospital were responsible for his loss of vision:

> Incidentally, I feel pretty sore with them. I've known [hospital name] for many years and I've had a very big major operation on one eye there…We knew the place and had always found them utterly charming and competent. This time I thought 'What a ham-fisted lot…' (Tony, 8/1)

The value of the participants' social connections is that they are supportive and enable them to see a continuation of being able to live in their own homes. Two of the participants are now housebound, so that their worlds have become much smaller. Through contact with others they continue to connect with lives and events beyond their front door.

Meaning of time

The participants all had life threatening illnesses so that time had a particular
meaning for them. The past seemed important to all of them, illustrated by the
amount of time that they focused on it in their interviews and the significance they
ascribed to the experiences they related. They all recognised that their future is
limited and that they are moving towards death. Their approach to life is influenced
by their awareness of their fragile existence. All of the participants tended to have a
short-term view of the future and all expressed understanding that death might be
imminent. They were reluctant to plan, but appeared to live for the moment and value
each day.

Many of the participants spoke about the importance of the past and how their
experiences have facilitated their living in the present. Two of the men had spent
time in the Armed Forces. They explained how their ability to live independently was
related to skills learned at that time:

> I think a lot of it goes back to me being in the Navy. I was in 12 years and I
> think a lot of my life goes back to that because from that I could…cook,
> clean, make beds to a high standard, you had to. There was no choice…
> (Douglas, 19/4)

The skills learned in the past have gained a new value as the participants adjust to
their increased morbidity and reduced capability. Robert described how he felt that
his past has provided him with well-developed organisational skills to cope with his
complex medication:

> …I've got little pots, every night religiously, before I go to bed, I get all my
> pills and my pots and divide them all up for the day. And then, they've got

different colours, pots and then different positions and I know when to take

them. That's my routine. I think that come with the Army. (Robert, 21/10)

Generally none of the participants planned more than a few days into the future.
When Angela was asked whether she had plans for the future. She replied simply,
'No' (Angela, 20/17). Janet summed up the feelings of the participants:

Haven't got a future, have I? ...I live from day to day now. I do what I can,

when I can. I don't like planning too far ahead, because…to have planned

anything, the whole lot would, you know… I wouldn't plan for a holiday now.

(Janet, 25/3)

There appears to be a sense of loss as Janet acknowledges that she feels no longer
able to take a holiday. However, she spoke about her lack of future in a very routine
and matter-of-fact way, as though it was just accepted.

Despite the lack of planning for the future, the participants expressed hope. Janet
described how she hoped that every new day might be enjoyable and expressed
gratitude for the possibility:

Well you do always hope. I mean, everyday when I wake up and, you know,

you wake up and think, oh good. You know, you might not have an ache;

you might not have a pain. You think, well I feel good today and you get up

and think 'Thank God, it's lovely to get up. (Janet, 28/10)

All of the participants expressed some hope for the future, even if only for the day
ahead. Robert spoke of his future in an afterlife where he believes he will be reunited
with his wife and son (Robert, 23/25). Some spoke about the improvements they

hoped for in their physical condition. Tony commented about the huge progress he feels that he has made:

> I've already an enormous confidence that we didn't expect, we didn't expect, of movement. I mean, I shan't do it I'm afraid, but I could easily get up and see you to the front door. I couldn't take you over the edge and round the garden, but if there was somebody with me, I most certainly could. As I say, yesterday was a miracle. (Tony, 25/5)

All of the participants spoke about death and its possible imminence. For some it was a source of panic and anxiety:

> And it does make me think when I get something or other, I think, especially if I'm really, really poorly, you know, you think, this is the start of the end sort of thing… I do think like that and that ain't a good think to think about, but personally I do and it panics me. (Janet, 20/18)

Robert, the oldest of the participants seemed to accept that death was near:

> If somebody was to say to me, "I'm afraid you're going tomorrow", I would say, "Oh, well, that's it. Thank you very much". I think the older you get, the less you fear death, if I'm being sensible. I mean I used to think it was awful, you know, but now… (Robert, 24/17)

Other participants expressed the view that they might prefer to die in their sleep, implying a gentle, passive death without suffering. Angela referred to death euphemistically by saying, 'I'm hoping that when my body can't cope anymore, I just go to sleep' (Angela, 19/19).

However Tony and Janet were clear that they do not want to die. Tony expressed outrage that he had a DNR in hospital without his knowledge:

> …the thing that shook my family afterwards was a paper in the file said "do not resuscitate". I said, "Who the hell do they think they are to say that?" …I do remember a conscious effort in my brain to say that nobody's going to tell me that I can't be resuscitated. (Tony, 2/13)

It seems that he felt powerless and his view disregarded. Despite being very ill in hospital he was able to make the effort to survive.

'It's just another thing'

The title 'It's just another thing' is a quote from Douglas and seems to sum up the approach of the participants in this study:

> It's just another thing and I think that you normally get a clue anyway beforehand, don't you? Well, like the legs, if you can only walk 100 yards and then you've got to stop and look in a window and pretend to look at things while the rest of them walk on and things like that, and you're only young, you know there's something wrong. (Douglas, 14/4)

All of the participants described that receiving diagnoses, including one of heart failure, was a routine, expected event, appearing to cause them little concern. They seemed to have developed strategies for adapting their day-to-day living and for regulating any emotions they found distressing.

General discussion

Most of the participants expressed the view that receiving a diagnosis did not cause them any significant distress. However, they were aware that their bodies were deteriorating so that a major focus for them all was to adjust their living accordingly. They seemed to be able to adjust to their changing circumstances repeatedly and solve the problems their situation presented them. Personal resilience of this kind is presented in other studies (Resnick and Inguito, 2011; Wiles et al., 2012; Smith et al., 2016)

It seems that a new diagnosis might be unsurprising because symptoms would have been experienced beforehand (White et al., 2015). It may be that age alters the perception of the impact of illness. As older people the participants might expect to be diagnosed with multiple illnesses and therefore the intrusive nature of illness is less (Liddy et al., 2014).

The participants appeared to use a range of protective strategies including the self-perception that they were not ill, but that they merely had problems to solve to enable their day-to-day living. Their focus seemed to be simply to get on with life. It may be that factors such as functioning, quality of life and survival are more relevant to them than focusing on their individual diseases (Blom et al., 2015).

It seems that all the participants strove to maintain their desired state by not allowing unwanted emotions to dominate their thinking. Although they seemed to be able to recognise that they had times when they felt down and questioned the purpose of their lives, they were somehow able to overcome this. They seemed to use a number of strategies, such as turning off or regulating their emotions, so that they did not have prolonged periods of unwanted feeling such as sadness. Another strategy was

to keep busily engaged in activity, as this was perceived to improve their mental state.

The lack of future, being close to death and awareness of physical deterioration seemed to keep the participants focused in the present moment. They seemed to be consciously aware of their emotions and bodily sensations. Further they were able to acknowledge them and accept the way they are, in a largely non-judgmental way. This may have a positive impact on how they adjust to their changing condition. The use of mindfulness skills (Hayes, Strosahl and Wilson, 2012) has been suggested as being helpful when living with chronic health problems (Carmody and Baer, 2008; Merkes, 2010).

The participants also appear to exercise some self-compassion. Acceptance of their condition may be related to the level of contentment they appear to enjoy.   They seem to look forward to the limited future, engaging with each day, hoping for some improvement and enjoying a meaningful existence.

Conclusion and clinical implications

This study provides some insight into the experience of receiving successive diagnoses and the meanings it may have for people. As the sample was small, no claims can be made about the findings being representative of people with multiple morbidities. There were only six participants, three male and three female, who were older people. Most people with multiple morbidities are older and therefore this is not surprising. However, this study does not provide insight into the experiences of those who are younger and for whom the impact of successive diagnoses may be different. It is suggested that younger people feel as though they age prematurely (Duguay et al., 2014).

It should also be noted that one of the selection criteria for the participants was that they should not be experiencing significant distress at the time of the interview. Clearly this ruled out people who were experiencing higher levels of distress and would have provided another perspective on the phenomenon being examined.

The findings suggest that the participants had developed a range of coping strategies to adapt to their changing physical capability and regulate any emotional distress they may experience. These seem to provide some protection from the impact of their illnesses. It may be that further examination of these protective coping strategies might be useful to gain further knowledge of the processes involved. Knowledge of these might inform psychologists and others working within the health care system about ways in which to support people with multiple morbidities who do not appear to be coping well. It may be possible to help individuals to develop an adaptive approach or ways in which to regulate their emotions and help them to feel less distressed and in doing so improving their quality of life. Perhaps mindfulness techniques might be taught to those experiencing distress so that they might be more able to accept their situation, feelings and deteriorating body. It seems that acceptance can bring about a feeling of peace and happiness. Mindfulness based therapy such as ACT asks people to take a new perspective on the way that they think (Hayes et al., 2012) and have compassion for themselves and their difficulties with living. It seems very similar to the process described by people in this study and may be a way in which to help others to accept difficult emotions and their changing physical selves.

up the study and facilitating recruitment; Dr Ana Draper, Macmillan Consultant

Systemic Psychotherapist, Palliative Care Service who supported the setting up,

ethics application and provided supervision throughout; Dr Fran Smith and Dr Lucy

Longhurst who provided support throughout the whole research process and

completion of the thesis.

References

Banham D, Hawthorne G, Goldney R, et al. (2014) Health-Related Quality of Life (HRQoL) changes in South Australia: Comparison of burden of disease morbidity and survey-based health utility estimates. *Health and Quality of Life Outcomes 12*(1): 113-123.

Barlow MA, Liu SY and Wrosch C (2015) Chronic illness and loneliness in older adulthood: The role of self-protective control strategies. *Health Psychology 34*(8): 870-879.

Bhattarai N, Charlton J, Rudisill C, et al. (2013) Prevalence of depression and utilization of health care in single and multiple morbidity: A population-based cohort study. *Psychological Medicine 43*(7): 1423-1431.

Blom JW, Azzi ME, Wopereis DM, et al. (2015) Reporting of patient-centred outcomes in heart failure trials: are patient preferences being ignored? *Heart Failure Reviews 20*(4): 385-392.

Carmody J and Baer C (2008) Relationships between mindfulness practice and levels of mindfulness, medical and psychological symptoms and well-being in a mindfulness-based stress reduction program. *Journal of Behavioral Medicine 31*(1): 23-33.

Duguay C, Gallagher F and Fortin M (2014) The experience of adults with mutimorbidity: a qualitative study. *Journal of Comorbidity 49*(1)*:* 11-21.

Egede LE (2005) Effect of comorbid chronic diseases on prevalence and odds of depression in adults with diabetes. *Psychosomatic Medicine 67*(1): 46-51.

Hayes SC, Strosahl KD and Wilson KG (2012) *Acceptance and commitment therapy: The process and practice of mindful change.* New York: The Guilford Press.

Hughes G, Martinez C, Myon E, et al. (2006) The impact of a diagnosis of fibromyalgia on health care resource use by primary care patients in the UK: An observational study based on clinical practice. *Arthritis and Rheumatology 54*(1): 177-183.

Leeming A, Murray SA and Kendall M (2014) The impact of advanced heart failure on social, psychological and existential aspects and personhood. *European Journal of Cardiovascular Nursing 13*(2): 162-167.

Liddy C, Blazkho V and Mill K (2014) Challenges of self-management when living with multiple chronic conditions. Systematic review of the qualitative literature. *Canadian Family Physician 60*(12): 1123-1133.

McKenzie KJ, Pierce D and Gunn JM (2015) A systematic review of motivational interviewing in healthcare: the potential of motivational interviewing to address the lifestyle factors relevant to multimorbidity. *Journal of Comorbidity 59*(1): 162-174.

Marengoni A, Angleman S, Melis R, et al. (2011) Aging with multimorbidity: A systematic review of the literature. *Aging Research Reviews 10*(4): 430-439.

Merkes M (2010) Mindfulness-based stress reduction for people with chronic diseases. *Australian Journal of Primary Health 16*(3): 200-210.

National Institute for Health and Clinical Excellence (2009) Depression in adults with a long-term physical health problem: Treatment and management. London: NICE. Available at: www.nice.org.uk/guidance/cg91 (accessed 22 August 2016).

Pettite T, Mallow J, Barnes E, et al. (2015) A systematic review of loneliness and common chronic physical conditions in adults. *The Open Psychology Journal 8*(Suppl 2-M9): 113-132.

Resnick BA and Inguito PL (2011) The resilience scale: Psychometric properties and clinical applicability in older adults. *Archives of Psychiatric Nursing 25*(1): 11-20.

Schofield PE, Butow PN, Tompson JF, et al. (2003) Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology 14*(1): 48-56.

Seah ACW, Tan KK, Huang Gan JC, et al. (2015) Experiences of patients living with heart failure. A descriptive qualitative study. *Journal of Transcultural Nursing.* Epub ahead of print 26 February 2015. DOI:10.1177/1043659615573840

Sheilds L, Molzahn A, Bruce A, et al. (2015) Contrasting stories of life-threatening illness: A narrative inquiry. *International Journal of Nursing Studies 52*(1): 207-215.

Smith F, Banwell E and Rakhit R (2016) 'I was in control of it from the start': A qualitative study of men's experience of positive adjustment following a heart attack. *Journal of Health Psychology* 1-10. Epub ahead of print 1 February 2016. DOI: 10.1177/1359105315627000

Smith JA, Flowers P and Larkin M (2009) *Interpretative phenomenological analysis. Theory, method and research.* London: Sage.

The King's Fund (2016) Time to Think Differently. Life Expectancy. Available at: www.kingsfund.org.uk/time-to-think-differently/trends/demography/life-expectancy (accessed 14 August 2016).

Vaccarino V, Kasl SV and Abramson J (2001) Depressive symptoms and risk of functional decline and death in patients with heart failure. *Journal of the American College of Cardiology 38*(1): 199-205.

White C, Lentin P and Farnworth L (2016) Multimorbidity and the process of living with ongoing illness. *Chronic Illness 12*(2): 83-97.

Wiles JL, Wild K, Kerse N, et al. (2012) Resilience from the point of view of older people: 'There's still life beyond a funny knee'. *Social Science and Medicine 74*(3): 416-424.

Appendices

Appendix A – New York Heart Association Scores

<u>Taken from the British Heart Foundation Guide to Living with Heart Failure</u> (2012)

Doctors divide heart failure into four "classes". These are sometimes known as the New York Heart Association (NYHA) scores. They are:

<u>Class 1 – No symptoms</u>

Your heart is not working as well as it should, but you may not have any symptoms. You can usually do everything you want to, and may have as much energy as you would expect. You may still need medication or other treatment to reduce the risk of your condition getting worse. Very occasionally, some people do have one or two symptoms which will need to be treated or controlled.

<u>Class 2 – Symptoms on moderate exertion</u>

You may not be able to do quite as much as you used to. You get breathless more than usual – for example, when you are gardening, shopping or doing the housework.

<u>Class 3 – Symptoms on mild exertion</u>

You are quite limited in what you can do. It doesn't take much effort to make you feel exhausted and too breathless to carry on. You are usually comfortable while you are resting.

<u>Class 4 – Symptoms at rest</u>

You become breathless even when you aren't being particularly active – for example when walking around at home or even when sitting down. You may find it difficult to look after yourself properly on your own – for example, you get too breathless when having a bath or shower. You may need to sleep sitting up because you get out of breath or cough when you lie down.

Appendix B - Ethics Release Form for Student Research Projects

Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

* An understanding of ethical considerations is central to planning and conducting research.
* Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
* The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
* **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc   M.Phil   M.Sc   D.Psych   x   n/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

> A qualitative study into the experiences of people who are living with multiple chronic illnesses.

2.   Name of student researcher (please include contact address and telephone number)

> Susan Taylor,

3. Name of research supervisor

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Dr Fran Smith

4. Is a research proposal appended to this ethics release form?   Yes

5. Does the research involve the use of human subjects/participants? Yes

If yes,

Between 8 and 10

a. Approximately how many are planned to be involved?

b. How will you recruit them?

Through the Community Nurse Specialists (heart failure) of the NHS West Herts Palliative Care team. My internal supervisor with the service will be Dr Ana Draper (MacMillan Consultant Systemic Therapist). I shall introduce the study to the team at MDT to ask them to identify suitable participants. The nurses know their patients well and will know whether they are likely to be willing and if they are robust enough to participate .

c. What are your recruitment criteria?
(Please append your recruitment material/advertisement/flyer)

People diagnosed with Stage 3 heart failure for at least 6 months and also receiving treatment for at least two other chronic conditions. They will need to be aware of their diagnoses. They will have scores of 7 or lower on the Distress Thermometer. They will need to be robust enough to cope with the interview. Their spoken English would need to be reasonably fluent.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent?   Yes

d1. If yes, will signed parental/carer consent be obtained?   Yes No

d2. If yes, has a CRB check been obtained?   Yes
(Please append a copy of your CRB check)
I have a CRB for the service and a DBS for my current placement. These are necessary because the participants are potentially vulnerable adults. They are appended to this form.

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

The investigation will be done using semi-structured interviews of individual participants. The interview will last about an hour, but I shall be flexible in terms of the length of the interview, whether frequent breaks are needed etc., because these are very sick people. I shall be clear that they can stop and take a break at any time. If I notice distress I will stop.

7. Is there any risk of physical or psychological harm to the subjects/participants?
     Yes

If yes,
a. Please detail the possible harm?

Physical – as they are very sick people and additional stress may be detrimental.
Psychological – talking about their illnesses may be upsetting.

b. How can this be justified?

> In my experience people tend to want to tell their story and may find the process therapeutic. Sometimes it is helpful to have a "voice". It may also decrease their isolation because some-one is interested in their story. If there is distress or concern, I will be able to pass that on to the clinicians supporting them.

c. What precautions are you taking to address the risks posed?

> Initially by talking to their CNS heart failure to discover what the risks might be, so that I am aware. I shall emphasise to participants that they can terminate the session whenever they want. I shall listen carefully to the participant during the session and debrief following the session and, using the skills I have, reduce any possible impact.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

See Appendix D

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes

If no, please justify

>

Appended as Appendix E

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

> Research notes, computer records and audiotapes.

12. What provision will there be for the safe-keeping of these records?

> Audiotapes and notes will be kept locked in a cupboard at my home. Computer records will be protected by a password. All notes and tapes will be coded so that they would not be identifiable to a third party.

13. What will happen to the records at the end of the project?

> Any information which is identifiable will be destroyed.

14. How will you protect the anonymity of the subjects/participants?

> The identification of the person will be locked away. All pieces of information will be coded. The participant's name or identifying features will not be used. Segments of audio-recording used will be anonymous with all identifiable information removed.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

> I shall debrief the participant at the end of the session to find out how the participant experienced the interview. Should they require further psychological support I shall refer them back to their heart failure nurse or other clinician for further support.

Debrief sheet appended as Appendix G.

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

> Additionally, I should like to make clear that I fully understand the vulnerability of this group of participants. They are physically very unwell and may have difficulty with engaging in an interview for one hour. I shall take a flexible approach and make it clear to the participant that they can stop the interview at any time, or perhaps have more than one short interview, if that is what they choose. I shall check at the start of the interview that they are still willing to participate despite having given their consent earlier.

Signature of student researcher --- Date ------

CHECKLIST: the following forms should be appended unless justified otherwise

Research Proposal   X
Recruitment Material   X
Information Sheet   X
Consent Form   X
De-brief Information   X

Section B: Risks to the Researcher

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1. Is there any risk of physical or psychological harm to yourself?　　Yes
If yes,

a. Please detail possible harm?

I shall probably be interviewing people in their own home. As such I shall be a lone worker and vulnerable to the behaviour of the patient and any other person present at the time. Additionally the interview might produce information which is potentially upsetting. I shall raise such issues at supervision. I shall do only one interview on any day as there will be a lot to consider and notes to write.

b. How can this be justified?

> I shall probably need to interview people in their own home, because they are very ill with poor mobility. They are unlikely to be able to travel.

c. What precautions are to be taken to address the risks posed?

> I shall leave the address (not the participant's name) I am visiting in a sealed envelope with my husband only to be opened if I don't return. The envelope will show what time I expect to call to say I am out of the house. I have a tracker device on my phone.

Section C: To be completed by the research supervisor
(*Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.*)

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department's Research and Ethics Committee

Refer to the School's Research and Ethics Committee

Signature ------- ███████████ -------------------------- Date-------- 28·03·14.

Section D: To be completed by the 2nd Departmental staff member

(Please read this ethics release form fully and pay particular attention to any answers on the form where __underlined bold__ items have been circled and any relevant appendices.)

I agree with the decision of the research supervisor as indicated above

Signature --------█████████████████--------------------- Date 4/4/14

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Appendix C – Participant letter

Sue Taylor (Researcher),

████████████████

██████████

███████████

█████

█████

E-mail: ███████████████

Dear

I am a doctoral student at City University in London and I am interested in understanding the experience of patients who are living with heart failure and other illnesses. I understand that receiving a diagnosis and adapting to life with such a condition is a significant, on-going event. I am writing to you to invite you to share your experiences with me in this research study as a person with a diagnosis of heart failure, as well as other illnesses.

During the interviews I would like to hear of your experiences of coping with and managing your conditions. Further details of this study, and what it will mean for you to be involved in it, can be found on the attached Participant Information Sheet.

If you're interested and want to hear more about the study please tick the box and return your contact details on the slip provided. I will then call to arrange a mutually convenient time for the interviews to take place in the next few weeks. The interview will take about an hour.

I shall be conducting the interview. You are not obliged to participate in this study and do not need to explain your decision to me. If you do decide to participate, you will be free to change your mind about taking part and can withdraw your contribution at any time until four weeks after I have interviewed you. Any information that you provide will be treated as strictly confidential and will not affect your treatment rights in any way.

What do you need to do now?

1. Decide whether you might like to participate.

2. Please read the enclosed Participant Information Sheet.

3. If you think you might like to take part in an interview about your experience, please complete your contact details on the enclosed reply slip and return it to me in the envelope provided. I will then telephone you and talk to you further about what is involved and answer any questions you might have.

Thank you for taking the time to read this letter.

Yours sincerely

Sue Taylor (Researcher)

I would like to discuss the research project further

Name:

Telephone Number:

Please return to me in the stamped addressed envelope provided.

Appendix D – Information sheet

CITY UNIVERSITY
LONDON

Title of study
A qualitative study of the experiences of people who are living with multiple chronic illnesses.

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?
This study is being undertaken as part of a Doctorate in Counselling Psychology course I am taking at City University. While on a placement I worked with a number of people with heart failure as well as other illnesses and became interested in how they cope with their illnesses, their medication, frequent visits to hospital etc. So over the next year or so I shall be interviewing a small number of people who have illnesses including heart failure. Using the information the participants provide, I might to be able to identify ways in which support and care might be adjusted so that it more accurately meets the needs of people with heart failure alongside other illnesses.

Why have I been invited?
You have been included because you have been diagnosed with heart failure that affects what you are able to do as well as some other medical problems. I shall be interviewing 8 or 10 people.

Do I have to take part?
It is entirely up to you whether you would like to take part. If you do take part, you may, of course, withdraw from the study without giving a reason until four weeks after the interview. You will not be required to answer questions you feel are too personal or intrusive. I can assure you that whether or not you take part will not affect any future treatment.

If you do decide to take part you will be asked to sign a consent form.

What will happen if I take part?
If you do decide to take part, we will agree on a date and a time to meet. If you would prefer me to come to your home, then we can arrange that. However, I could also meet you somewhere else convenient for you if you would prefer. I should like to interview you for about an hour, although this can be longer or shorter depending on how you are feeling. The interview will take the form of some general questions about how you cope with everyday life, particularly with the difficulties with collecting medication, visiting to hospital, getting to see your GP etc. I shall be recording the interview so that I have an accurate record of what you have said.

What do I have to do?
If you are willing to participate, I should like you to complete the tear off slip on the letter giving some information about how I might contact you. I shall then call you on the telephone and talk about when we can meet. When I interview you I shall ask you some questions that will give you the opportunity to tell me how you are managing your illnesses. I should like you to be clear and honest about how you are coping with having heart failure and what that means to you.

What are the possible disadvantages and risks of taking part?
It may be that you become very tired during the interview and feel are unable to continue. If that is so, you must tell me that you want the interview to end. Thinking about your illnesses and how you are coping with the way they may have changed your life may make you feel sad. If you find it too distressing, then once again we will stop.

What are the possible benefits of taking part?
Some people find it helpful to talk through their experiences. Any information you can give me in the interview, may help us to understand how people like you cope and so will help us to understand other people if they have similar illnesses.

What will happen when the research study stops?
When the research study ends, any data collected about you will be destroyed. However, the analysed information, which will be anonymous, will be kept so that it can be used as a part of my research report.

Will my taking part in the study be kept confidential?
Yes. Only I will have access to information about you, including the audio recording, prior to it being anonymised. It will be kept securely and no one else will have access. None of your personal information will be used for any other purpose than this research. My research supervisors will have access if they need it once it has been anonymised. Once the information has been used for my research, it will be destroyed.

However, there are some limits to confidentiality. If you tell me about any harm to yourself and others, which may be abuse, self-inflicted harm, or criminal activity, I will have to pass that on to the appropriate authority. I will tell you if that is the case.

What will happen to the results of the research study?
The results of the study will be part of my thesis. In the future I may write up my findings in a paper for publication and I may quote the words you used in the interview, but it will remain anonymous. If you would like to receive a summary of the findings, please let me know at the end of the interview.

What will happen if I don't want to carry on with the study?
You are free to withdraw from the study without an explanation at any time until four weeks after the interview.

What if there is a problem?
If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. 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 "What are the experiences of people who are living with multiple chronic health conditions?"

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: Anna.Ramberg.1@city.ac.uk

Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee and by NHS REC South-Central Oxford C (REC: reference: 14/SC/1328)

Further information and contact details
My supervisor will answer any queries about the research. Her name is Dr Fran Smith, email, ███████████████████ Tel: ███████████

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

Appendix E – Consent form

Appendix E

<u>Consent Form</u>

CITY UNIVERSITY LONDON

Title of Study: An investigation into the experiences of people who are living with multiple chronic illnesses.
Ethics approval number: *[Insert approval number here]*

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 audiotaped	
2.	This information will be held and processed for the following purpose(s): • analysis by the researcher 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 organization.	
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 the data collection stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University 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 take part in the above study.	

_____   _____   _____
Name of Researcher   Signature   Date

_____   _____   _____
Name of Participant   Signature   Date

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

Appendix F - Semi-Structured Interview Questions

I shall begin by introducing the project and reminding the participant that I should like to talk about diagnoses of their illnesses, their feelings and how they cope with them. I shall remind the participant that I shall be using two audio recorders.

The schedule that follows will be used flexibly.

Diagnoses

1. Could you give me a brief history of the illnesses you are being treated for and when (approximately) you were diagnosed?

2. Do you feel that diagnosis had an impact on the way you live? If yes, can you describe the impact on your day-to-day living? *Prompt: social, self, relationships, work.*

3. On a day-to-day basis, how do you deal with having your illnesses? *Prompt: Do you have particular strategies for helping you? Ways of coping, practical, mental.*

Impact

4. Could you describe in your own words how you felt when you got each diagnosis? *Prompt: physically, emotionally, mentally.*

5. What was it like for you to experience the impact? *Prompt: to tell more whenever appropriate.*

6. How do you feel now that you are living with these illnesses? *Prompt: physically, emotionally, mentally.*

7. Have your illnesses made a difference to the way you see yourself? *Prompt: Do you think you have changed?*

8. What about the way other people see you? *Prompt: members of your family, friends. Has that changed?*

Coping

9. How much do you think about your physical health?

10. Do you regard yourself as an ill person? How do you think others see you?

11. What do you think about your future? *Prompt: hopes, fears, feelings.*

12. Can you think of anything that would make your life easier?

Miracle Question

13. If I had a magic want in my bag (I don't have), what would you like to change about the way things are? Something feasible.

14. Is there anything that I haven't asked you that you think is important?
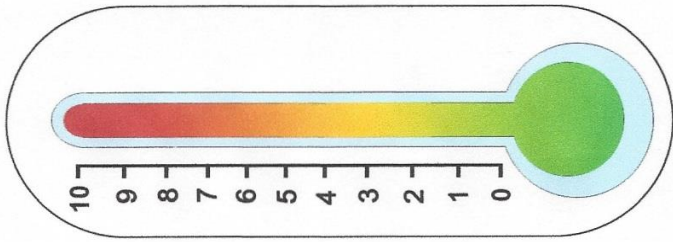
Sue Taylor
24th January 2015

Interview schedule based on information given in "Qualitative Psychology. A Practical Guide to Research Methods" J.A. Smith (Ed.)

Appendix G - Debrief Sheet

- Thank the participant for allowing me to interview them.

- Explain again why their part in the study is really important.

- Explain that I will transcribe the interview and analyse what they have said.

- Check whether they have any questions.

- Ask if there's anything they would like to say about the interview and how they experienced it.

- Ask whether they would like a summary of findings when they are complete.

- Check that they have a contact number for their heart failure nurse/other professional, if needed.

Appendix H – Distress Thermometer

First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme Distress

10
9
8
7
6
5
4
3
2
1
0

No Distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

Practical Problems

YES	NO	
☐	☐	Child Care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school

Family Problems

YES	NO	
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Dealing with close
☐	☐	Friend/relative

Emotional Problems

YES	NO	
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities

Spiritual/religious concerns

YES	NO
☐	☐

Physical Problems

YES	NO	
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhoea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling Swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry itchy
☐	☐	Sleep
☐	☐	Tingling in hands/feet

Other problems
_____
_____

Appendix I – Letter to NHS Research Authority

<div align="right">
Department of Psychology
City University
Northampton Square
London
EC1V 0HB
21st November 2014
</div>

NHS Health Research Authority

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Dear Professor Wellman,

Study Title: **A qualitative study into the experiences of people who are living with multiple chronic illnesses.**

REC reference: **14/SC/1328**

IRAS project ID: **160080**

Thank you for your letter dated 6th November 2014 in which you ask for further information and clarification. The points are covered below:

1) I have checked the University's policy for storage and retention of data. The policy is that data is stored in a locked cabinet or password protected if it is electronic data for 10 years. I confirm that this will be abided by.

2) Cross validation of themes will be done with my research supervisor at several points during the analysis process.

3) I confirm that there is a lone worker policy in place and that I have a copy of it.

4) Data will be anonymised by coding in a way which does not identify the participant, or any identifying details of the participant. An example would be using a letter or number for coding. Any data which might identify the participant will be removed from the transcript. The code will be used for analysis. The identity will be stored as in 1) above.

5) The Participant Information Sheet (version 2) has been revised and uploaded to IRAS.

6) The Participant Invitation Letter (version 2) has been revised and uploaded to IRAS.

On the issue of demographic data, some, such as age, gender, type of additional illnesses, will be available. This will help me to describe my sample and to critically

appraise it. Further information, which may be relevant, such as whether a participant lives alone, may come out during the interview.

I look forward to hearing from you,

Sue Taylor

Appendix J - Demographics

Code	1	2	3	4	5	6
Gender	M	F	F	M	M	F
Age	84	64	81	88	93	77
Ethnicity	White/ English	White/ Scottish	White/ German	White British	White British	White British
Occupation	Retired (60) RN and business	None	Retired Factory Worker	Retired naval architect	Retired watchcase maker	Retired demonstrator / Receptionist
Marital Status	Widowed	Divorced	Recently widowed	Married	Widowed	Widowed for 12 years
Living alone?	Yes	Yes	Yes	Wife and sometimes daughter and grandson	Yes	Yes
Support?	Daughter and son close by large family	2 daughters close by	Daughter and g/daughter close by		Daughter, G/daughter, carers etc.	2 sons, 1 daughter locally.

Appendix K – Example of transcript, emergent themes and exploratory coding

Emergent themes	Transcript		Exploratory Coding
Acknowledgement of multiple morbidity? Gratitude for self + others Social Contact Relationships with others Independence / autonomy	I.	1 2 3	So, tell me how much you think about your physical health, how much do you think about your health. [About this? (gesturing at heart) About your health? How much do you think about your health?	knows himself – seems aware. acknowledgement of mm 'thankful' of? ? conflation of age + illness. Coping / Management acknowledgement that he does not have dementia? Interesting he's coping. Important to know people around him – supportive circle?
	P.5.	4 5 6 7	About me health, well I think what I've got wrong with me and for how old I am, I think I'm managing very well and I am only thankful I'm able to do what I do, er and that and to be able to know what I am doing. [And you know] I know all the people around me.	
	I.	8 9	You're able to do your pills and all that kind of thing. You know when to do them. [To what?] Your tablets, your medicine.	Attention of independence Positive he is able to cope with medication
Management / coping (mm)	P.5.	10 11 12 13	Oh yes, absolutely, yes I've got little pots, er, every night religiously, before I go to bed I get all my pills and all my pots and divide them all up for the day. And then, [Hm] they've got different colours, pots and then different positions and I know when to take them. That's my	Resiliency – think at order + direction has worked out a system to plan + organise med taken. Military training implicit between mind detracts.
Importance of the past		14 15 16 17 18 19	routine. [Hm] I think that comes with the army. [Do you think it's that?]. Yes,definitely. And I've always been a tidy person. [Hm] Er, and my home help said to me, "I know you've been in the army you open your cupboards and everything is all, all your blankets are all level and everything." And all that's how you was and I don't know if that's it. I can't stand being untidy.	importance of the past? importance of past training. Past in the present. Seems to know himself well Importance of having others come back and converstion / relationships with them. knows himself. Sure of himself – importance
Knowledge of self	I.	20	So you think that order, that, is still there?	Emphasis of statement. Self – knowledge. Army – an important part of the past. Richness of the army asked him.
still the person he was?	P.5.	21 22 23 24 25	I think that I was always a tidy person, [Hm] So it didn't come hard to me [No] being in the army. Because you had to put your blankets all together and all, and your cupboards and everything had to be dinky dorey and straight and that. And I'm the same at home. I can't stand stuff being untidy. Mind it's a bit untidy in here at the moment, [is it?	Another detailed description knows that he is still childlike ? Judges himself / the way he were to his

Emergent themes	Transcript		Exploratory Coding
	1	(laughter)] but [By your standards, is it?] by my standards you see. You	lots of humour throughout (?minimising) knows the very bad is and what the slides
	2	see, there's a lot of books under there that need to be got rid of but ..	are
			A social person : uses humour promote
	I.	3	social interaction? (C)
		So, ok, do you regard yourself as ill? Do you, when you think about	Not really – unsure whether he is ill ' (L)
	4	yourself do you think of yourself as an ill person?	
Reluctantly acknowledges 'ill'	P.5.	5	Uncertain – conflict between self-perception and the way he may be seen by others?
		No, [No] not really. I suppose I am, but when I consider all the things, I	Is he dodging? Not ill – but suppose he is (C)
Acknowledgement of depression sometimes	6	don't, I don't think, I don't think oh, you poor old.. Oh dear, you are ill	Says doesn't feel same for himself frequently
	7	(laughter). I get depressed sometimes.	buys hts. Able to acknowledge depression (L)
No self pity	I.	8	Do you? Tell me about that. What happens then?	Doesn't understand depression – suddenly
	P.5.	9	Oh, I don't know why, [Hm] er but all of a sudden. Er, I don't know	Acknowledge emotion 'bursts out crying' thicken
	10	why it hits me, er but I start thinking about different things and I burst	impact
takes control of emotions	11	out crying. [Do you?] Yes, and then I, then I thought get hold of	Almost tells himself off 'you had to of yourself' –
	12	yourself, you know. [So, sometimes you feel really sad?] Yes, oh yes,	seems able to get a grip?
	13	[Hm] er.	
	I.	14	Do you know what you're thinking about?	Renown (L)
Unsure about meaning of his life, sometimes	P.5.	15	Seems to be...Stands to reason doesn't it? Well, I, I suddenly think	Existential issues. Thinks to rationale
	16	what's it all about? [Mm] What am I living for? If this is you life, what	Suddenly 'thinks' what his life is for
	17	is it? What are you doing? You know, and I don't think like that and	Says he is able to 'let it go', that does he do that?
	18	then I, then I let it go and I'm, then I'm alright then. Sometimes I go	Continued humour (C)
emotional regulation	19	and have a glass of wine and then I feel a bit better. (laughter).	change the subject to talk about wine
	20	Because I do like a glass of wine with my dinner [Do you?] I have a	enjoys life so able to regulate his emotion? (C)
	21	glass of wine with my dinner every day [Hm] and I like Italian wine, if	Likes talking about himself - an open book?
importance of past experiences to self present	22	that's got anything to do with it. [Do you?] Oh I do, I like my Italian	Goes back to the past, the importance of
	23	white wine. [Your white wine, not your red wine? White wine.] No, I	his time in the Army & Italy & Italian : developed
	24	don't like red wine, I like white wine and I was introduced to it in my	him (C)
	25	army service in Italy and I have never disliked to it since. (laughter). And	

Appendix L - Emergent Themes Janet

Themes in Chronological Order (Reduced List)

1. Minimising illness   P1, L7/ P3, L4/ P7, L18

2. Excessive thinking   P1, L22/ P16, L13

3. Detailed description   P2, L7/ P9, L2

4. Importance of response of medics   P2, L12/ P3, L9

5. Seriousness of illness   P2, L1/ P3, L18/ P6, L25

6. Being alone   P3, L11/ P10, L12/ P13, L2, 12, 13/ P15, L26/ P16, L19/ P20, L4/ P20, L24, 27/ P23, L9

7. Questioning origin of illness   P3, L27/ P4, L6/ P6, L2/ P14, L5/ P16, L28/ P27, L3

8. Importance of quality medical support P4, L2/ P4, L25/ P4, L26/ P5, L2

9. Importance of caring relationship with medics   P4, L19, 24/ P12, L1

10. Deteriorating body   P5, L9, 13/ P15, L1, 5

11. Impact of deterioration   P5, L22/ P17, L27

12. Importance of family   P5, L26/ P10, L13/ P13, L14/ P19, L24/ P22, L23

13. Impact of multiple morbidityP6, L6/ P17, L13/ P25, L18, 22/ P26, L4, 7, 20

14. Concern about balancing drugs   P6, L20/ P8, L9/ P9, L14/ P11, L14, 18

15. Impact of multiple morbidity on emotional stateP6, L26/ P7, L11/ P8, L26

16. Looking for improvement   P6, L14, 29/ P7, L6/ P7, L14/ P16, L1/ P27, L25

17. Hope for no deterioration   P7, L18/ P12, L18/ P15, L10/ P28, L10

18. Impact of morbidity   P7, L19, 26/ P17, L5/ P22, L17

19. Coping with deteriorating body   P1, L11\ P7, L26/ P22, L14

20. Emotions - stress/panic   P7, L28/ P18, L6/ P20, L20, 21

21. Recognition of changing physical state   P8, L4/ P8, L26/ P14, L11

22. Confusion about medication   P9, L17, L25

23. Coping with multiple hospital visits P10, L1, 6, 12/ P17, L10/ P19, L10

24. Concern about understanding medics P1O, L17, 21, 23, 28/ P11, L3/ P11, L23

25. Anxiety about deterioration   P11, L7, 8/ P12, L11

26. Needing peopleP11, L10, 3/ P16, L19/ P18, L12, 20/ P19, L3/ P19, L23/ P21, L2

27. Panic/worry about uncertaintyP11, L24, 25/ P12, L23/ P13, L4, 12/ P15, L25/ P17, L17, 21

28. Reducing worry   P12, L6/ P19, L5/ P27, L2

29. Concern about death P12, L12/ P20, L15/ P20, L19/ P21, L23/ P23, L17/ P27, L19/ P28, L3

30. Fear of future   P12, L20/ P13, L2

31. Remaining independent   P13, L25/ P14, L13, 17/ P15, L14/ P15, L24/ P16, L10, P24, L19

32. Practical solutions   P13, L26/ P15, L27/ P16, L8/ P22, L7

33. Impact of pain   P14, L8/ P24, L6, 8, 13/ P24, L23

34. Coping through adjustingP14, L20/ P15, L16/ P21, L8/ P23, L10, P24, L2/ P28, L23

35. Living her life   P15, L18/ P16, L3/ P21, L16, 20/ P23, L20/ p23, L28/ P25, L23

36. Loss of people   P20, L14/ P21, L11/ P27, L11/ P27, L26

37. Helplessness/ vulnerability   P9, L29/P20, L22/ P23, L13

38. Emotional response   P23, L12, 17

39. View of herself as ill   P24, L17, 18, 22

40. View of future   P25, L3, 5, 11/ P28, L14

Appendix M – Table of clusters and theme labels for Janet

Cluster	Theme Label	Page Reference	Quote/Keyword
Concern About Treatment	Confusion about Treatment	P9, L17	*What are all these for?*
		P9, L25	*Very confusing*
		P9, L29	*No-one's collating together*
	Balancing Drugs	P6, L20	*…a fine balance*
		P8, L9	*I have to keep watching now.*
		P9, L14	*So it changes again.*
		P11, L11	*Must be like a cauldron.*
	Coping with Hospital Visits	P10, L1	…say my diary, you'd laugh.
		P10, L12	…very worrying.
		P17, L10	…so many hospital visits.
		P19, L10	I don't quite know how.
Impact of Morbidity	Loss of capability	P7, L26	*I had to leave work.*
		P17, L5	*All of a sudden I'm not.*
		P22, L17	*It does change your life.*
		P25, L18	*It's too much hassle.*
		P26, L4	*You can't do anything.*
		P26, L7	*Health governs your life.*
	On the Body	P6, L5	*Everything has been affected.*
		P6, L25	*Really, really ill.*
		P8, L26	*Everything seemed to be going wrong.*
		P17, L13	*…from one thing to another.*
	Impact of Pain	P14, L8	*…painful getting up.*
		P24, L8	*…shooting pains.*
		P24, L12	*…wouldn't think.*
		P24, L11	*…conscious when things are live.*
	On Emotions	P6, L26	*…they get to you.*
		P7, L11	*…as miserable as*

			sin.
		P8, L26	*…getting a bit low.*
		P17, L17	*I'm more nervous.*
The Deteriorating Body	Impact of Deterioration	P5, L9	*…affects all your main organs.*
		P5, L22	*…it's murder.*
	Changing Physical State	P8, L4	*It had actually shifted.*
		P14, L11	*I was walking up and down.*
		P22, L14	*…within a year.*
		P15, L1	*…get out of breath.*
Dependency on Medics	Concern about understanding language	P10, L17	*…the way they talk to you.*
		P10, L21	*…good old plain English.*
		P10, L23	*…haven't got a clue.*
		P11, L2	*I don't understand. Not really sure.*
		P11, L23	
	Importance of care	P3, L20	*…gobsmacked.*
		P4, L19	*…under her wing.*
		P4, L24	*…like friends.*
		P12, L1	*…got the patience.*
	Importance of high quality medics	P4, L2	*…really good.*
		P4, L25	*Like a breath of fresh air.*
		P4, L26	*a little bombshell.*
		P5, L2	*…very, very thorough.*
Rejecting Deterioration	Hope for status quo	P7, L14	*to hold it back.*
		P7, L18	*…holding my own.*
		P12, L18	*…doesn't mean it will be.*
		P15, L10	*Don't want to be reliant.*
		P28, L10	*You do always hope.*
	Hope for improvement	P6, L29	*An improvement.*
		P7, L6	*An improvement.*
		P16, L1	*…are temporary.*
		P27, L25	*Live on that hope.*
	Minimising illness	P1, L7	*…only got scleroderma.*
		P6, L14	*…got rid of.*

Needing Others	Importance of Family	P5, L26	*…my sister*
		P10, L13	*…my kids have come.*
		P13, L14	*…a sister who's brilliant.*
		P19, L23	*My kids couldn't come.*
		P22, L24	*He will pop in.*
	Need for Company	P11, L10	*…when somebody else is there.*
		P15, L26	*…somebody holding your hand. somebody to take it off.*
		P16, L19	*…a brick.*
		P18, L13	*…with somebody.*
		P21, L2	
Living her Life	Self View as Ill	P24, L17	*No (not ill)*
		P24, L18	*not…what I consider ill.*
		P24, L22	*I know deep down.*
	Being herself	P15, L18	*How I want to be.*
		P16, L3	*I want to try.*
	Contentment/Acceptance	P21, L16	*I'm very content.*
		P21, L20	*I'm happy for it.*
		P25, L23	*Doesn't bother me now.*
		P25, L23	*I'm quite content.*
	Controlling Emotions	P12, L6	*Takes a lot of worry away.*
		P19, L5	*…takes all the worry.*
		P23, L20	*The more I do, the better I feel.*
		P27, L2	*…down to me.*
Future	Fear Associated With	P12, L20	*…like a vegetable.*
		P12, L2	*Is this going to happen?*
	Concern About Death	P12, L12	*…me number was up.*
		P20, L15	*…the doom part of life.*
		P20, L19	*The start of the end.*
		P21, L23	*Stupid things like dying.*
		P23, L17	*Makes you think.*
		P27, L19	*That is unreal.*
	Self and the Future	P25, L3	*Haven't got a*

		P25, L5	*future.* *Live from day to day.*
		P25, L5	*I wouldn't plan.*
Loneliness	Loss of people	P20, L14	*You're losing people.*
		P21, L11	*You get them less.*
		P27, L11	*My husband died.*
		P27, L26	*World wiped out.*
	Being alone	P3, L11	*I'm on my own.*
		P13, L12	*I've got no-one here.*
		P13, L13	*I've got no-one here.*
		P16, L19	*…you can dwell.*
	Isolation	P20, L4	*I felt cut off.*
		P20, L24	*How much on my own.*
		P23, L9	*You're on your own.*
Independent Self	Making Adjustments	P14, L20	*I do a bit and sit down.*
		P15, L16	*I like to take my time.*
		P23, L10	*Learned to live with it.*
		P24, L2	*You get by.*
		P28, L23	*You literally cope.*
	Remaining Independent	P13, L25	*I manage to do most things.*
		P14, L17	*How independent I can get.*
		P15, L14	*I'm just slow.* *You get up and do it.*
		P15, L24	*I can do these things.*
		P24, L19	*…able to walk around, do things.*
		P21, L8	
	Seeking Practical Solutions	P13, L27	*I do have a cleaner.*
		P15, L27	*Bought myself a stick.*
		P16, L8	*…something to lean on.*
		P22, L7	*I've got a few aids.*

Enquiring Self	Origin of Illness	P4, L6 P6, L2 P14, L5 P16, L28 P27, L3	*I was right.* *How that started.* *How this came about.* *Whether it's something in the family.* *Sit and wonder.*
	Excessive Thinking	P1, L22 P16, L13	*Don't know what it was.* *I don't know.*
Unwanted Emotions	Helplessness	P20, L22 P23, L13	Nothing you can do. I ain't got a lot going.
	Depression	P23, L12 P23, L17	*…a low spell.* *Makes you think.*
	Panic/worry	P11, L24 P11, L25 P12, L23 P13, L4 P17, L17	*It worried me.* *Panicking like mad.* *I just panic.* *I do worry, badly.* *Getting there worries me.*
	Fear of an uncertain future	P11, L7 P11, L8 P12, L11	*…slightly bad.* *…blank off.* *…almost in tears.*
	Stress	P7, L28 P18, L6	*…stressing me out.* *Go into one.*

Appendix N - Overview of overarching themes for the group

1. Acceptance of successive diagnoses

The relationship with illness

Lilian: It's something that I just have to put up with.   11/15
Lilian: …but it goes in one ear and out the other. I don't listen to these things. I
don't.   27/7
Lilian: It's just another thing that I've got to contend with.   28/6
Douglas: I've got other problems, so…the one that hurts the most is the one that you
worry about.   6/8
Douglas: No, I see myself as medical problems, not ill.   28/14
Robert: Things have snowballed a bit. One thing has led to another.   13/15
Angela: I don't know if …I'm ill or not because I haven't got any pain.   10/2
Angela: You can't do anything about it so you might as well get on with it.26/1
Angela: What is it supposed to do to me? What am I supposed to feel? 6/15
Janet: If I'm really poorly I think…   20/18
Janet: I suppose whatever I've had go wrong with me, has not made me, what I
consider ill.   24/17

Adjusting to life with illness

Angela: I don't think it has made much difference to me.   15/16
Angela: I'll do it in bits and pieces. I'll sit down a while and then I'll go and do a bit
more.   18/22
Angela: But I just like to be independent.   22/4
Angela: I mean some days I haven't got the energy.   25/21
Robert: Well it didn't stop me, because I had a disabled son and my problems were
still there.   4/12
Robert: You've got to think learn to do things slowly, not to think what you used to do.
                                                                                                              14/25
Robert: You adjust yourself for what you can do.   15/12
Robert: "Oh well, I've got through the day today, dear".   24/2
Janet: I'm trying to see how independent I can get.   14/17
Janet: I live from day to day now. I do what I can, when I can.   25/4
Douglas: It's making your job rather useless.   18/12
Douglas: I am an independent old sod.   25/1
Douglas: Some people even regard me as incassap   28/6
Douglas: …the way I live is to learn to overcome what could be problems.30/8
Douglas: I can stand of course   30/18
Tony: I had a damned obstinate, strong determination that my limbs were going to get
right.   16/25
Lilian: I just get on with it.   26/11
Lilian: I mean I'm still independent even though I can't do things for myself.14/16

Impact of diagnoses

Lilian: It's not doing anything.   11/9
Lilian: Oh well, it's just something else to add to everything else that I've got wrong
with me.   27/18
Douglas: It's just another thing and I think you normally get a clue anyway
beforehand.   14/4
Janet: It does change your life rather a lot really.   22/17
Tony: We say that I was far less well than I realised.   11/1
Tony: The heart is not too bad.   13/1
Angela: I can't really complain about my heart.   5/5
Angela: I never knew anything about it.   5/21
Angela: What am I supposed to feel?   6/15
Angela: That's new that is.   21/2
Robert:

Managing emotional responses

Angela: I just feel as though I want to sit in a corner and cry. I don't let myself.
                                                                                              11/1
Angela: I was dead frightened. I was dead scared.   24/11
Robert: I didn't. Well at the time…   13/19
Robert: I'm only thankful I'm able to do what I …and to be able to know what I am
doing.   21/5
Robert: I don't think, oh you poor old sod…   22/5
Robert: …I don't think like that and then I, then I let it go and…I'm alright then.
                                                                                              22/17
Tony: I was somewhat peeved.   6/18
Tony: I wasn't aware.   19/22
Tony: I wondered, I didn't despair, no, I never did that, I never considered it, in a
sense, my business.   23/7
Tony: Intensely lonely. Intensely lonely.   27/13
Janet: I seem to blank off, you know, I'm aware of it, you hear it, but from a distance.
                                                                                              11/8
Janet: …I got quite depressed.   12/9
Janet: …the more I do the better I feel.   23/20
Lilian: It doesn't do anything to me.   13/1
Lilian: I've missed out a lot on life.   13/7
Douglas: I don't get depressed.   10/3
Douglas: I felt robbed.   11/7

2 Importance of others

Social Self – need for others

Robert: If I was all on my own and I never saw anybody, I would probably have a
different outlook.   25/21
Janet: If you're with somebody, you've got somebody to take it off, but when you're
on your own you can dwell on these things rather, and that doesn't help.
                                                                                              16/18
Tony: I quite often think goody, goody, goody, you know, they're coming. 24/8
Lilian: I have Jehovah's Witnesses.   19/13
Douglas:

<u>Angela</u>:

Dependence on professional support

<u>Robert</u>: They look after me.   2/25
<u>Robert</u>: I'm so well looked after by everybody and everybody is so concerned and
kind, …that's what I like.   25/22
<u>Angela</u>: I have all these doctors that I've had for so long and they are all so lovely
they make you feel better.   20/22
<u>Tony</u>: I feel pretty sore with them.   8/1
<u>Tony</u>: Most of them don't listen, you know. She listens alright.   11/24
<u>Janet</u>: …it was a bit like being taken under her wing…it's… a bit like a bond in away.
                                                                        4/19

<u>Lilian</u>:
<u>Douglas</u>:

Relationships with family

<u>Douglas</u>: I think sometimes that we are closer that what we were.   24/14
<u>Robert</u>: I know my granddaughter loves me very much. I know because she said,
she told me.   18/17
<u>Angela</u>: They just love me. They always tell me they love me.   15/23
<u>Janet</u>: I've got a sister who's brilliant. She's always at the end of the phone for me.
                                                                        13/14
<u>Janet</u>: …my sister has this problem…   16/25
<u>Lilian</u>: It was only twenty minutes, but that twenty minutes made my day.
                                                                        20/18
<u>Tony</u>: …three people got me to where I am; it was Him, my wife and my daughter.
                                                                        21/10

3. Meaning of Time (Temporality)

Importance of the past

<u>Lilian</u>: I was knocked down by a car going to school…I suffered a lot of injuries.1/8
<u>Douglas</u>: I think a lot of it goes back to that because I could cook, clean, make beds
to a high standard.   19/6
<u>Angela</u>: …people…were quite horrible to me at times and that way I learned to keep
away from people.   14/11
<u>Janet</u>: …you live on that hope and when that minute comes, you sit there and a
complete world has been wiped out.   27/25
<u>Robert</u>: I think that comes with the Army.   21/10
<u>Robert</u>: We always did everything together.   26/12
<u>Tony</u>:

Hope for the future

<u>Lilian</u>: My heart is 50% better than it was a year ago.   25/11
<u>Lilian</u>: I really don't look too much into the future.   28/1
<u>Janet</u>: Haven't got a future, have I?   25/3
<u>Janet</u>: You do always hope.   28/10

Tony: …it must have been three months to get me from fixed here to being jolly well able to get up. 20/16

Tony: …probably a week ahead. 24/5

Angela: …so the last time I went, I didn't have any and everybody went "hooray" because I didn't have to have a blood transfusion. 12/8

Angela: I don't. 20/18

Robert: It won't be long now… 23/25

Douglas: I mustn't say much I think. 32/5

Focus on death

Douglas: Blimey, I think I've had a fair run if I die tonight. 21/6

Tony: …nobody's going to tell me that I can't be resuscitated. 2/13

Janet: …if I'm really poorly…you think, this is the start of the end… 20/18

Lilian: …I don't know when the end of my time's up. It probably won't be for years. 28/12

Angela: I'm hoping that when my body can't cope anymore, I just go to sleep. 19/19

Robert: If somebody was to say to me, "I'm afraid you're going tomorrow", I would say, "Oh well, that's it". 24/17

Appendix O – Journal of Health Psychology – Submission guidelines

Journal of Health Psychology is an international peer reviewed journal that aims to support and help shape research in health psychology from around the world. It provides a platform for traditional empirical analyses as well as more qualitative and/or critically oriented approaches. It also addresses the social contexts in which psychological and health processes are embedded.

1. Article types

The Editorial Board of the **Journal of Health Psychology** considers for publication:
(a) Reports of empirical studies likely to further our understanding of health psychology
(b) Critical reviews of the literature
(c) Theoretical contributions and commentaries
(d) Intervention studies