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**Outcome from total hip replacement:
From standardised measures to patient-focused
narrative-based assessment**
(Volume one)

Nasrin Nasr

A thesis submitted in partial fulfilment of the requirements
of Sheffield Hallam University
for the degree of Doctor of Philosophy

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"Today the only thing that is permanent is change".

Charles H. Mayo, 1930

Dedicated to those who value individuality

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Abstract

The dynamic construct of quality of life (QoL) and evidence of the response shift phenomenon in longitudinal studies can lead to biased and incomplete evaluation of change over time. This study examines the current approach to measurement of QoL, particularly the validity of measures routinely used in health care, using three different types of standardised measurements in association with narrative interviews of patients following total hip replacement:

- To explore the outcome from patients' perspectives by obtaining highly individualised data and encouraging them to identify domains of concern in their lives.
- To compare patients' expectations of outcome with their measured functional ability on the standardised measures.
- To establish whether there is a relationship between patients' expectations and characteristics and perceived QoL prior to surgery.
- To determine how well standardised generic measures fulfil patients' particular needs by comparing data obtained using them with individualised data.

Narrative interviews were conducted with 25 participants, nine of whom participated in follow-up interviews. Different aspects of their lives, such as values, feelings, job, attitudes and relationships, were explored and analysed using content analysis and narrative analysis. The findings from content analysis were categorised into two major components, themes related to life dimensions and coping-related themes. Core concepts related to life dimensions were collated to develop an instrument representing participants' perspective of hip condition. Performance analysis of narrative showed that understanding of an experience relies on the structure of narrative rather than the content. Participants used different coping strategies not to get rid of pain and physical limitations but to alleviate the damaging effects of hip-related problems, supporting the notion of re-interpretation of life experiences through employing psychological mechanisms.

The main recommendations are that (a) health outcomes should be evaluated through models of communication and (b) individualised, qualitative methods be used to generate further understanding of the impact of response shift on self-report measures.

Glossary of Abbreviations

AD	Alzheimer's disease
AIMS	Arthritis impact measurement scales
BP	Bodily pain
CRQ	Chronic respiratory questionnaire
DoH	Department of health
GH	General health perception
HRQoL	Health-related quality of life
MCID	Minimal clinically important difference
MH	Mental health
MID	Minimally important difference
mSRM	modified standardised response mean
PF	Physical functioning
QoL	Quality of life
RE	Role limitations because of emotional problems
RP	Role limitations because of physical health problems
SEM	Standard error of measurement
SF	Social functioning
SF-36	The Rand short form - 36
SRM	Standardised response mean
The DLQI	The dermatology life quality index
The PGI	The patient generated index
The SAC	The scientific advisory committee
The SEIQoL	The schedule for the evaluation of individual quality of life
THR	Total hip replacement
VAS	Visual analogue scale
VT	Vitality
WHO - ICDH-2	WHO international classification of impairment, activities a participation
WHO	World health organisation
WHOQoL group	World health organisation quality of life group

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Chapter One

Introduction

The well-being of a population has been an important concern in socio-economics for many years. It is a major factor in standard of living, which uses standard data such as incomes, life expectancy, number of health care professionals, records of crime, and other data to rank countries throughout the world. Policies and programmes have been created to fit these comparatively easily measured and manipulated economic numbers while other factors that are more difficult to plan for or assess have been ignored.

Consequently, even among two nations or societies that have similar material standards of living, quality of life (QoL) factors may make one of them more attractive to a given individual or group.

Quality of life takes into account not only the material standard of living but also other more subjective factors that contribute to human life, such as leisure, cultural resources, social life and health. Understanding QoL is particularly important in areas such as health care, where monetary measures do not readily apply. Decisions on what research or treatments to invest the most in are closely related to their effect on the QoL of individual patients.

Historically speaking, the theoretical assumptions underlying instruments for measuring QoL reflect the transformation of the eugenic idea of “worthy life” to post-war discussions of “life quality” (Koch 2000). Accordingly, the current theory underpinning QoL instruments is based on the assumption that both measurement and prediction of physical conditions determines the QoL of an individual (Koch 2000). The development and evaluation of QoL instruments is founded within the positivist paradigm that assumes a knowable and predictable world. According to O'Brien (2001) the

instruments can explain and predict the effects of negative health changes on individuals as well as the outcomes of appropriate interventions.

Subjective assessment based on individuals' values, standards and experiences is central to evaluation of outcomes in clinical context (Rosenberg 1995). According to Olthuis and Dekkers (2005), the inadequacy of objective outcome measures to reflect the effect of medical interventions was the main reason for introducing QoL instruments in addition to subjective measures. Quality of life measures are predetermined by researchers (O'Boyle, et al. 1992). The content of instruments includes a range of dimensions from the specific such as physical functioning, general health, symptoms, and psychological well-being, to broader dimensions, such as social and role functioning (Fitzpatrick, et al. 1998a).

The current approach to the measurement of QoL defines the concept of QoL from a functional perspective. The approach designates domains such as physical, emotional, role and social functioning as health-related quality of life (HRQoL) and focuses on statistical interpretation of aggregated data rather than analysing individuals' data. Accordingly, psychometric tests of reliability, validity and responsiveness are used on grouped data (Fitzpatrick, et al. 1998a, Fitzsimmons 2004). Although QoL is an individualised and dynamic construct (Allison, et al. 1997), this approach poses a standardised threat to QoL instruments and positions them at the level of predictive and diagnostic measures (Birnbacher 1999). There are no external criteria against which QoL instruments could be evaluated and there is no agreed definition for the concept. Rather, definitions are implied based on the existing QoL instruments and pre-defined theories (Hunt 1997). According to Hunt (1997) and Bowling (2001), the concept of HRQoL was a solution to the demands of measuring QoL. The assumed link between

QoL and health status has also been questioned by evidence that patients perceive QoL and health status as different constructs. For example, Smith and colleagues (1999) showed that the effect of mental health on QoL is greater than physical functioning. Bradley (2001) has stressed the distinction between the two concepts, especially because HRQoL has added more complication to any distinction between them (Smith, et al. 1999).

Complicating the picture is the fact that the "built-in" theoretical modification systems of QoL instruments misrepresent the concept of QoL by producing summary scores. Although the simple transformation of personal words into numerical scores has less damaging effect on the notion of QoL (Rapley 2003, p.66), it is not employed by the instruments.

The theory behind the development of QoL instruments reflects a contemporary philosophy on QoL and well-being as its main indicator known as 'Griffin's prudential perfectionism' (Griffin 1986, cited in Olthuis and Dekkers, 2005). According to Olthuis and Dekkers, (2005, p.308), "Griffin's prudential perfectionism acknowledges the independent existence of prudential values and argues that there are some things that are valuable in every life."

Nevertheless, the existence of independent values does not surpass the subjectivity and individuality of an experience, as revealed by Sumner's theory of "authentic happiness" (Sumner 1996, cited in Olthuis and Dekkers, 2005, p.308). According to this theory, values are understood only in terms of individuals' worldviews and their perceptions of life (Olthuis and Dekkers, 2005). The evolving narrative inquiry as a way of understanding suffering and illness has outweighed personal and individual judgment of

illness significantly. According to Mattingly (1998, p.8) narrative has three characteristics that make it appropriate for the studies of illness:

1. "Narratives are event-centred".
They are related to human actions and interactions.
2. "Narratives are experience-centred".
Narrative is a way of understanding someone's life and the lives of others in the world. It focuses on shared understanding of one's life with others.
3. Narratives establish a relation with their audiences, challenge them and as a result create experiences for them.

It has been through narrative that the dynamic and context-related concept of QoL is depicted, such as qualitative studies of persons with physical limitations in which patients value their QoL higher than it is expected particularly from clinicians (See Koch 2000). By reporting a positive and acceptable level of QoL, patients reveal the phenomenon of adaptation to their health conditions (Sprangers and Schwartz, 1999). When individuals face a harmful experience such as a serious health problem, along with their changed situations they reconsider the areas of life that they believe to be most important. Individuals change their prospects through changing their standards, giving primacy to alternative life domains and redefining what is important to them in order to accommodate to the new stressful situation. When the disease-related life domains are not controllable anymore, individuals make necessary changes in their lives in an attempt to maintain an acceptable level of confidence and QoL (Sprangers and Schwartz, 1999). Adaptation constitutes several elements such as change in activity, change of goals, and improvement in skills over time, which results in psychological enhancement and a revised perception of health called "humanistic" perception based on positive adaptation to a negative life event (Menzel, et al. 2002, p.2151). Moreover, the incongruity between patients' and healthy individuals' ratings of QoL, in which healthy individuals overestimate the adverse effects of health conditions on their overall QoL (Ubel, et al. 2001), highlights two possible facts: patients adjust to a disease through the process of adaptation (Sprangers and Schwartz, 1999) and healthy individuals

miscalculate their ability to adapt to a disease (Loewenstein and Schkade, 1999). The observed discrepancies between patients' and clinicians' ratings of health and QoL (Daltroy, et al. 1999) draws even further contradictory results. These findings, however, are overlooked by the QoL instruments (Koch 2000).

Evidence of adaptation or response shift (Sprangers and Schwartz, 1999) has been well documented in longitudinal studies of QoL measures (Sprangers, et al. 1999, Visser, et al. 2005, Schwartz, et al. 2004, Ahmed, et al. 2004, Kern and Brown, 2004, Sharpe, et al. 2005, Ahmed, et al. 2005). The most often used methodological approaches for evaluating response shift operate within a theoretical model of standardising individual experience, the same model that underpins the measurement of QoL and QoL summary scores (Rapley 2003). In fact, evaluation of response shift starts with the assumption of prediction and a positivist paradigm of adaptation process, similar to that observed in the studies of QoL assessment (Koch 2000). To minimise the impact of pre-defined perceptions of response shift, some researchers use individualised measures of QoL over the course of a disease to identify patients' most important life domains and any change in those domains. In other words, by using individualised measures they assess any change in values and re-definition of QoL over time (Sharpe, et al. 2005, Ahmed, et al. 2005). Regardless of the type of method undertaken, an instrument-based response shift is questionable in a similar way to QoL instruments. Just as Koch (2000) urged researchers to consider the assumptions underlying measurement scales, researchers measuring response shift in the context of QoL measures should turn a critical eye to the assumptions underlying the instruments. Currently, they appear to be evaluating response shift using methods similar to those used to address the measurement criteria of QoL instruments by providing evidence on validity and responsiveness. The inadequacy of quantitative methods in examining validity and responsiveness has led

some researchers to qualitatively evaluate these measurement criteria in patient-based outcome measures (Hak, et al. 2004). Interest in qualitative validation of outcome measures marks a departure from most studies of response shift when researchers use quantitative summary scores to assess the process of adaptation. Qualitative assessment of response shift focuses on meaning of disease experience from individual's perspective using their personal language and other qualitative methods such as observation (Korfage, et al. 2006).

This project concerns the critical assessment of outcome from treatment. Specifically, it investigates the gap between patients' perspectives of outcome from total hip replacement (THR) surgery (Appendix 1) and data collected on self-reported standardised outcome measurement scales. Three different types of standardised measurements were utilised in association with narrative interviews to fulfil the aims of the study:

1. To explore the outcome from THR from patients' perspectives by obtaining highly individualised data and encouraging them to identify domains of concern in their lives.
2. To compare patients' expectations of outcome from THR with their measured functional ability on the Rand short form -36 (SF-36), the Patient Generated Index (PGI) and the Oxford Hip Scale.
3. To establish whether there is a relationship between the patients' expectations and characteristics and perceived quality of life prior to surgery.
4. To determine how well standardised generic measures fulfil patients' individualised needs by comparing individualised data obtained with findings from the SF-36 and the Oxford Hip Scale.

Determining the similarity between standardised outcome measures and interview schedules in which participants are presented with fixed and classified questions, I let participants talk about their experience of hip arthroplasty and elaborate on what was really important to them. The open and non-proscriptive method of data collection shaped my approach toward data analysis. I needed to rethink what it meant by

classifying data into categories. Obtaining standard data on every participant by using a pre-arranged checklist is more likely to restrain the analysis by categorising the data. By advancing the method of data collection to the level of narrative, I took into account a practice beyond those normally seen in mainstream research. Choosing a performance analysis of narrative, I have experimented to understand data within the context in which they were generated.

The thesis begins with a discussion of QoL measures and their theoretical assumptions in the Background chapter. I examine the dynamic concept of QoL that leads to the notion of change and how it is measured in health care. Examining essential properties of QoL instruments, I discuss standard assessment of change as a measurement criterion with specific focus on three different instruments: the SF-36 as a generic measure, the Oxford Hip Score as a disease-specific measure and the PGI as an individualised measure. The inconsistency between objective and subjective evaluation of health as a frequently observable fact jeopardises the validity of studies that measure change with patient-based outcome measures over a course of a disease. Hence, my appraisal is concerned with adaptation or response shift phenomenon through which health changes can cause changes in patients' internal standards (scale recalibration), patients' values and a redefinition of the concept of QoL (re-conceptualisation) (Sprangers and Schwartz, 1999). There has been a tendency among researchers to measure response shift quantitatively. This practice is also subject to criticism from those who are interested in how individuals make personal meanings of disease experiences.

Depicting the standard assessment of change in which individual re-interpretation of an experience has no place, in the Methodology chapter I embark on a process that will enable me to exercise greater knowledge of patients' perceptions of hip condition. The

chapter begins with a look at the characteristics of the knowledge underpinning QoL measures that is generated through quantitative validation. Seeking a way of knowing that is more compatible to the nature of QoL, the chapter then highlights qualitative research and issues of validity in qualitative research are explored. The main part of the chapter focuses on narrative as the method of choice for the study. Finally, it discusses the study's design, sample and research methods.

The Findings chapter examines experience of hip condition from patients' perspectives using different approaches. The content analysis of participants' narrative accounts revealed some empirical themes. The themes were related to chunks of data and reflected the existence of some independent values shared among the participants. Theoretical categories were generated by relating the themes to the study aims and were the basis for constructing a semi-structured interview schedule to evaluate patients' experience of hip condition. Participants' perceptions of hip condition were also examined by obtaining uniform data using standardised measures. The standardised data were analysed in detail for two cases. To develop the idea of context-dependent knowledge, I began by analysing the content of accounts of two participants using the personal language they employed to describe their experiences. Although the content analysis of participants' accounts was one step further toward understanding their perceptions, the data were divided into segments corresponding to the study theoretical perspectives. From this stage, particularly inspired by the work of Mishler (1997), Mishler (2005, Personal Communication) and Riessman (2002), I started to appreciate the interviews as interactions and the accounts as stories. As a result,

! Throughout this thesis, "hip condition" means pain and physical limitations associated with hip joint(s), which lead patients to have hip replacement.

performance analysis of participants' narrative accounts provided small and detailed data in order to appreciate a broader perspective.

Important emerging findings showing how participants constructed their stories were distinct from the theoretical aims of the research. Understanding participants' perceptions of hip condition within the context of their values put the study in touch with the issue of communication in health care. It suggests that QoL outcome measures should be evaluated within the framework of patient-professional communication. It also draws attention to the potential of case study as a method for generating practical context-dependent knowledge (Flyvbjerg 2001). Given that outcome measures are developed and evaluated based on the evidence of reliability and validity, studies of outcome measures often use large sample sizes to generalise theoretical knowledge.

The various methods used in this study helped me to unfold a rather complex continuum of knowledge (See Flyvbjerg 2001, Mishler 1990) (Figure 1.1). At one end of the continuum there is theoretical knowledge characterised as being rule-based, analytical and predictive. It is context-independent and uses large sample sizes to derive standard data and to establish reliability and validity so that it can be generalised. At the other end of the continuum, however, there is a type of knowledge viewed as context-dependent, practical and experience-based knowledge. It relies on deep and detailed data generated from case studies to learn and understand human matters. It focuses on the question of "how" in order to analyse data (Flyvbjerg 2001), the very same question, which is the focus of narrative in examining "how" people tell about an experience rather than "what" they say (Riessman 1990). Therefore, narrative and dialogue are central in value-based, context-dependent knowledge (Flyvbjerg 2001).

Continuum of knowledge

Large sample size	Case studies
Standard data	Detailed data
Reliability and validity	Qualitative validation
Generalisation	Exemplary
Rule-based rationality	Value-based rationality
Predictive/explanatory theory	
Theoretical knowledge/ Context-independent knowledge	Practical/Context dependent Knowledge

Figure 1.1: The continuum of knowledge

The attitude toward measuring QoL is shaped by rules and standards, so the bulk of knowledge generated by QoL measures has features of predictive theoretical knowledge. Nonetheless, in the wake of growing qualitative findings and in contrast to objective and clinical assessment of QoL, there has been a tendency to improve QoL measurement to new levels including methods of data collection and data analysis that reflect practical and value-based knowledge.

In reading the chapters that follow, it is important to bear in mind that the field of health outcome measures is challenged by the temporal order of the research process. At the outset of the study, my appraisal was concerned with the nature of knowledge generated by the measurement of health outcomes. In this way, my focus was on theoretical perspectives and methodology and how these can support the theory of knowledge. Over the course of the research process, my critique was exercised back and forth between different research methods that have left little room for developing a theory of knowledge. The end results had a crucial effect on the initial thoughts and emphasised that human-generated knowledge takes more than one theory to support it.

The thesis comprises five chapters. The Background chapter is designed to address a number of topics including: QoL measures, the dynamic construct of QoL, the concept of change, standard assessment of change and assessing response shift. Finally, these topics are examined and discussed in connection with three instruments. The Methodology and Methods chapter includes justification of the methodology, validity in qualitative research, research interview, narrative interview, transcription, and the methods used in the study. The findings chapter comprises content and framework analysis, standard measurement of QoL, case studies, patient-professional communication, patients' experience of health conditions and ethical considerations.

Chapter Two

Background

2.1. Introduction

Studies show that severely ill patients report a level of QoL similar to that of less ill patients or healthy individuals. In other words, people can maintain or increase their level of QoL through a serious illness (Breetvelt and van Dam, 1991, Andrykowski, et al. 1993, Bach and Tilton, 1994, Groenvold, et al. 1999). For example, Hagedoorn and co-workers (2002) documented patients with cancer who were able to maintain their level of QoL despite their physical deterioration. Similarly, a longitudinal study by Ahmed, et al. (2004) showed that patients with stroke had significant post-stroke improvements on the physical and mental components summary scales of the SF-36, whereas no significant improvements on these summary scores were detected in the caregivers of these patients who formed the control group. In a study by Albrecht and Devlieger (1999), an excellent or good QoL was reported by more than half of patients with moderate to severe disability despite their functional, social and financial difficulties.

There are also discrepancies between clinicians' ratings of health and patients' own evaluation of their health (Kagawa-singer, 1993, Wilson and Cleary, 1995, Daltroy, et al. 1999). Daltroy and colleagues (1999) found that a measure of function based on observed performance can explain half of self-reported disability in an elderly population. For example, patients who experienced a recent decrease in their function scored worse on self-reported measure of disability. Moreover, patients are inclined to evaluate their own QoL at a higher level compared to the evaluations of proxies such as health care providers (Sprangers and Aarason, 1992, Friedland, et al. 1996). These contradictory findings regarding the inconsistency between objective evaluation and

subjective assessment of health reflect a change-related phenomenon that is observable in longitudinal studies of QoL over time.

2.2. Quality of life measures

Fitzpatrick and colleagues (1998a) referred to QoL measures as "patient-based outcome measures" and defined them as "the array of questionnaires, interview schedules and other related methods of assessing health, illness and benefits of health care interventions from the patient's perspective". The existing publications deal with the subjects of selecting QoL and HRQoL measures (Wade 1992, Wilkin, et al., 1993, McDowell & Newell 1996, Bowling 1997, 2001) have given little consideration into the complexities of the nature of the QoL construct.

Wade (1992) used the World Health Organisation's (WHO) model (1980) as a framework in terms of classifying measurement instruments. The instruments are classified into: measures of impairment, measures of disability and measures of handicap and QoL. Parry (1982) used the World Health Organisation's (WHO) (1980) definitions of impairment, disability and handicap as a framework to construct and validate an assessment of stroke patients. Wade (1992) used the same model to classify instruments ten years later, QoL was included within the definition of impairment. Although the model uses a holistic approach to measurement, it has little concern with the dynamic construct of QoL. Treating the whole person including mental and social factors, rather than just symptoms of disease, is not an alternative paradigm to the medical model but an aberrant holism, a definition of holistic medicine (see Chambers Dictionary 1994). It is what Engel called the biopsychosocial model (Engel 1977), which divides human beings into three interrelated entities - a biological being, a psychological being, and a social being - and then adds them together to make a whole.

Bowling (2001) has categorised health outcome measures based on several major health problems: cancers, psychiatric conditions, respiratory, neurological and rheumatological conditions, cardiovascular diseases and other disease or condition specific scales.

Within each chapter on condition and disease-specific QoL measures, the commonly used generic and domain-specific (e.g. anxiety and depression) measures are addressed. Disease-specific QoL scales are supplemented with disease-specific symptom items, such as clinical indicators and self-report measures of functional ability in rheumatological conditions.

McDowell and Newell (1996) reviewed selective health measurement instruments based on the evidence for the validity and reliability of each measurement. The review included measures of functional disability and handicap, psychological well-being, social health, measures of QoL and satisfaction, pain measurements and general health measurements.

Fitzpatrick and colleagues (1998a) classified QoL measures or patient-based outcome measures into different categories with three major types of instruments: disease specific, generic, and individualised instruments. Disease specific measures evaluate the impact of a particular disease or health condition from patients' perspective. An example of this type of measure is the Oxford Hip Score (Dawson, et al. 1996a), which evaluates patients' perception of THR surgery. Generic measures are used to assess a wide range of health problems from patients' views. A widely used generic measure is the Medical Outcome Study 36-item short-form (SF-36) (Ware and Sherbourne, 1992). Its single multi-item scale measures eight dimensions of life. Taking account of individuals' perspective, the individualised measures give patients an opportunity to show a preference for domains of concern. For example the Patient Generated Index (Ruta, et al.

1994) investigates patients' own definition of QoL. The concept of investigating individuals' own definitions of HRQoL in order to supplement disease-specific and generic scales is an exciting development that counteracts the prevailing approach of pre-definition of QoL by the researcher and, consequently, clinicians who use his or her scale.

2.3. The dynamic construct of quality of life

The multidimensional construct of QoL has a dynamic nature (Allison, et al. 1997). Quality of life is special to each individual (Jenkinson, et al. 1994) and has different meanings to different people. There is no agreement about the definition of QoL. As Ziller (1974) says QoL is in the eye of the beholder.

Definitions of quality of life

Caiman (1984) defines QoL as "the difference, at a particular moment in time, between hopes and expectations and present experiences" (p.125). It means that QoL is a gap between a person's hopes and expectations and what he or she experiences as reality. To improve QoL, the gap should be narrowed, either by helping people to reach their own goals or eliminating their desires and to change their expectations. These goals change over time, by age and in different circumstances. Caiman's theory, or, as Hayry (1999), describes it, "the want approach", points out that the illness and treatment may change and transform the goals. As a result, the standard against which a patient's life is measured may decrease to substandard in order to restore his or her QoL.

Therefore, QoL instruments must consider dimensions of life that are important to the individual and the only way to discover a patient's need and priorities is to discuss them with the patient prior to the intervention. Celia and Tulskey, (1990) refer to QoL as the "patients' appraisal of and satisfaction with their current level of functioning as

compared to what they perceive to be possible or ideal" (p.30). The World Health Organisation's Quality of Life group defines QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group 1995, p.1405). Campbell and colleagues (1976) use the concept of satisfaction as an indicator of QoL to define it as "absolute and interpersonally comparable measurement of aspiration" (p.174). Diener (1984) believes that individuals employ an evaluative process to compare their present situations with their personal principles in order to assess their QoL. Cohen's theory of QoL (1982), known as "life plan approach", highlights the role of three different factors to explain the capability of patients in identifying their own problems, including objectivity, subjectivity and individualised components. According to Cohen (1982: suppl III, p.30), "It is the plan of life and the interrelated purposes of a person that give his life what unity it has, and bring us to regard him and ourselves as individuals who are irreplaceable and beyond price".

All definitions of QoL are characterised explicitly by individuality and comparison. It means that QoL is an individual and dynamic construct. In other words, QoL appraisal involves constant subjective evaluation of life. Therefore, not only does QoL mean different things to different people (Bulpitt and Fletcher 1990) but its meaning is unlikely to remain stable for an individual over time (O'Boyle, et al. 1992). On the other hand, definitions of QoL based on physical divergence from the norm have led thought and planning in health care research (Koch 2000).

Given its multidimensional nature, it is easier for researchers to attempt measurement of QoL by using several different variables with each variable directly represented by a measurement operation (Ford 1975, cited in Lincoln and Guba, 1985). Health is a

dimension of QoL and an important aspect of everybody's existence (Bowling 1995, 1996, Farquhar 1995). This has led to a more specific term, *health-related quality of life*, to be used instead. Health-related quality of life refers to "optimum levels of mental, physical, role and social functioning, including: relationships, and perceptions of health, fitness, life satisfaction and well-being" (Bowling 2001, p. 3). Lovatt (1992, cited in Fitzpatrick, et al. 1998a, p. 6) defines HRQoL as "the level of well-being and satisfaction associated with an individual's life and how this is affected by disease, accidents and treatments from the patient's point of view". These definitions seem to satisfy many researchers who seek theory-laden facts (Lincoln and Guba 1985). The concept of HRQoL is converted into observable variables, so the concept can be measured by an instrument. From this standpoint, the concept of QoL itself is not viewed as a whole, but is divided into objective and subjective QoL (Lehman, et al. 1995).

2.4. The concept of change

During a disease process, as individuals' conditions and health change, so do their perceptions of the meaning of life and their interpretation of the QoL, which results in accommodating to the disease and their new state (Allison, et al., 1997). Dependent on personality, sociodemographic characteristics, expectations, etc., people adapt themselves to a new stressful situation using different kinds of psychological phenomena. Using these psychological mechanisms can result in changes in internal standards, values and redefinition of the concept of the QoL which is called *response shift* (Spranger and Schwartz 1999). An operational definition of response shift refers to "a deviation of an observed score from some expected value, associated with a change in the way that individual appraises QoL" (Rapkin 2000, p.55).

Response shift was initially examined in organisational change design (Golembiewski, et al. 1976) and educational psychology (Howard and Dailey 1979, Howard 1980). Golembiewski and colleagues (1976) made some distinctions between three types of change:

- Alpha change is the traditional notion of change. It complies with change detected in conventional pre-post study designs, assuming that the stable conceptual dimensions are measured by a constant calibrated instrument with fixed intervals. Concepts of width and length and in health care blood pressure and range of movement are examples of alpha change.
- Beta changes are measured along changing intervals and include the recalibration of some intervals used to measure a constant domain. Measuring psychological dimensions of treatment outcomes in pre and post-treatment studies, is associated with beta changes.
- Gamma change, described by Golembiewski as "big bang" change, involves a change in state, a profound change in meaning and reconceptualisation of some concepts, unlike alpha and beta which involve a change of degree or condition within a state.

Scale recalibration was also examined by Howard and Dailey (1979) and Howard (1980) as a potential threat to internal validity of self-report measures. These original studies acknowledged that in evaluating interventions with self-reported measures, it is necessary to identify changes in individuals' internal standards (Golembiewski, et al. 1976, Howard and Dailey, 1979, Howard 1980) and re-conceptualisation of their objective constructs (Golembiewski, et al. 1976). Patient-based outcome measures, which report patients' responses to their disease and treatment are influenced by patients' knowledge, experience, cultural and socio-emotional back ground. Therefore, these instruments unlike measures of physiological dimensions are prone to have intervals with stretching and compressing potentials (Golembiewski, et al. 1976).

According to the theoretical model of response shift (Sprangers and Schwartz, 1999), a change in an individual's health status over the course of a disease, known as catalyst, is

modified by mechanisms that may provoke a number of behavioural, cognitive and affective processes such as spiritual practice, social comparison, social support, goal reordering and reframing expectations.

Characteristics of the individual referred to as antecedents have influence on both the type of the mechanisms and the type of induced response shift. So a feedback circle (Figure 2.1.) consists of five interrelated factors of catalyst, antecedents, mechanisms, response shift and perceived QoL aims to maintain or improve the QoL (Rapkin and Schwartz, 2004).

In longitudinal studies where the dimensions of treatment outcomes are examined pre and post-intervention, the response shift may occur and the observed change may not be a real change. Therefore, response shift can be a threat to the validity of longitudinal studies, if a change in an individual's status is attributed merely to the selected intervention (Arrindell, 2001, Schwartz, et al. 2004).

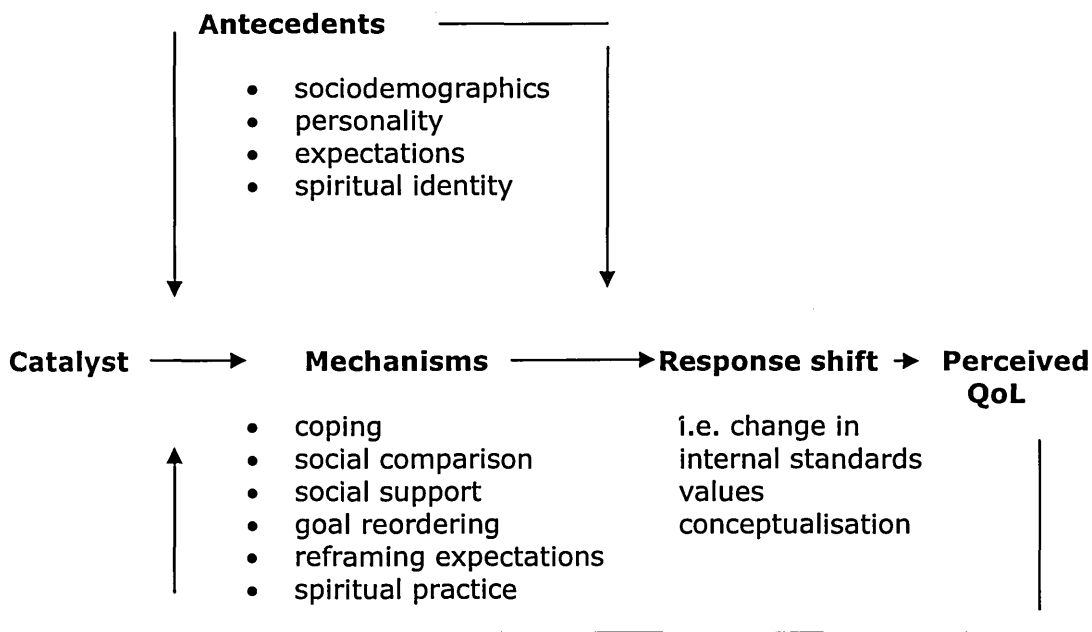


Figure 2.1.A theoretical model of response shift and quality of life (QoL).
 Sprangers, M.A.G. and Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine*. Vol. 48, No. 11: 1507-1515. Copyright 1999 by Elsevier Science Ltd. Reproduced by permission of the publisher and the author (Appendix 2).

Summary

No generally agreed definition has been reached on QoL as a multidimensional construct with a dynamic nature. The broad definitions, however, stress individuality and comparative evaluation. It means that the meaning of QoL is subject to intrapersonal as well as interpersonal differences. The lack of a basic theoretical conceptualisation of QoL has caused researchers to operationalise the concept of QoL in terms of various life dimensions such as health. This has led to a more specific term as HRQoL whose observable variables can be measured by an instrument. There are three major QoL instruments: generic measures, disease-specific measures and individualised measures. Given individuality as the most prominent feature of QoL definitions, the idea of individualised measures is an exiting challenge to the current approach of pre-defined QoL measures.

The inconsistency between objective evaluation and subjective assessment of health indicates that in the face of unchanged or even deteriorated health conditions, people may evaluate their QoL differently over time as a result of shifting their standards and values. This observable fact can be a threat to the validity of longitudinal studies. Therefore, in evaluating medical interventions with self-reported measures it is important to take into account any scale recalibration and reconceptualisation of constructs. Over the course of a disease trajectory, individuals based on their characteristics use different psychological mechanisms in the process of adjusting the disease. This can result in changes in internal standards, values and redefinition of the construct of interest which is called response shift. So when the dimensions of treatment outcomes are examined in pre-post study designs, the perceived QoL can be attributed to response shift as well as the intervention.

2.5. Standard assessment of change

2.5.1. Measurement criteria

The criteria used for assessing the health status and QoL instruments were reviewed by Fitzpatrick, et al. (1998a) and the Scientific Advisory Committee (SAC) of the medical outcomes trust (2002). These criteria address research activities carried out in developing instruments exclusively at levels of methodology and method. In other words, the criteria address the psychometric assessment of the instruments. The criteria set for the QoL instruments reviewed by SAC (2002) are the same for all instruments. No matter how they are administered or to what extent they use a more qualitative approach, they aim to reach a convincing conclusion based on consistency and accuracy by providing evidence on reliability, validity, responsiveness and so on.

The most important criteria or attributes, a more general term employed by the SAC, are: reliability (internal consistency, reproducibility), validity, responsiveness, and feasibility or burden. These are well established for many standardised instruments. Regarding the nature of my study, which examines change over time, the focus will be on validity and responsiveness as the main criteria.

Validity

Validity of a measure is the extent to which it measures what it intends to measure (Streiner and Norman, 1995). Evidence for the validity of a measure has been examined routinely using three approaches: criterion validity, face and content validity and construct validity (SAC 2002, Fitzpatrick, et al. 1998a).

Construct validity

Construct validity is a way to measure the validity of an instrument quantitatively. For example, hypothetical relations (on the basis of previous knowledge) are tested against scores on a QoL measure and patients' clinical and sociodemographic characteristics (Ruta, et al. 1994, 1999, Brazier, et al. 1992) such as GP severity rating, using analgesic medications, sex, housing tenure, marital and employment status, the patient's referral for an out-patient appointment, social class, using health services, etc. According to Streiner and Norman (1995, p.9) "The burden of evidence in testing construct validity arises not from a single powerful experiment, but from a series of converging experiments".

The concept of convergent and discriminant validity (Campbell and Fiske, 1959) is another approach for establishing construct validity. The idea they advocate is a "building up" approach of evidence of a concept's relationships with different variables. A measure under study is supposed to have stronger relationships with some variables and weaker relationships with others. For example, the sub-scale of emotional well-being of a measure is expected to be more correlated with other measures of emotional well-being rather than measures of physical functioning. It seems that the evidence for establishing construct validity of a measure develops gradually over time through numerous studies. There are various techniques for examining the correlation of a measure against a range of other variables, until it reaches satisfactory achievement in the research community (Seale 1999). Construct validity is established by accumulative evidence and through various observations to make a picture of a measure's relationships with other variables (Bergner and Rothman, 1987). The main feature of construct validity demonstrates a single reality that can be divided into separate unrelated variables and they can be examined independently. The evidence from each single variable comes together and finally the whole reality emerges (Lincoln and Guba,

1985). Evidence on validity of QoL measures provides the kind of knowledge that is true at any time and place.

Criterion validity

Knowledge achieved through QoL measures that is independent of both time and context brings the concept of generalisation to our attention. This itself supports the idea of control and prediction, and underpins the concept of criterion validity, which takes the form of concurrent validity (confirmation of the results of a measure with some other variables at the same time) and predictive validity (ability of the measure to predict future changes) (Bowling 1997). Concurrent validity involves the correlation of a measure with an accepted validated measure known as "gold standard". In the area of QoL measures, however, there are not such measures as "gold standard" measures (Fitzpatrick, et al. 1998a). Therefore, researchers use correlation of a score measure with other accepted criteria such as physicians ratings of the condition being evaluated (Martin, et al. 1997). Thus physicians' ratings are being used as an effective criterion for validating health-status and QoL instruments (Tugwell, et al. 1990), despite evidence of large differences in evaluation of treatment outcome between patients and doctors (Bowling 2001).

Content and face validity

To be examined in a scientific way, the concept of QoL must be described and converted into measurable forms. In other words, it is necessary for a QoL measure to have face and content validity (Bowling 2001). "Face validity examines whether an instrument appears to be measuring what it is intended to measure and content validity examines the extent to which the domain of interest is comprehensively sampled by the items, or questions in the instrument (Guyatt, et al. 1993: p.624). Face and content validity are in effect equivalent to the positivist term "operationalism and it amounts to

the methodological assertion that any variable that cannot be directly represented by a measurement operation has no place in science" (Ford 1975: p. 149, cited by Lincoln and Guba, 1985). By making the distinction between the concept as a "theoretical entity" and the indicator as a "measurable empirical entity" (Rose 1982) through operationalism, the concept of QoL is measured by a questionnaire with certain items and domains as an indicator. For example, measuring QoL by a generic questionnaire like the SF-36 is based on the concept-indicator distinction. The theoretical concept of QoL is reflected by eight dimensions of life (eight sub-scales of the SF-36) as variables that are measured by defining the variables through operators (Rose 1982).

Responsiveness

Kirshner and Guyatt's taxonomy of assessing health indices (1985) distinguishes between three kinds of outcome measures based on their measurement properties:

- Predictive measures for prediction purposes.
- Discriminative measures to detect changes between individuals at a single point in time when no gold standard is available.
- Evaluative instruments to detect magnitude of change within individuals over time.

The essential properties required for any kind of instrument are validity and a high ratio of true differences (signal) to the measurement error (noise). The nominator of this ratio will depend on an instrument's purpose, prediction, discrimination or evaluation differ (Guyatt, et al. 1992). For a discriminative instrument, the nominator is the between-subject differences and, therefore, the ratio is the between-subject differences to within-subject differences. This is called reliability. The nominator for an evaluative instrument is the true within-subject variations and the ratio is the true within-subject variations to the intra-subject variation (random). This is called responsiveness. Responsiveness as the power of a measure to detect a clinically important change over time (Kirshner and

Guyatt 1985) is an additional property for evaluative instruments and is not relevant to predictive and discriminative instruments. The magnitude of longitudinal change over time in an individual or group on the dimension of interest is measured by responsiveness as an evaluative index property.

Types of responsiveness / responsiveness statistics

There are two main features of responsiveness that have their own definitions and methods of evaluation: internal and external responsiveness (Husted, et al. 2000). By definition, internal responsiveness is the ability of a measure to detect change over a period of time, whereas external responsiveness measures the correlation of changes in a measure over a time period to some external criteria used to measure health status.

There is a variety of statistical methods that present the extent of QoL changes quantitatively. These are the internal responsiveness statistics that include related t-test (Deyo, et al. 1991), effect size (Kazis, et al. 1989), standardised response mean (SRM) (Liang, et al. 1990) and modified standardised response mean (mSRM) (Guyatt, et al. 1987). There are some measurement approaches to assess external responsiveness that develop an analogy with diagnostic measures, classifying individuals as a proportion of individuals who are identified with true changes and also a proportion of individuals who are not truly changing. In other words, they assess sensitivity and specificity of change scores or a more developed form of it, receiver-operating characteristics (Deyo and Centor 1986). This method is characterised by the ability of a measure to classify individuals as improved or unimproved, without a change in the external criterion (Husted, et al. 2000). The frequently used statistic that is used to calculate external responsiveness is intra-class correlation co-efficient (Deyo, et al. 1991, Wright and Young, 1997).

Whatever method is used to assess responsiveness, the important issue is to provide a clinically meaningful interpretation of change by an index score (Jaeschke, et al. 1989). Nothing much has been done to define clinically important change by clinicians who use physiological measures, because they get clinical experience with a measure through repeated use (Wells, et al. 2001). Lydick and Epstein (1993) use two classifications similar to the classification introduced by Husted and colleagues (2000) for examining the methods that are used to study clinical meaningfulness: distribution-based and anchor-based approaches. Distribution-based methods use statistical distributions such as means and standard deviations to interpret change like effect size measures (Kazis, et al. 1989). Anchor-based approaches use some external criteria to compare a change score in QoL to other changes. The anchor-based approach can be classified into criterion-anchored and construct-anchored (Guyatt, et al. 2002). Criterion-anchored uses patients' evaluation of change as the standard against which the QoL is assessed. The construct-anchored compares changes in QoL to biological and clinical outcomes.

The most frequent used anchor-based approach is global ratings of change, which was introduced by Jaeschke et al. (1989) as the minimal clinically important difference (MCID) or the newly used term as "minimally important difference" (MID) (Celia, et al. 2002). It is defined as "the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate ... a change in the patient's management" (p. 408). The new revised definition refers to the MID as "the smallest difference in score in the domain of interest that patients perceive as important, either beneficial or harmful, and which would lead the clinician to consider a change in the patient's management" (Guyatt, et al. 2002, p.377).

Researchers use different approaches towards establishing a MCID. These studies can be classified according to the cube classification system by Beaton, et al. (2001), which uses categories based on three characteristics: individual or group setting, between or within individual change and the type of change being measured. The methods used for determining MCID were reviewed by Wells, et al. (2001). Jaeschke, et al. (1989) for example, developed an approach to interpret changes in score in QoL instruments by comparing them to a global rating that requires patients to judge the extent of improvement or deterioration in their condition. The MCID was reported by mean change in score per item. They examined changes of score over time in the Chronic Respiratory Questionnaire (CRQ). This questionnaire measures dyspnea, fatigue and emotional function. In their method, the MCID as a feature for interpreting longitudinal change, was measured for three different domains of interest separately. That is, patients rated their level of dyspnea on a global rating scale independently from fatigue and emotional functions. This resulted in different estimated MCID in three domains.

Riddle et al (1998) identified within-individual change from patient perspective at both group and individual levels. They used more in-depth external criteria such as the use of treatment goals achievement. The goals are set at the beginning of a treatment programme and are reviewed for achievement at the time of discharge. Clinicians and patients decide whether the patients achieve their goals. Using the Roland Morris Back Pain questionnaire in their study, a change score was calculated for patients who were reported to achieve their goals and for those who reported they did not achieve their goals. For example, in the studies of low back pain the goal could be for the patient to return to work. Clinicians will make the judgement as to whether patients achieve their goals based on regaining normal physical functioning relative to activities performed prior to their ill health condition. As these studies use some kind of external indicator to

confirm the occurrence of change, they claim that the change would be important (Beaton, et al. 2001), as experienced by patients.

What is really important is to weigh the significance of change against the minimal important change and not against any observed change (Wright and Young 1997).

Studies that evaluate the effectiveness of well-known medical interventions are designed to detect observed change. These changes are expected after those medical interventions such as hip joint arthroplasty (Deyo and Centor, 1986, Liang, et al. 1990).

Summary

Reliability, validity and responsiveness are used as the main psychometric criteria to evaluate QoL instruments. The validity of a measure is the degree to which it measures what it claims to measure. Construct validity, criterion validity, face and content validity are three main ways of establishing the validity of an instrument. The idea underpinning construct validity is to establish a measure's relationship with other variables by adding up evidence through different observations. Construct validity features a single reality that can be divided and examined independently as unrelated variables. Criterion validity refers to the correlation of a measure with other accepted criteria such as clinicians' ratings. Face and content validity examines how a theoretical concept can be operationalised into measurable variables in the forms of questionnaires' items. Responsiveness is the ability of an instrument to detect clinically important change over time. It is an essential property for evaluative instruments that identify magnitude of change within individuals over time. There are two major methods used for examining clinical meaningfulness: distribution-based and anchor-based approaches. Distribution-based methods use statistical distributions such as means and standard deviations to interpret change. Anchor-based approaches use some external criteria to compare a change score to other changes. The most common used anchor-based method is global ratings of change known as the minimal clinically important difference (MCID). To establish MCID researchers use some kind of external indicators to balance the significance of change against the minimal important change. Unlike MCID the observed change is expected after famous medical intervention like hip joint arthroplasty.

2.6. Assessing response shift

Increasing evidence for response shift in QoL evaluation requires methodological assessment approaches in both cross-sectional and longitudinal QoL research. Response shift can be examined as differences between self-report criteria and external standards at one point in time as well as being measured for changes in one's standards and values over time (Rapkin and Schwartz, 2004). Schwartz and Sprangers (1999) described several methods that can address different aspects of response shift, indicating a possible natural inter-relation between internal standards, values and conceptualisation. Although quantitative methods take the lead on response shift assessment research (Sprangers, et al. 1999, Daltroy, et al. 1999, Visser, et al. 2000, Ahmed, et al. 2004, Schwartz, et al. 2004, Kidd, et al. 2004), qualitative approaches (Rapkin 2000, Richards and Folkman, 2000) as well as individualised methods (O'Boyle, et al. 2000) are used to examine changes in three components of response shift. The existing methods are evaluated based on four criteria, including reliability, validity, feasibility and availability of empirical evidence (Schwartz and Sprangers, 1999), regardless of the type of the method and its theoretical perspective. Methods examining response shift use the same criteria that are used to evaluate QoL (SAC 2002).

2.6.1. Quantitative methods

The most documented quantitative used method for evaluating response shift is the *Then-test* approach (Sprangers, et al. 1999, Kidd, et al. 2004, Ahmed, et al. 2004, Ahmed, et al. 2005). In this method, in addition to a conventional pre-test and post-test, the participants are asked to provide new information on their pre-intervention status and reconsider their baseline conditions, while taking into account their post-intervention perception. The *Then-test* or retrospective pre-test is able to measure the full treatment effect by comparing the *Then-test* and post-test (then-test-minus-post-test)

and see how significant it is from zero, while the reported effect or standard analysis of change compares pre-test and post-test scores to evaluate change in QoL over time.

Schwartz, et al. (2004) explored response shift in a longitudinal study of 93 multiple sclerosis patients over a five-year period. They operationalised QoL as role performance, adaptability and psychological well-being. The three components of QoL in this study were measured by well-documented standardised instruments in terms of reliability and validity. Internal standards or recalibration response shift was assessed by *Then-test*. Standard analysis of difference scores between post-test and pre-test showed that there was a deterioration in the patients' physical functioning over time, but no change in psychological, work role limitations, fatigue, self-efficacy and well-being. Patients recalibrated their internal standards regarding their physical functioning by fixing their idea of functioning at a more upper level when they were providing a new opinion of their base-line functioning at follow-up. In contrast, they retrospectively anchored their level of perception on fatigue at a lower level and rated their fatigue as less severe than at base-line. Despite an improvement on their *Then-test* score for fatigue, the *Then-test* minus post-test score for fatigue was significant, indicating increasing experience of fatigue over time. The study concludes that the induced response shift is accountable for a stable level of QoL despite physical worsening.

Kidd and colleagues (2004) examined internal standard response shift in a longitudinal study investigating the effectiveness of narrative stimulation exercises targeting back and fall injuries. The *Then-test* was measured by comparing the mean scores and mean differences for a visual analogue scale (VAS) safety climate for the intervention group and control group. There was no significant difference between the two groups at the pre-test. There was a significant decrease in mean score in intervention group at post-

test, which was administered four months after the pre-test. A *Then-test* was administered to both groups at the same time as the post-test. The mean difference in VAS score between the pre-test and then-test was significant for the intervention group, but not significant for the control group. Standard evaluation of change after the intervention was illustrated by the difference between pre-test and post-test, assuming that a constant calibrated instrument measures stable conceptual dimensions, as the participants' understanding of the measured concept (Golembiewski, et al. 1979). However, a significant difference between the participants' understanding of the concept of interest at pre-test and their reinterpretation of the same concept at the time of the post-test can be an evidence of recalibration response shift (Kidd, et al. 2004).

Changes in internal standards among individuals with stroke was investigated by Ahmed, et al. (2004) using the retrospective pre-test and comparing it with prospective evaluation of health status. Health status was measured by a QoL instrument at base line and at six weeks and 24 weeks post-stroke. A then-test was administered simultaneously with a post-test at six week and 24 week follow-up evaluations. The recalibration response shift effect between the base-line and six-week and between six-week and 24-week evaluations were significant. It indicated that response shift was induced in a positive direction. It means that stroke patients rated their health status lower retrospectively than their rating at base-line. In other words, they positioned their perception of health at a lower level compared with their understanding of health at base-line. A significant conventional change in mean score was calculated between base-line scores and scores at six week assessment. However, the corresponding response shift change, the *Then-test* score minus post-test score was higher than the conventional change. Although the mean difference between the scores at six week and 24 week evaluations was not significant, the response shift change was significant. They

reported no significant scale recalibration in control group. Therefore, there was no difference in standard measure of change and response shift related estimates of change in the control group.

2.6.2. Qualitative-based evidence and individualised methods

Response shift has been evaluated by using different qualitative methods as well as individualised approaches which the latter has a combination of quantitative and qualitative data (Schwartz and Sprangers, 1999).

Richards and Folkman's (2000) study on response shift has its base in Folkman and Stein's (1996) adaptive theory. In the context of the study of everyday memory, Folkman and Stein (1996) examined how individuals adapt themselves to stressful situations. Their model explains how individuals maintain their psychological well-being despite their worsening and uncontrollable circumstances, which are very important to them. According to their theoretical framework, people constantly appraise and reappraise the events through goal processes. When people's understanding and expectations about their current situations are defied by a stressful event, they revise their beliefs and expectations that enable them to generate new practical and meaningful goals in regards to their new shifting circumstances. Finally, to maintain an optimistic and constructive view of their life, they need to replace the unsustainable goals with the new ones (Folkman and Stein, 1996). They analysed narrative accounts of caregiver partners of men with AIDS based on goal processes in the form of maladaptive and adaptive goal processes. Maladaptive goal processes occur when people have knowledge that their respected goals are no longer attainable, nevertheless their focus

z In this study, "qualitative-based evidence" does not refer solely to studies with qualitative designs but to studies that use qualitative evidence to support quantitative data. For example, Rapkin (2000) supported his results from several outcome measures with analysis of responses to open-ended questions (See page 36).

stays on the goals. This could prevent them from creating new goals. They insist on managing the uncontrollable situations, which results in experiencing negative feelings such as anger and frustration. On the other hand, during an adaptive goal processes people realise that their valued goals are no longer tenable, so they modify their beliefs and expectations and generate new goals, which are likely to be sound and plausible under stressful circumstances (Folkman and Stein, 1996).

Richards and Folkman (2000) used qualitative data in a study of caregiving partners of people with AIDS and their experience of bereavement. They showed that in the face of worsening and stressful conditions of their partners, the caregivers were capable of sustaining their positive psychological well-being. Evidence on response shift was supported through the modified model of coping theory (Folkman 1997), which is based on the original model of coping (Lazarus and Folkman, 1984). According to this theory, in stressful situations, a chronic condition, when people have less control over their situation, the distress can create meaning-based coping. It means that people can positively reappraise the situation, revise goals, practise spirituality and have a positive view of ordinary events (Folkman 1997). Response shift occurs through the meaning-based coping process in which people reach to the point of realistic appraisal where their previous goals and expectations are not rational any more (Richards and Folkman, 2000). They feel that they need to revise their goals with respect to both situational and global meanings (Park and Folkman, 1997). Global meaning refers to "peoples' basic goals and fundamental assumptions, beliefs and expectations about the world" (Park and Folkman, 1997: p.116). Situational meaning is "the interaction of a person's global beliefs and goals and the circumstances of a particular person-environment transaction" (Park and Folkman, 1997: p.121). Following the re-evaluation of their goals, new

pragmatic purposes are adopted at both situational and global levels resulting in a response shift (Richards and Folkman, 2000).

Rapkin (2000) in a longitudinal study used an open-ended method of identifying the goals to assess personal goals of people with AIDS. Structured interviews were used at two points in time to examine changes in personal goals over time. A content analysis of their accounts identified different kinds of goals. Any change in the number of goals or changes in the relative weight given to the goals were consistent with changes in participants' health status over time as it was measured by several measures of health status. Although the goals were assessed qualitatively at two points in time, based on operational definition of response shift as the difference between observed and expected values, they used a regression model to explain in statistical terms how changes in goals can ease the effect of the disease progression, life events and treatments on QoL. In other words, response shift in the form of reprioritisation or re-conceptualisation of goals was accounted for any unexpected level of QoL in the studied sample.

O'Boyle and colleagues (2000) illustrated that an individualised measure of QoL called the Schedule for the Evaluation of Individual Quality of Life or SEIQOL (O'Boyle, et al. 1992) can measure aspects of response shift, which are related to changes in values and re-conceptualisation. The SEIQOL measures three factors of QoL by asking the participants to nominate the five most important areas of their lives or cues, to rate the levels of the cues by a Visual Analogue Scale (VAS), and to give weight to each area or cue on a VAS. It also calculates a global QoL score or the SEIQOL index score. They proposed that in longitudinal studies by administering the SEIQOL on two or more occasions, a change in the cue content would reflect re-conceptualisation, a change in the cue level would be an indicator of a change in internal standards and finally a

change in values would be represented by changes in cue weights. Longitudinal data at three points in time on the SEIQOL for a 51-year-old terminally ill man with prostate cancer showed that how the individual could maintain or show improvement in his overall QoL by making changes in the cues, his levels and by giving different weights to the cues over time. For example, while on the first administration, family and health were the most important domains of his life, on the third evaluation, which was six months before his death, spirituality ranked first followed by family as the most important areas of his life. Table 2.1 shows the classification for the studies of change and summarises some of the studies carried out in this field.

Distribution-based studies (Lydick & Epstein, 1993)	Anchor-based studies (MID) (Lydick & Epstein, 1993)	Qualitative-based evidence
<ul style="list-style-type: none"> • effect sizes (Kazis, et al. 1989) • related t-test (Deyo, et al. 1991) • SRM (Liang, et al. 1990) • mSRM (Guyatt, et al. 1987) 	<ul style="list-style-type: none"> • global ratings of change (Jaeschke, et al. 1989), (Osoba, et al. 1998) • ROC method (Deyo & Centor, 1986), (Riddle, et al. 1998) • ICC (Deyo, et al. 1991), (Wright & Young, 1997) 	<p>Examining response shift</p> <ul style="list-style-type: none"> • Quantitative <p>Thentest approach (Schwartz, et al. 2004), (Kidd, et al. 2004), (Ahmed, et al. 2004)</p> <ul style="list-style-type: none"> • Qualitative <p>(Richards & Folkman 2000), (Rapkin 2000) (O'Boyle, et al. 2000)</p>
		Others

Table2.1. Studies of change, using QoL outcome measures

Summary

The concept of response shift challenges the established standard approach to the assessment of change. Response shift explains the difference between self-report assessment and external standards at one point in time. It is also examined regarding changes in one's standards and values over time. Quantitative, qualitative and individualised methods are used to address three different and inter-related aspects of response shift. Then-test is the most known quantitative method for assessing response shift. In addition to pre and post tests evaluation, participants are asked to make a reassessment of pre-intervention status in the light of post-intervention circumstances. Quantitative methods dominate research studies on response shift assessment. Nevertheless, to some lesser degree response shift is examined by qualitative methods. Adaptive coping theory in psychology is the starting point for examining response shift in a number of exciting qualitative studies. Stressful and uncontrollable situations can create meaning-based coping. Response shift occurs through meaning-based coping, when people reappraise the situation, modify goals and create new realistic goals compatible to their new distressing situation.

2.7. Selected outcome measures

The need to include patient-based outcome measures in assessment of THR surgery was emphasised in two systematic reviews of primary THR (Faulkner, et al. 1998, Fitzpatrick, et al. 1998b). A number of patient-based outcome measures has been used to evaluate THR such as the SF-36 (Ware and Sherbourne, 1992), The Oxford Hip Score (Dawson, et al. 1996a) and the Schedule for the Evaluation of Individual Quality of Life (O'Boyle, et al. 1992).

2.7.1. The SF-36

The Rand short form -36 (SF-36) (Ware and Sherbourne 1992) is a generic instrument recommended as the generic core in disease-specific batteries of HRQoL (Bowling 2001). The SF-36 was developed from the Health Insurance Experiment, a 108-item questionnaire given to a representative sample of general population, which itself was a product of extensive literature search (Jenkinson, et al. 1996). It is a self-administered questionnaire that takes 5-10 minutes to complete. Its single multi-item scale measures eight dimensions: physical functioning, role limitations because of physical health problems, bodily pain, social functioning, general mental health, role limitations because of emotional problems, vitality, (energy/fatigue), and general health perception. Scores for each of the dimensions are summed and scale scores have a range of 0-100 from 'poor health' to 'good health' (Ware and Sherbourne 1992). There is no consensus of opinion or explicit definition of criteria for assessing QoL instruments (Fitzpatrick et al. 1998a). In the early studies validating the SF-36, cross-sectional data were used (Brazier, et al. 1992, McHorney, et al. 1993, Garrat, et al. 1993, Jenkinson, et al. 1993). Brazier and colleagues (1992) tested the construct validity of the SF-36 in a general population divided in different groups with different expected health using sociodemographic characteristics such as age, sex, social class, suffering from chronic

diseases and the amount of using health services. They used a non-parametric between-subject statistical test to examine how significantly the SF-36 scores are different among these groups. In a study by McHorney, et al. 1993, the cross-sectional construct validity of the SF-36 was tested in a patient population by using psychometric criteria and clinical criteria and the agreement between them. They tested the validity of the eight dimensions of the SF-36, which measures two different health constructs, physical and mental health. They also used clinical criteria, disease-specific severity scales and psychiatric diagnostic criteria to differentiate patients based on their physical and mental health status. Garratt, and colleagues (1993) examined cross-sectional validity of the SF-36 in patients with four common clinical conditions. The study examined clinical construct validity of the SF-36 based on a pre-assumption that the SF-36 scores should be varied among the four clinical conditions, which were corrected sociodemographically. General Practitioners' perceptions of disease severity were the external indicator in this study. The study of Jenkinson and colleagues (1993) that is in agreement with Brazier, et al. 1992, provided evidence on validity of the SF-36, using cross-sectional data from a general population. The sample was classified into sex, age, social class, reporting long illness and recent medical consultation. Statistical t-tests were used to show how significantly the SF-36 scores were different among these patient groups.

Later studies of validity of the SF-36 have also examined construct validity of the instrument at a point in time. Provenzale, et al. (1997) investigated construct validity of the SF-36 by measuring the correlation between its physical and psychological subscales with some other instruments and Stavem, et al. (1999) and Van-de-Molen, et al. (1997) used clinical markers such as objective and subjective measures of a disease as external indicators. Evidence of validity of the SF-36 supports the ability of the

instrument to discriminate between groups with physical and mental disabilities (Ware, et al.1997). Therefore, as a discriminative instrument with the purpose of distinguishing between patients groups at a point in time, the SF-36 is a well-validated health status outcome measure. However, to be used in longitudinal studies as an evaluative instrument we need evidence on longitudinal construct validity of the SF-36.

Standard assessment of change by the SF-36

The responsiveness of the SF-36 is described with summary statistics such as effect size, standardised response mean (SRM) and relative efficacy (Nilsdotter, et al. 2001, Taylor, et. al. 1996, Freeman, et. al. 2000, Ahroni & Boyko, 2000, Garratt, et al. 1996). Some studies have used an external indicator of improvement or deterioration such as using changes in patient assessed global disease activity (Hagen, et. al. 1999) and using global ratings on satisfaction and perceived improvement to distinguish clinically important changes (Bessette, et al. 1998). Wyrwich and co-workers (1999 a, b) used standard error of measurement (SEM) to examine MCID using the SF-36. Angst and colleagues (2001) determined MCID in a longitudinal study of Osteoarthritis patients using the SF-36. They calculated effect size and SRM following measuring change in score from base-line to the three-month follow-up. In addition, they used a transition questionnaire that gave the patients an opportunity to compare their current general health status with that of three months earlier. The transition questionnaire comprised of five categories of much worse, slightly worse, equal, slightly better, and much better. Then they compared the mean scores of the SF-36 and the score changes in different categories of the transition questionnaire (Angst, et al. 2001). The transition method has been used earlier in the studies of MCID (Jaeschke, et al. 1989, Deyo, et al. 1991).

Spiegel and colleagues (2005) established the clinical significance of the SF-36 score changes by anchoring them to changes in clinical outcomes in patients with chronic

hepatitis C virus infection. By using construct-anchored HRQoL published data resulting from comparing QoL data with clinical outcomes, they established the MCID for the vitality scale of the SF-36 as 4.2 corresponding to effect size of 0.2. A value less than 0.2 represents a small clinical effect, a value of 0.5 represents a moderate effect and a value greater than 0.8 can be interpreted as a large effect size (Cohen 1969). They concluded that a change of score of 4.2 or more on the vitality scale of the SF-36 over time can be an indicator of the MCID in hepatitis C infection.

Qualitative-based evidence on the SF-36

According to Dorman, et al. (1999), the first qualitative interpretation of the SF-36 was carried out by the authors in a quantitative-designed study of the examination of individual differences in response to the SF-36 and EuroQoL (The EuroQoL Group 1990) in a group of patients after stroke. They provided qualitative evidence to see to what extent different domains of health status measures are interrelated and represent components of a larger construct, QoL. They investigated how and to what extent the two instruments can reflect any change in QoL of stroke patients in a different way. The skewed distribution of scores was a problem with some domains of the SF-36 but not with the EuroQoL. A large proportion of patients scored the worst possible score for the domains of physical role functioning and emotional role functioning, which indicates that floor effect may be present in these domains. Similarly, one quarter of patients scored the maximum score for the bodily pain and psychological functioning domains of the SF-36, suggesting that these patients have little capacity to show improvements in those domains (ceiling effect). The physical functioning, social functioning and pain domains of the SF-36 were correlated with the corresponding domains of the EuroQoL. Moreover, there was a strong correlation between general health domains of the SF-36 and overall health related QoL domain of the EuroQoL. According to the authors, (Dorman, et al. 1999) one possible explanation for these strong correlations is that the

two instruments target areas of life that represent the main dimensions of HRQoL and patients find them important. However, the mental health domain of the SF-36 did not correlate with the psychological functioning domain of the EuroQoL. This problem highlights the fact that these two similar domains measure different constructs. While the mental domain of the SF-36 measures positive emotions, the psychological domain of the EuroQoL reflects negative feelings of anxiety and depression (Dorman, et al. 1999).

Kim and colleagues (2000) investigated spiritual well-being, emotional well-being, life satisfaction and functional status change over time in a longitudinal study of a rehabilitation programme. They used vitality, mental health, emotional role, social functioning, pain and general health status scales of the SF-36 to measure the construct of emotional well-being. Spiritual well-being, life satisfaction and functional status were assessed by using different standardised outcome measures. Participants' emotional well-being increased over the course of the rehabilitation. The authors related the emotional improvement to significant functional gains during the intervention period. They also suggested that the construct of QoL consists of elements such as spiritual well-being, emotional well-being and life satisfaction, because there was a positive correlation between these constructs both at a point in time and over time. Moreover, the fact that the score on one variable was not able to predict later changes in another variable suggests that the constructs represent three different aspects of QoL. The positive relationship between emotional well-being and functional status over the course of the intervention shows that these two constructs are interrelated. The authors support the notion of summing physical and emotional health to reach an overall score for QoL. The SF-36 summary scores divide health into two separate concepts (Ware, et al. 1994). For example, the developers of the summary scores argue that the lower level

of vitality associated with physical problems is caused by physical health differences and reduction of vitality in psychological disorders is a result of mental health change (Simon, et al. 1998).

Widar and colleagues (2004) applied qualitative method of interviewing combined with the SF-36 to get a more inclusive perspective of HRQoL in stroke patients with long term pain. Although there were similarities between the qualitative data and the SF-36 domains, there were some identified themes that are not covered in the SF-36. These included family, relationships and social interaction, which were important to the patients in terms of HRQoL domains. Additionally, economic and financial securities were considered by the patients as implicit factors affecting the quality of their life. Furthermore, the transition question of the SF-36 could not measure any change in patients' health over the past year, as the patients might accommodate to the physical and psychological limitations of the stroke over time by using different psychological mechanisms (Spranger and Schwartz, 1999).

Camp and colleagues (2000) used a disease specific measure, the SF-36 as well as qualitative data to evaluate QoL changes in patients with chronic obstructive pulmonary disease in a pre-post study design using pulmonary rehabilitation. The qualitative data were collected by conducting semi-structured interviews with seven participants after the rehabilitation and showed improvements in participants' energy level, confidence, control over the disease, emotional well-being, and physical performance. These improvements were in accordance with physical and emotional components of the disease-specific measure. However, the findings of the qualitative method were reflected only in the physical summary component of the SF-36. Neither the SF-36 nor

the disease-specific measure was able to identify the entire improvement themes generated by the qualitative method.

Treat-Jacobson and colleagues (2002) examined the limitations of standardised measures including the SF-36 in capturing a complete effect of peripheral arterial disease and its treatment on HRQoL of patients. The findings of their open-ended interviews with the patients were in conflict with previous studies, which had used standardised instruments. The flaw of the standardised instruments in identifying the effect of the peripheral arterial disease on emotional and social functioning could be ascribed to the inability of the instruments to detect change in social and emotional domains of life (Treat-Jacobson, et al. 2002).

Mallinson (2002) challenges quantitative methods such as psychometric testing in developing and evaluating subjective health outcome measures. Using in-depth qualitative techniques, she illustrated some problems with the SF-36 regarding the meaning of the questionnaire items and subjective interpretation of the questions. The participants made spontaneous contributions while responding to the SF-36 during a face-to-face interview. The themes that were raised during the interviews varied from technical aspects of questionnaire construction to issues with the conceptual basis of questions and implicit problem of adaptation to limitation, comparison and response shift. To examine diversity in individuals' understanding of the SF-36 items, the physical functioning scale and the general health perception questions (questions no.1& 10) were included in the study. Double questions, unusual terms and phrases, vague and unclear questions were problems associated with the physical functioning items that resulted in answers based on participants' assumptions. The subtle problem with the physical functioning and general health perception scales was individuals' adjustment to

the imposed health problem over time. In other words, response shift and its mechanisms such as social comparison (Sprangers and Schwartz, 1999) had significant impact on how the participants managed to rate their physical functioning and their general health perceptions.

Acknowledging the influence of response shift on the evaluation of QoL, some studies used the SF-36 to examine methodological approaches to evaluate response shift (Ahmed, et al. 2004, Visser, et al. 2005, Ahmed, et al. 2005). For example, Ahmed and colleagues (2005) compared *Then-test* with an individualised approach like the PGI to test the effect of response shift on the measurement of change in QoL as it is assessed by a generic measure like the SF-36. A summary of the studies using the SF-36 is presented in Table 2.2.

Distribution-based studies	Anchor-based studies (MID)	Qualitative-based evidence	Response shift-based studies
(Garrat, et al. 1996)	(Wyrwich, et al. 1999a,b)	(Dorman, et al. 1999),	(Ahmed, et al. 2004)
(Nilsdotter, et al. 2001)	(Angst, et al. 2001)	(Kim, et al. 2000),	(Visser, et al. 2005)
(Taylor, et al. 1996)	(Spiegel, et al. 2005)	(Camp, et al. 2000),	(Ahmed, et al. 2005)
(Freeman, et al. 2000)		(Treat-Jacobson, et al. 2002)	
(Ahroni & Boyko, 2000)		(Widar, et al. 2004),	
		(Mallinson 2002)	

Table 2.2. Studies of change using the SF-36

Summary

Evidence on validity of the SF-36 has been well-documented by using cross-sectional data. The SF-36 has been used to assess change in longitudinal studies. Majority of the studies on the responsiveness of the SF-36 use distribution-based methods and describe its responsiveness in terms of summary statistics. Few recent studies document the responsiveness of the SF-36 by using anchor-based methods, resulting in the establishment of the MCID for some scales of the SF-36. On the whole, the findings of qualitative-based evidence on the SF-36 show that the measure represents some aspects of QoL. Moreover, the lack of correlation between particular domains of the SF-36 with similar domains of other generic or disease-specific measures indicates that the comparable domains of different instruments measure different constructs. In other words, although the instruments claim to measure QoL, they are more likely to evaluate different concepts. These findings highlight concerns about the meaning of the SF-36 items and subjective interpretation of the questions. Furthermore, the impact of response shift on accommodating the disease has failed the transition question of the SF-36 in addressing change in patients' health over time.

2.7.2. The Oxford Hip Score

The Oxford Hip Score is a 12-item questionnaire that is administered by practitioners to patients having THR. The items are summed to produce a single score with lower score reflecting a higher level of QoL (Dawson et al. 1996a). Studies of the Oxford Hip Score show that distribution-based methods as well as anchor-based methods were used to examine the ability of the instrument in detecting change over time (Dawson, et al. 1996a, b, c Fitzpatrick, et al. 2000). Dawson and colleagues (1996b) compared the responsiveness of the Oxford Hip Score and the SF-36 in a prospective study of patients undergoing THR surgery. They examined effect sizes for both questionnaires. Patients' and clinicians' perspectives were assessed and compared with changes in scores for both instruments. Patients determined the occurrence of change in the form of three transition questions.

Fitzpatrick and colleagues (2000) investigated the responsiveness of the Oxford Hip Score by calculating the mean change score and effect sizes. They also examined the magnitude of change by associating change scores to an external indicator, patients' global satisfaction. The findings showed that the score is responsive to change over time and has positive correlation with patients' satisfaction with their hip replacement.

Unlike most studies of the SF-36, studies of the Oxford Hip Score used it as an evaluative instrument. They designed longitudinal studies to assess the ability of the instrument to detect change over time. Although most studies in this respect utilised distribution-based methods, they also used a particular perspective to demonstrate the magnitude of change and its relation with an external indicator. However, no study seems to have the capacity to provide data on MCID and so the MCID standards for the Oxford Hip Score have not yet been established.

McMurray and colleagues (1999) in a qualitative study examined the Oxford Hip Score's structure and conceptual features. The score was used as a prompt for a series of semi-structured interviews with 58 patients before THR surgery and four months after the surgery. They found that there were some limitations regarding the clarity of the questions. The possibility that a patient can perform an activity using an aid was not considered in Questions 2 and 4, which asks patients about their physical performance in terms of washing, drying, and putting on socks, stockings and tights. Likewise, problems with lack of clarity were evident in response category of question 6. The confusion arose when the concept of pain and walking time were combined to make the first response category: "no pain/more than 30 minutes". Also relating pain severity to walking time in the fifth response category of the question 6 was confusing for several patients: "not at all/pain severe on walking". Further difficulty was the meaning and subjective experience of pain over time, which could not be reflected in questions 1 and 2. These questions ask patients to describe their pain they usually have from their hip. Finally the score as a disease-specific instrument could not capture and specify pain and functional limitations in patients with multiple health problems.

The Oxford Hip Score was included in a qualitative study by Heaton, et al. (2000). The study investigated patients' perspectives on the rehabilitation programme before and after total hip replacement. The findings of the study showed that the patients were generally satisfied with the rehabilitation programme in respect to receiving information, equipments, and therapy. The rehabilitation programme, however, needed to be modified to be perceptive to the requirements of individual patients, such as patients with multiple health problems and patients with post-operative complications. The change scores on the Oxford Hip Score were consistent with patients' level of satisfaction with the treatment. That is, among a group of patients with similar pre-

operative scores those who expressed dissatisfaction with the outcome from treatment during the semi-structured interviews scored worse post-operatively.

2.7.3. The Patient Generated Index (PGI)

One significant implication of Caiman's (1984) theory of QoL as described by the author is that "it can only be assessed and described by the individual". Based on Caiman's definition of QoL, Ruta and colleagues (1994) developed an individualised QoL measure, The Patient Generated Index (PGI). The PGI is characterised as having two main features that distinguish it from standardised outcome measures:

1. Patients are allowed to select domains of personal concerns, which have been affected by their health condition.
2. The opportunity to assign weights to different domains in order to rate them based on degree of importance.

The validity of the original version of the PGI was tested by Ruta, et al. (1994). It was sent to 359 patients with low-back pain. Criterion validity of the PGI was tested by observing correlation between the PGI and the SF-36. The correlation between the PGI and seven scales of the SF-36 was significant. Only the general health perception scale of the SF-36 was not correlated with the PGI scores. There was also a high correlation between the PGI score and low-back pain clinical score. The relation between the PGI scores and some hypothetical variables such as GP severity rating, using analgesic medication, sex, housing tenure, marital and employment status was used to test the construct validity of the PGI. For example, referred patients, patients who took stronger analgesic, patients who lived in rented houses, single people and unemployed patients had lower mean PGI scores. However, only the mean PGI scores for referred patients were significantly lower than those who were not referred to the hospital.

The second study on validity of the PGI was a longitudinal one year follow-up study, in which the PGI, SF-36 and condition specific measures were posted to patients with four common conditions (Ruta, et al 1999). Unlike the first study on the PGI which was a cross-sectional study, the second one tried to evaluate the ability of the PGI in detecting change over time. In other words, the PGI was used as an evaluative index. So responsiveness was a necessary property for measuring clinically important changes. The distribution-based method that was used to compare the responsiveness of different outcome measures in this study was the standardised response mean (SRM). The larger the SRM the more responsive to change is the instrument. They used this method to compare the responsiveness of the PGI, the SF-36 and condition specific measures. The PGI showed greater responsiveness than the five scales of the SF-36. The validity of the PGI was tested by showing the correlation between the PGI scores and the SF-36 scales, the condition specific scores, sociodemographic and other variables similar to the first study.

More evidence on validity of the PGI was shown by a study of patients with atopic dermatitis (Herd, et al. 1997). The PGI and the Dermatology Life Quality Index (DLQI) were administered by interviews to 56 patients with atopic dermatitis. They assessed criterion validity of the PGI by calculating the correlation between the PGI and DLQI and also between the PGI and each single item on DLQI. The overall PGI scores showed a moderate correlation with DLQI scores. Sixty four percent of patients nominated domains of their lives in the PGI that were not included in the DLQI, and 20% mentioned only areas included in the DLQI. The correlation between the PGI scores and the DLQI in this group of patients were significant. This showed that those constructs that are not included in the DLQI are of value in measuring QoL of patients with atopic dermatitis.

One of the problems with the original PGI was low response rate (74%). There was also difficulty in completing the questionnaire with 63% completion rate, particularly among less educated patients and patients with lower level of physical functioning (Ruta, et al. 1994). A revised version with less complicated numbers for scoring stage and weighting stage was developed and used by Macduff and Russell (1998). The revised PGI and the SF-36 were mailed to 161 people who were recognised as disabled or handicapped based on their positive answers to a UK Census question. The follow-up assessment was carried out 4.5 months later. In this study a prompt list was used to encourage respondents to complete the PGI. Only 1% of the participants did not use any items from the list. As a prime rule in social knowledge, individuals use the most available information to make judgements (Bodenhausen and Wyer 1987, cited in Browne, et al. 1997). When making judgments about their overall QoL, individuals give special importance to particular life domains they have been asked about (Strack, et al. 1988). It is also possible that when individuals are informed about particular life domains, they disregard them in their overall judgment of QoL (Schwartz and Strack, 1991).

The criterion validity of the PGI was tested by calculating the correlation between the PGI and the eight scales of the SF-36 using Spearman's rank correlation test. The PGI showed the highest correlation with social functioning, energy, mental health and general health perception scales. The responsiveness of the PGI was tested by the standardised response mean (SRM) in three group of patients recognised as unchanged, improved and deteriorated based on the SF-36 transition question. The SRM was higher in those who reported improvement in health. However, no external indicator determined the magnitude of change.

The response rate was 65%, even less than the response rate reported for the original PGI. So the revised version did not perform better than the original version regarding response rate. The authors suggest that an interview approach may be more reassuring, because an individualised measure with capacity to evaluate a dynamic construct such as QoL can perform better in a conversational context (Macduff and Russell, 1998).

The PGI as an individualised measure seeks to functionalise the definition of QoL from individuals' perspectives. Based on this special feature of the PGI, Tully and Cantrill (2000) used a combination of quantitative and qualitative methods to examine the validity of the modified PGI. The criterion validity of the PGI was assessed by correlating the total PGI scores and scores of six scales of the Arthritis Impact Measurement Scales (AIMS) (Meenan 1982). The correlation between the PGI scores and quantitative variables such as arthritis severity, attending doctor or hospital between time 1 and time 2 and taking analgesics for arthritis, was examined based on pre-defined criteria. The in-depth interviews were an attempt to highlight the problems associated with completing the modified PGI. It showed that the areas chosen by the respondents were areas that are affected by patients' arthritis condition. In this study the modified PGI with a prompt list was posted to patients with arthritis. The results showed that at least one area in the prompt list was used by most of the patients. Patients with more severe arthritis used more examples from the trigger list. The findings of the interviews revealed a significant confusion about Box 6, which asks patients to rate and then give points to all other aspects of their lives. By adding this box, the PGI tries to measure a closer concept to QoL, other than HRQoL. However, the problem is that patients are asked to divide their life into two separate parts: one influenced by their health condition and the other affected by other problems unrelated to their main health condition (Anderson and Burckhardt 1999).

Lintern and colleagues (2001) in a comparative study of the PGI, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) and the SF-36 in patients with advanced multiple sclerosis found that the QoL measures and their principal values have important effects on how individuals assess and rate their QoL. Comparing these two individualised measures with the multidimensional SF-36 revealed that the physical aspect of life is represented by the PGI, while the SEIQoL is more likely to demonstrate general health, mental health and vitality. They pointed out that because the PGI asks patients to nominate those aspects of their life that have adverse effects on their overall QoL, the measure reflects a negative change. The PGI does not take into account any positive or unchanged aspects of life. The SEIQoL, on the other hand, focuses on positive aspects of life and represents real well-being. Finally, the study highlighted several points regarding self-rated questionnaires, including the importance of change over a course of a disease as a result of employing coping and adjusting mechanisms. If the effects of these processes on overall QoL are overlooked, they can account for misinterpretation of longitudinal studies (Lintern, et al. 2001).

Incorporating response shift evaluations into the measurement of outcomes of disease and interventions has attracted more researchers to use QoL measures in the context of response shift and its effect on change. The unique feature of individualised measures in selecting domains of interest has led some researchers to use these measures as a method of examining response shift. Ahmed and colleagues (2005) used the PGI as a technique to assess response shift in post stroke patients. They interpreted reconceptualisation as any changes in the definition of areas that are most important to patients. The changes in the weights assigned to each area were perceived as changes in values over the course of the disease.

Summary

The ability of the Oxford Hip Score to detect change over time has been examined using distribution-based and anchored-based methods. The minimal clinically important difference standards, however, have not been established for the score in any health condition. Flaws regarding the Oxford Hip Score's construction and theoretical features such as the clarity of questions, pain experience, and exclusion of co-morbidities have been explored in qualitative-based evidence.

The concept of individuality as the underlying value of a QoL measure was used to develop the PGI. Therefore, the PGI gives the participants an opportunity to select domains of personal concern and weigh them based on their relative importance. Validity of the PGI has been examined in cross-sectional and longitudinal studies. The responsiveness of the PGI has been assessed by using distribution-based methods. In addition to problems associated with low response rate, studies show that people are inclined to use items from the PGI's prompt list. Finally, as the PGI emphasises aspects of life that have adverse effects on overall QoL, the measure is more likely to illustrate a negative change on QoL.

2.8. Discussion

The model underpinning the assessment of change in QoL outcome measures is derived from psychometric theory and experts' definitions of health and QoL (See Fitzpatrick, et al. 1998a). In other words, despite growing interest in measuring change over time, understanding of change has been predominantly based on standard approaches to the assessment of change. Regardless of substantial emphasis on self-report measures from generic measures to individualised instruments, the apparent lack of employing qualitative methods for developing and evaluating outcome measures is confounding. Although there is sufficient evidence that the majority of health outcome measures are reliable, valid and easy to administer, they all share one major drawback: an individual's perception of a disease experience relies on her/his understanding of the experience. In other words, individuals' perception of an experience is a question of whether response shift has occurred in their self-report evaluation of their health (Daltroy, et al. 1999).

It has been nearly 30 years since the concept of response shift surfaced in studies of change and challenged the conventional measurement of change as the difference between base-line and follow-up score values. The conventional method assumes that neither the measure nor the subjects' understanding of it alters over the period of measurement (Golembiewski, et al. 1976, Howard and Dailey, 1979, Howard 1980). This form of stability is true with regard to biomedical measures and physiological tests (Kirshner and Guyatt, 1985). However, in measuring subjective constructs like QoL, change of interpretation of measures can be a result of the intervention as well as the subject's re-evaluation of the construct of interest (Sprangers and Schwartz, 1999).

Nevertheless, response shift has been challenged by the implicit theory of change (Norman 2003). While response shift gives more validity to the retrospective re-assessment of the base-line status, from the point of view of the implicit theory, the

prospective evaluation at the time of pre-test is more valid. The implicit theory questions the perfection of memory in retrospective judgments of the initial position. It starts with the current situation and considers retrospective assessment different and less valid from the primary assessment. Response shift, on the other hand, assumes that people's standards and values change over time. In view of the revised standards and values, their post-test interpretation of their initial status also differs from the pre-test time (Norman 2003).

The contemporary challenge to the measurement of QoL from patients' perspective is to address understanding and meaning of change for individual patients. The most frequently used method for addressing change that is meaningful to the patients is anchor-based, of which the global ratings of change and receiver operating characteristics have widely been used. These techniques stress the importance of detecting MID or "subjectively significant" difference (Osoba, et al. 1998). The concept gives significant weight to the patient-based evaluation of QoL as the main and primary approach to the assessment of QoL. However, establishing MID for an instrument does not necessarily mean it will remain stable across different patient groups and different health conditions (Guyatt, et al. 2002). Moreover, anchor-based methods of clinical meaningfulness such as MID are based on transitional scales, so the patients can make global ratings of changes in different aspects of their condition. In describing the original global ratings of change by Jaeschke, et al. (1989), an analogy was made with clinical tests. As clinicians get clinical experience with clinical tests by frequent application of them on a large number of patients, they also reach an agreement on MCID. So Jaeschke and colleagues (1989) established global ratings of change as the most common used anchor-based technique based on two expectations. Firstly, they anticipated that a certain degree of score change on a dimension would be important in

daily lives of their patients. For example, a change of three points on fatigue dimension of the Chronic Respiratory Questionnaire would be perceived as important by the patients. Secondly, they assumed small changes in patients' condition to be represented by changes of -3 to -1 or +1 to +3 on a 15 point global ratings scale. Similar to clinical tests, their approach in establishing MCID for a QoL measure is based on clinicians' experience with the instrument. Relating this to a clinical test like range of movement, a change of 10° in knee flexion between, for example, 60° and 70° is much less significant than 90°±5°, which is a difference between sit to stand easily or with difficulty.

While the transitional scale is used as a stable anchor to define meaningful change from patients' point of view, the scale employed by the patients to weigh their level of QoL changes as a result of accommodating to the new situation. In other words, patients undergo response shift, which means that they change their internal standards, values and the conceptualisation of QoL (Sprangers and Schwartz, 1999). As a result, methods that are used to examine clinically important change in patients overlook the dynamic nature of evaluation process. Through this process patients constantly evaluate and re-evaluate their QoL by putting different weights to various domains of their lives. Like ideas of functioning and well-being, perceptions of QoL may vary over time.

Improvement after an intervention can be attributed to either the natural history of the condition or the effect of the intervention on pathological mechanisms of the disease (Wilson 2000). If changes after the intervention cannot be characterised by any of these possibilities, it can be ascribed to placebo effect as a form of response shift (Brody 1985). Response shift can explain change in health perception despite the existence of any abnormal biological effects. On the other hand, a stable health status in the light of

biological change can also be a result of response shift (Wilson 2000). Although examining response shift has important implications in methodological studies, its significance in self-therapeutic or even self-damaging mechanisms is worth consideration. In respect to clinical effects of response shift, it can therefore be said, that if an intervention cannot generate true change biologically, there is a chance that it can induce a scale recalibration, a change in values and re-conceptualisation (Wilson 2000).

Chapter Three

Methodology and Methods

3.1. Introduction

According to Muldoon (1998), a lack of consensus on the conceptualisation of QoL (Rogerson 1995), as well as methodological limitations and inadequate exercise of operationalism in the area, have confounded interpretation of outcome in measurement of QoL. Furthermore, patient-based information derived from QoL measures in the form of a questionnaire has little or no impact on clinical decision making or change of patient management, given the importance of reflecting individualised views by the measures over time (Greenhalgh, et al. 2005). Although problems associated with definition and measurement of QoL appear ongoing, there has been a slight emphasis towards individuality, from health professionals to patients, with respect to who should be actively involved in measuring QoL (Maynard 1993). This is the case particularly in chronic conditions in which a "holistic approach" is required to detect the worthiness of the intervention (Ebbs, et al. 1989).

There are well-established criteria to evaluate or develop QoL instruments. According to Crotty (1998) whatever approach is used it needs to provide context for the research such as the relevant theoretical perspective or philosophical logic, theory of knowledge and its general basis (epistemology). Research in the QoL measurement area has put little energy into explaining the nature of knowledge and the context for the chosen method.

There are numerous validated QoL instruments used to measure HRQoL and QoL of patients (Bowling 2001). Nevertheless, the structure of QoL instruments and the criteria that are used to develop or validate them such as validity and responsiveness are based on knowledge that represents the positivist paradigm. Despite a great emphasis on

patient-based outcome measures, the clear lack of use of in-depth methods in measurement of QoL has cast doubt on the validity of QoL measures. This routinely draws criticism because QoL is an individual, multidimensional concept with a dynamic characteristic. It means that understanding of QoL and the QoL measure differs between individuals and also changes intra-individually over time, a phenomenon that fails to be addressed by standard methods.

3.2. Justification of the methodology

Biomedical knowledge has a different structure from clinical knowledge (Nederbragt 2000). In biomedical knowledge, evidence from different disciplines is built up on each other and the interaction between these disciplines makes a coherent theoretical construct. However, clinical knowledge is based on the knowledge of the patient and the various domains of the knowledge of the patient and their relative importance compete with each other to construct a balanced structure of knowledge (Nederbragt 2000).

Now the question is: What is the type of knowledge that provides context for QoL outcome measures? Has it got a similar structure to that of the biomedical knowledge or is its knowledge based on the knowledge of the patient? And to what extent can measurement criteria inform us about any type of knowledge?

To investigate the nature of knowledge, I started by reviewing the methods (Background chapter) that are used to assess the measurement properties of the instruments such as responsiveness. For example, the method introduced by Jaeschke and colleagues (1989) and also the approach used by Riddle and co-workers (1998) showed that the knowledge about the responsiveness of the instrument and its ability to detect the MCID over time comes from distinct entities: biological being and

psychological being. Integrating these entities would not give a holistic and humanistic picture of the illness evaluation. Yet, the standard methods for the assessment of responsiveness advocate a dualistic and a mechanistic approach.

Many outcome measures including disease-specific and generic measures consist of items that relate to both body and mind when assessing outcome of a treatment. This means that the outcome measures have kept their distance well from Cartesian dualism, which has the most significant role for the objectivist and reductionist view of the patient (Switankowsky 2000). It is the same approach used by the WHO International Classification of Impairment, Activities and Participation ICDH-2 (WHO 1999) that tries to integrate different dimensions of disablement into a biopsychosocial model. This approach is more likely to fit into Nagel's interactive dualism theory (1986). This view of health care considers both physical and emotional aspects of illness and regards the patient as a dual entity affected by illness (Switankowsky 2000).

The interactive knowledge provided either through a quantitative or qualitative approach appears to give a similar picture to that for biomedical knowledge (Nederbragt 2000). That is, different types of physical, emotional and social knowledge obtained by QoL measures work in agreement and in harmony to give an assessment of perceived QoL, such as the relation between functional limitations, routine function and seeking medical care. It is assumed that the patient's routine function, e.g, returning to work, depends on her or his disability and physical limitations. This functional limitation is the main reason for seeking medical care in the first place (Nagi 1965). Nevertheless, what informs patient's knowledge particularly in measuring change is the diversity and struggle among various domains of life, which their relative importance alters through the course of a disease. This dynamic phenomenon may explain the discrepancy

between clinical evidence of health and patients' own assessment of their health (Daltroy 1999). It elucidates why the general well-being of some cancer patients is better than less severely ill patients or even better than a group of the general population (Cassileth, et al. 1982). Moreover, research shows that patients with a life-threatening disease or a severe chronic illness report a fixed level of QoL during the disease process (Bach and Tilton 1994).

The knowledge underpinning QoL outcome measures has a characteristic similar to the health theory offered by Boorse 1977: "... health is normal functioning, where the normality is statistical and the functions biological" (p.542, cited by Richman and Budson 2000). In this view the concept of QoL has no value inherent in itself and is determined by some values set and judged by health professionals. In contrast, biomedical knowledge has notions of intrinsic values such as normal functioning of heart, kidney and muscles (Richman and Budson 2000). Even those methods in which patients' goals and desires are taken into consideration, the possibility of changing goals and choosing alternative targets over time have been ignored.

The knowledge of outcome measures

The knowledge of outcome measures does not have the limitations of mind-body dualism. It is concerned with objective as well as subjective dimension of assessment. It reflects on both physical and psychological aspects of illness. The knowledge of outcome evaluation is not restricted to body and physical organs, but also pays a great deal of attention to the personal stand point of a health condition. However, we can conclude that there are two major problems regarding the current epistemology that provides knowledge for the responsiveness of outcome measures.

1. Despite viewing the outcome assessment of an illness from various dimensions, physical, psychological, emotional and even social, the discipline individualises each dimension and gives a separate perception of each aspect, as was seen with the methods used for detecting MCID. Integrating these dimensions does not give a whole picture of the QoL of the patient as a person whose goals and objectives change from time to time according to their relative importance.
2. The standards by which the outcome of a treatment is assessed are external standards that are weighed by health professionals and researchers. Thus, the level of QoL of a patient depends on external criteria determined and valued by specific others.

Characteristics of knowledge

Likewise, the evidence on validity of QoL measures yields a kind of knowledge with three main characteristics:

1. A knowledge that represents a single divisible reality. The distinct variables can be studied separately and the accumulated evidence from the variables makes the reality (Lincoln and Guba, 1985).
2. The correlation of a measure with an accepted validated criterion such as a clinical marker is known to be an effective way of deriving knowledge for validating QoL measures (Martin, et al. 1997).
3. Finally, knowledge in the area of QoL is characterised through defining the theoretical concept of QoL by a measurable indicator such as a questionnaire (Rose 1982).

The perceived confidence drawn from the measurement of QoL is mainly misleading, because it is based on assumptions that do not correspond to the fundamental nature of the concept of QoL.

Generally speaking, a distinction can be made between qualitative and quantitative research that has its roots in the nature of theory of knowledge. The dominant feature of quantitative research is theory-testing. The agreed theoretical concepts are put into test by empirical indicators through the processes of "operationalisation" and "instrumentation" (Wengraf 2001, p.56). The qualitative research, however, is characterised by "model-testing" and "model-rectification" through which theory comes out of the empirical work (Wengraf 2001, pp.55, 56).

3.3. Qualitative Research

Doing qualitative research is based on two major models: the inductivist model or the traditional grounded theory model (Glaser and Strauss, 1968) in which the theory emerges from the data. When pre-existing knowledge is used to test a hypothesis, the deductivist model is used (Wengraf 2001). There is a middle way of generating ideas called abductive reasoning (Peirce 1979, cited by Coffey and Atkinson, 1996) in which the data neither disconfirms existing findings, nor can be exactly positioned in current theories. It allows a constant interaction between present knowledge, prior findings and new data (Coffey and Atkinson, 1996).

3.3.1. Validity in qualitative research

It is evident that the research community has a great concern about validity and its assessment. However, the proposed criteria and methods of validation used to legitimise qualitative research are grounded in experiment-based model by which the validity of experimental studies are assessed (Mishler 1990). The new perception of the concept of validity emerged after Cronbach and Meehl (1955, cited by Seale 1999) divided validity into four types: content, predictive, concurrent and construct validity. This approach to validity was followed by studies that proposed other categories for validity assessment. Campbell and Stanley (1966) introduced concepts of internal and external validity. Internal validity is the extent to which the findings of a study are true within a setting and external validity is the extent to which the findings are true in other contexts, a matter of the generalisation of findings. However, Campbell and Stanley (1966) acknowledged that both identification of various threats in a study and examination of those threats from one study setting to another depend on researchers' decision of the relative importance of those threats. Therefore, there is no concrete rule for assessing validity in a particular study (Mishler 1990). Parallel to Campbell's proposal on validity assessment in quantitative approach, Lecompte and Goetz (1982) attempted to apply

this reasoning to qualitative research, while sharing the positivist ontology and epistemology of naive realism and objectivism, respectively. Their idea was to establish replication and convergence through providing full description of a qualitative study such as contexts, methods, field work and theoretical background, so the study could be replicated by other researchers in order to produce the same results. A positivist approach to measure validity was the concept of convergent and discriminant validity (Campbell and Fiske 1959). It underpins triangulation technique advocated by Denzin (1970). Denzin points out four types of triangulation: data, investigator, theory and methodological triangulation. Triangulation is based on concept-indicator operationalism rationale in which concepts are examined by different indicators from different settings. However, adding up data from different sources is unlikely to give a perfect picture of a single reality (Hammersley and Atkinson, 1983). In the post-positivist version of triangulation, however, the idea of convergence has faded and the technique is used to improve the credibility of a study and to increase better understanding of a concept from different perspectives (Seale 1999).

In later studies, Lincoln and Guba (1985) and Guba and Lincoln (1994) rejected realism and developed their own criteria for establishing the trustworthiness of a study based on the constructivist paradigm as a feature of relativism. They replaced traditional criteria of truth value (internal validity), applicability (external validity), consistency (reliability) and neutrality (objectivity) with naturalistic criteria of credibility, transferability, dependability and confirmability, respectively. They also proposed a fifth criterion of authenticity with a relativist view of providing multiple realities within a context, a constructivist paradigm.

Lincoln and Guba suggested member validation as "the most crucial technique for establishing credibility" (Lincoln and Guba, 1985: p.314). Different types of member validation are suggested, among them a weak version such as members' remark on interview transcripts and a strong version like members' assessment of a research report (Seale 1999). The original idea underpinning triangulation and member validation was merging confirming data on a single reality. However, Bloor (1983) and Fielding and Fielding (1986) criticise member validation as a process for validating a research account. They consider it as another source of generating knowledge that provides additional perception for further examination. They question both participants' capability and interest in following a research report that is represented in theoretical language for a research audience. Silverman (2001) takes on the criticisms of triangulation and member validation and reviews some alternative methods such as the constant comparative method, deviant-case analysis, comprehensive data treatment and using appropriate tabulations.

To move away from this naive realism-relativism dichotomy, a mid-way approach called subtle realism was advocated by Hammersley (1992). It means that there is an independent reality and we can know that reality based on a cultural construction whose validity is open to error. In this paradigm, criteria by which qualitative research should be assessed are validity and relevance. Instead of reproducing the reality, the assessment of validity involves representing different aspects of reality, specifying types of claims made by the research and providing sufficient evidence to represent plausible and credible claims. The relevance of a study is concerned with the types of audience that the study may address such as fellow researchers and practitioners. The aim of research should be creating knowledge so some problems in a particular area could be answered,

though it is unlikely that knowledge can bring about fundamental enhancement in practice (Hammersley 2004).

It is worth noting that rejecting objectivism does not necessarily mean setting aside realism, because of the fundamental difference between scientific objectivism and scientific realism. Scientific objectivism is represented only through operationalism that divides the reality into objects and entities. However, scientific realism while assuming a single reality, allows for more than one way of knowing the reality through conceptual approaches (Lakoff 1987, cited by Maxwell 1990).

An alternative approach to assessment of validity was proposed by Miles and Huberman (1994). As a substitute for categorising validity, they divide the research activity into three process of interrelated components of data reduction (coding), data display (creating matrix) and conclusion drawing and verification. For assessing the validity of conclusions, they propose a series of questions as guidelines that represent the five criteria of conventional/naturalistic inquiry (Lincoln and Guba 1985).

If the standard rules designed for experimental model are applied to qualitative studies then many dimensions of evaluation including linguistic features, contexts, and social standards could be excluded (Mishler 1990). Various alternatives to the experimental model have been proposed. For example, both participatory inquiry and the use of exemplars reject application of predefined rules and standards in validation of qualitative research.

Mishler (1990) suggested the role and capacity of exemplars in evaluating the validity of qualitative research from Kuhn's idea of exemplars (Kuhn 1996). Kuhn substitutes

"disciplinary matrix" for the notion of paradigm and defines it as "the full set of assumptions, theories, and practices shared within a community of specialists" (Mishler 1990, p.421). An important component of this matrix is the exemplars that "contain within themselves the criteria and procedures for evaluating the trustworthiness of studies" (Mishler 1990, p. 422). Therefore, it is the researchers' duty to provide clear descriptions of the methods and characteristics of their studies and demonstrate how the study is done and highlight any raised problems, not as "standard rules", but by relying on contexts the process of generating data from observations and the establishment of the analysis and findings should be clarified (Mishler 1990).

The shift from experiment-based criteria with the application of prescribed rules to more experience, contextual-based criteria applicable to a known reality (Mishler 1990) is also seen in the participatory paradigm (Heron and Reason, 1997). The participatory paradigm moves away from the extremes of both naive realism and relativism to an experiential-based realism, which is the basis for presentational, propositional and practical knowing within the paradigm. The presentational knowing in the forms of musical, vocal and verbal art, the propositional knowing expressed by the use of language to describe entities and the practical knowing of how to do things shown in a skill are the symbols of experiential knowing, a direct face-to-face experience (Heron and Reason 1997). The participatory paradigm advocates a subjective-objective reality. In this paradigm the researcher and the researched are part of a unified field of knowingness like the rest of the creation. The reality is structured subjectively whose objectivity is dependent on how it is formed by the knower. The knower is an object who is also known by other knowers. Therefore, knowing is a reciprocal process of consciousness between participants. The ultimate knowing is knowing in experiential

and empirical forms, unlike many other paradigms in which knowing ends by presentational and propositional knowing (Heron and Reason 1997).

"... we can only understand our world as a whole if we are part of it, as soon as we attempt to stand outside, we divide and separate. In contrast, making whole necessarily implies participation: one characteristic of a participative worldview is that the individual person is restored to the circle of community and the human community to the context of the wider natural world" (Reason, 1994, p. 10).

3.4. Research interview

Standardised survey interviewing is differentiated from other methods of interviewing such as in-depth and life story interviewing by epistemology or the theory of knowledge, which in survey interviews is more positivist (Warren 2002). Qualitative and in-depth interviews look for deep knowledge. According to Johnson (2002) "deep" has multiple meanings. It means that the interviewer needs to reach the same level of understanding about participant's experience as the participant. In addition to understanding the experience rationally, it brings to the surface more concealed emotional information that underpins the experience. Moreover, deep understanding uncovers the researcher's own feelings and interests through the way he or she conducts the interview and analyses it. Finally, an event or an experience can be understood and expressed from different perspectives through methods of deep understanding (Johnson 2002). Referring to in-depth interviewing, Wengraf (2001) views depth as either getting more detailed knowledge about something or getting a deep understanding of it.

Mis/tier's critique

Mishler (1986) examines common practice in research interview. In his analysis, he identifies some characteristics of research interviews that are hypothetically taken for granted in the studies of human sciences. Reviewing different definitions of an interview, he illustrates that what it means by an interview is a "verbal exchange" rather

than talk or communication. In that respect, an interview cannot be viewed as a meaningful discourse between two people. For example, according to Oppenheim (1992) "an interview is not an ordinary conversation...Although words and sentences are exchanged in both directions, an interview is essentially a one-way process. Indeed, if it becomes a two-way process of communication...it will lose much of its value because of the biases introduced by the interviewer" (Oppenheim 1992, pp.65, 66).

Mishler's next critique of the accepted approach in research interview is concerned with its basis within an experimental model (Mishler 1990). The experimental model that emphasises on rules and standardised procedures advocates a "stimulus-response" theory. What counts as an unbiased stimulus is a series of questions that are carefully examined in terms of phrasing, ordering, and placement to reduce the possibility of bias as a result of variability of questions and interviewers (Mishler 1986).

The last issue discussed by Mishler (1986) focuses on what is referred to as "de-contextualisation" of the interview, which is seen at the coding process. Participant's responses are interpreted in isolation, while they are detached from the life and sociocultural background of the participant. On one hand, the responses are separated from their ground. On the other hand, "because such responses have no meaning in themselves, everyday contextual understandings are reintroduced, slipped into the analysis through the back door of a coders' subculture" (Mishler 1986, p.5).

Mishler's (1986) argument regarding "de-contextualisation" challenges Tesch's (1990) description of "de-contextualisation" and "re-contextualisation". In qualitative analysis, the data fragments are coded based on predefined categories such as theoretical frameworks and research questions and then meanings are derived from these categories

and applied to the chunks of data. In other words, after de-contextualising the data segments, they are given new contexts through the process of re-contextualizing. This happens through the process of coding in many qualitative analyses.

Bruner (1986) identifies two fundamental human cognition forms: one is the logico-scientific mode and the other is narrative mode. In logico-scientific mode, meaning is constructed while it is removed from the context, while in narrative mode meaning is constructed within the spatial and temporal contexts. We understand the truth in the narrative mode by paying careful attention to components and their relation which makes the whole, while the logico-scientific mode seeks single and universal truth free from time and place.

3.5. Narrative interview

There are extensive models of narrative analysis and different proposed definitions for narrative. Mishler (1995) suggests a typology for the purpose of comparative analysis of narrative. Mishler's typology has three main categories with subcategories in each describing different models of narrative analysis. The core approach in the first category is the association between the temporal order of "the told" or "the actual event" and "the telling" or "the narrative" (Mishler 1995, p.91). Models in category two focus on linguistic features of narratives and their structures. Instead of "reconstructing a told from [a] telling", these models illustrate how a narrator creates his/her life story through selecting and positioning life events to make a sound and rational story (Mishler 1995, p.107). Finally, function, context and outcome of a narrative are the focal points of the models in the third category.

Riessman (1993) assigns five levels in representing a research process. The first level is "attending to experience". It is the immediate experience as an individual lives it and makes meaning out of that event. To transfer the actual experience and its meaning into words, the narrator tells his/her narrative by talking and listening (level 2). A single experience may be represented in different forms if it was told to different listeners. Likewise, the narrator generates a particular self when telling the story to different audience (Riessman 1993). The third level of representation is transcribing the experience. A researcher represents his/her own world view by selecting the way he or she present spoken language into a text, just like photographers who use the photography technology to create varied versions of the same object. Similarly, science has represented the world through naive realism (Mishler 1991). The process of interpretation which has already started in transcribing level, continues in the fourth level as analysing the experience. Through the process of analysis the researcher sums up the identified similarities in narrative accounts and recreates an abstract that is different from the oral stories of individuals (Riessman 1993). Reading experience is the final stage in Riessman's levels of representation. "The meaning of a text is always meaning to someone" (Riessman 1993, p. 15). Therefore, the written text as a product of an interaction between a listener and a talker within a specific setting can be the subject of different interpretations when it is represented to different readers (Riessman 1993).

On the whole, narrative analysis is carried out by focusing on one of the issues of sentence structure, meaning and interactional context, depending on the significance of the issue from the researcher's point of view (Mishler 1986).

3.5.1. Narrative definitions

One of the influential definitions of narrative is from Labove and Waletzky (1997). They define narrative as "one verbal technique for recapitulating experience- in particular, a technique of constructing narrative units that match the temporal sequence of that experience" (Labove and Waletzky, 1997, p.4). The unit of narrative is called the narrative clause. "Any sequence of clauses that contains at least one temporal juncture is a narrative" (Labove and Waletzky, 1997, p.21). From their perspective, a narrative has two complementary functions: referential and evaluative. The temporal order of narrative defines its referential function. The evaluative function refers to "the attitude of the narrator towards the narrative by emphasising the relative importance of some narrative units as compared to others" (Labov and Waletzky, 1997, p.32). However, the core feature of narrative in their analysis is the match between the sequence of events in real life and the sequence of clauses in the narrative account. In other words, their approach to narrative analysis emphasises on a clock-time model where the clauses without a temporal order are defined as non-narrative (Mishler 2005, Personal communication).

While temporal order is the main characteristic of narrative in Labov and Waletzky's model, according to Ricouer (1980), a narrative consists of two dimensions: one is the series of events or "the episodic dimension" and the other is "the configurational dimension". It is through the latter dimension that the plot of a story makes the separated events meaningful. Ricouer's approach puts significant emphasis on the ending of a story as the main factor influencing the formation of a story, "...the story governed as a whole by its way of ending constitutes an alternative to the representation of time... a plot establishes human action not only within time...but within memory. Memory, accordingly, repeats the course of events according to an order that is the counterpart of time as stretching along between a beginning and an end" (Ricouer 1980,

p.180). While acknowledging the mutual link between temporality and narrativity, Ricouer (1980) distinguishes between "within-time-ness" and linear time. Unlike linear time, within-time-ness is not characterised by a series of impartial events following one another along an unrealistic line in one direction. Narrative stories happen while "being in time", which is different from the notion of time as a measurable interval between events (Ricouer 1980).

Highlighting the perspectives' of these two leading narrative theorists, Mishler (2005, Personal communication) examines the clock/chronological model of time versus experiential/narrative model of time in studies of narrative. He points out that the chronological model of time as a "linear succession of instants" (Misher 2005, Personal communication) is embedded in most human sciences where concepts such as change and identity development are studied. It is assumed that initial tests in longitudinal pre-post study designs are independent from follow-up tests and are not affected by over-time changes. The use of the linear temporal-order causal model is justified in the physical world. The constant process of reinterpreting and redefining life events and endless process of revising life stories, nonetheless, require a different model from the clock-time model (Mishler 2005, Personal communication).

Mattingly (1998) proposes six features for the narrative time (Ricoeur 1980, Mishler 2005, Personal communication). She emphasises the contrast between linear time and narrative time to make the concept of plot more explicable. The role of a plot is to arrange a sequence of events, as the characteristic of linear time, into a meaningful whole. The significance of each event is determined by its presence within this narrative arrangement (Ricoeur 1980, Mattingly 1998). The six features of narrative time as described by Mattingly (1998) are:

1. Narrative time is controlled by plot. Although the events have their own transparency, their relation with the plot forms the narrative. In other words, it is based on an ingredient-recipe structure. While each ingredient has its momentous place, narrative comes into sight through the recipe as a whole.
2. Narrative time is structured by human aim and intention. From biomedical perspective, the goals of an individual as an organism is different from the motives of an individual as a person and these goals are different from person to person (Richman and Budson, 2000). In biomedical time, therefore, the individual is dominated by the centrality of the disease and pathology, while in narrative time the individual has a role as an active agent (Sacks 1985, Cited in Ryan 1999).
3. Narrative time is overseen by desire. The meaning of the present is formed by the past and a vague future. Longing for a certain future and fear of another, gives the present a dynamic feature that is being inspired by the future.
4. Change is an indicator of narrative time. In narrative, particularly when people are threatened by a disease or a change in their health condition, they may modify their viewpoints based on their realisation of the imposed limitations. People change their principles, values and even interpret a concept of interest differently in the wake of a health change (Sprangers and Schwartz, 1999).
5. Narrative time is characterised by inconsistency and contradiction. This contradiction is a result of the nature of actions in narrative that are associated with desire and motivation. The stronger the desire, the more likely it is to create tension between different points of views either between agents or within the same agent.
6. Narrative time is uncertain. As the meaning of the present and the past are dependent on what the future brings, they are not viewed as facts but possibilities. The ending of a story is always subject to anticipation, because a desired outcome may not happen and or one may change his/her desire as the story develops.

Mishler (2005, Personal communication) examines the narrative time model in more detail by raising a discussion on one aspect of life history narratives that can be observed regularly in studies of narrative. It is referred to as "turning points". Sometimes an event in life brings about changes in how people think and feel about their past experiences. In the light of that event, they revise their experience, redefine some concepts related to that experience, and recreate new meanings of their past. By telling their story over again on account of turning points, they establish a new identity for themselves while maintaining a connection to their multiple identities (Mishler 2005, Personal communication). Each identity derives from a particular relationship with others in a specific context. The concept of "multiple identities" challenges consistency

in our life narrative and coherence in meanings of life experiences which are central to the critique of linear time (Mishler 2005, Personal communication).

3.6. Transcription

Analysis of narrative starts with transcribing the narrative as an "interpretive practice" rather than a "technical procedure" (Mishler 1991, p.259). A growing number of researchers now use transcription objectively with emphasis on details and precision of the procedure. For example, conversation analysts with emphasis on length of pauses and overlapping talk apply a detailed and standard approach to transcription (Silverman 2001). However, interest in transcription as a technical and standard procedure raises problems associated with language-meaning relationships and reality-representation relationships (Mishler 1991).

Computer-aided qualitative data analysis programmes

There has been a growing interest in the use of computer-aided qualitative data analysis software. Networking projects such as seminars and workshops provide support, training and information in the use of software programmes designed to assist qualitative data analysis. Nonetheless, there are concerns on whether computer software facilitates or hinders the process of qualitative research. Dainty and colleagues (2000) and Blismas and Dainty (2003) refer to two characteristics of qualitative data: 1) large volume, 2) lack of methodological precision and accuracy. Many researchers adopt computer software packages to address these two issues in order to aid and speed the research process and to avoid methodological bias and subjectivity associated with qualitative data. Researchers, however, need to rethink what is meant by qualitative data and its features. It is the rational of positivist paradigm and quantitative research that a larger sample will give a better representation of a population (Oppenheim 1992). The lack of clear understanding of a sample size in qualitative research, has restrained

researchers to follow the principal line of quantitative research in choosing samples (Morse 1991), resulting in a large volume of unstructured data. A large amount of data does not necessarily lead to a deep understanding of the experience, which is the main purpose of qualitative research.

Sampling in qualitative research is varied and complex. Two main methods of sampling in qualitative research are theoretical sampling and purposeful sampling. Glaser (1978) defines theoretical sampling as "the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides which data to collect next and where to find them, in order to develop his theory as it emerges" (Glaser 1978, p.36). According to Patton (1990) the "logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling" (Patton 1990, p. 169).

Qualitative research seeks for rich information and thus small samples and even single cases can provide sources of data (Patton 1990). The sampling strategies in qualitative research have granted researchers a privileged position in relation to participants and lead the qualitative research in one direction, through which the researcher obtains rich information from the informants. In other words, by the means of sampling strategies the research process is determined by the researcher's theoretical standpoint. There is, however, a great difference between "deep understanding" and "rich information" as differentiating features of knowledge in qualitative research. In contrast to seeking rich information, the notion of "deep understanding" transforms the qualitative research into a dynamic and interactive process, through which meanings are constructed as a result of mutual understanding between two parties (Johnson 2002). The notion of "saturation"

ascribed to theoretical sampling (Glaser 1992) reflects the emerging theory and how different categories based on the researcher's theoretical views are provided with data.

In qualitative research and in particular in narrative research meanings are constructed contextually and interactionally (Mishler 1986). Therefore, what counts as methodological bias in quantitative research can be viewed as central to qualitative research stance. One of the advantages of computer aided qualitative research software is coding, re-coding and linking codes to chunks of data (Coffey and Atkinson, 1996). This process of de-contextualisation can force predetermined categories into the study. The chunks of data are coded based on the researcher's theoretical framework and thereby they are shifted into newly created contexts (Mishler 1986). This problem is reinforced by the codification process of computer-aided programmes that over code data by allocating numerous codes to segments of text (Blismas and Dainty, 2003).

Moreover, computer-aided programmes designed for qualitative research analysis impose restrictions on representation approaches that are available for qualitative research. The crisis of representation, that is to what extent a text can represent a lived experience has created many problems in qualitative research (Denzin 1994). Reliance on computer-aided programmes indeed hampers the array of methods that can be used to represent an experience. For example, methods exploring oral discourse rather than written texts such as Gee's sociolinguistic model for the analysis of oral narratives (1991) use changes in pitch and intonation as well as thematic changes to organise a discourse. Organising a discourse thematically and linguistically, researchers would experience restrictions using computer-aided programmes. Paget (1995) used theatre to recapture the experience of a patient-doctor encounter. She represented the text as onstage performance, because she believes that the written text is not the real text but an

interpreted version of the experience. The performance was able to represent the patient-doctor communication as it happened in real life, a communication between "the one-who-would-not-listen and the-other-who-was-not-heard" (Paget 1995, p.236). In short, computer-aided programmes restrict the researchers to analytical limitations starting with restricted approach on representation process.

Transcription involves the translation of an oral discourse into a written text, which cannot represent the reality (Miller and Crabtree, 1999). Mishler (1991) used two different structural units to analyse a piece of medical interview between a physician and a patient. First he organised the discourse based on the physician's questions and the patient's answers. Then he reframed the discourse in terms of two voices: voice of medicine and the voice of the lifeworld. Acknowledging these two voices as the basic analytical unit of the transcription, Mishler (1991) gave both similar analytical significance. Arguing from the stance that both voices have the same influence on the analysis, a medically dominated interview can be viewed as a more balanced discourse between physicians and patients.

This view calls attention to the significant role of the interviewer and why it must be taken into account. Furthermore, it leads us to come to understand the nature of narrative accounts as interactionally constructed (Mishler 1997). Mishler (1997) examines the dominant text-based model in analysing narrative studies. Regardless of the context, the model assumes one version of the story that is told in response to the interviewer's question. The model overlooks the dynamic process of story telling through which an account is generated as a result of an interaction between an interviewer and a participant within a specific context. Supportive of this view, Mishler (1997) regards a narrative account as one "retelling" among many stories a narrator can

produce in collaboration with an interviewer. Therefore, what is seen as a story varies across different contexts and with different interviewers (Mishler 1997, p.239).

The initial definition of interview is central to the approaches we take in terms of conducting interviews, transcribing oral speeches into a written texts and analysing accounts. For example Mishler (1986) defines interviews as speech events and from there a distinction is made between "the standard antilinguistic, stimulus-response model" and a different model to interviewing as "discourse" (Mishler 1986, p.35). The standard model of interviewing relies on predetermined interview schedules in the form of some questions. The respondents' understandings of the questions, however, vary widely across them. This would jeopardise the standardising procedure to generate similar responses in respondents (Oppenheim 1992). Moreover, there has been a tendency among interviewers and within the same interviewer that despite having the interview schedule as text, they do not adhere to the questions as it appears on the schedule (Mishler 1986). Making problematic the departures from the interview schedules by the interviewers as well as variations in perceived meanings of the questions by the respondents, Mishler points out: "Rather than serving as a stimulus having a predetermined and presumably shared meaning and intended to elicit a response, a question may more usefully be thought of as part of a circular process through which its meaning and that of its answer are created in the discourse between interviewer and respondent as they try to make continuing sense of what they are saying to each other" (Mishler 1986, pp.53, 54). The purpose of life story interviews is to provide the participants with the option to tell their stories in their preferred ways (Atkinson 2002). In a life history interview with a woman potter, Mishler (1997) did not have a list of clear questions prior to the interview. The story as well as the study itself was constructed over the course of the interview interactionally. In discourse, through

reframing the questions and answers continually, the interviewers and the participants reach the point that they have the same understandings of meanings. One conclusion to be drawn is that the emerged themes from a discourse have multiple, fluid meanings that are grounded contextually (Mishler 1986). "... discourse is a multi-faceted public process through which meanings are progressively and dynamically achieved" (Davies and Harre, 1999, p.35).

Researchers continue exploring different approaches to find better ways of representing lived experience than written texts. Characterising scientific texts with "distance, dispassion and objectivity", Paget (1995, p.224) had a patient-doctor interview performed onstage to represent a "science with a small 's'", a human science, sensitive to dialogue, social context and life experience" (Paget 1995, p.225). Performance with its ability of multiple interpretations explains any changes in an event. For example, it would justify a different outcome for an interview if the participant was a person from a different ethnical background, the ability which social science texts are not privileged with (Paget 1995).

Briggs-Wengraf's model of components of an interview is shaped by a particular model of "human inter/subjectivity" involving reciprocal evaluation and exchange of emotions (Wengraf 2001, p.46). The model consists of two major parts: the part that constitutes materials related to the communication process itself including encoding and decoding of the interaction through verbal and non-verbal communication. As a result, a topic or a referent can be understood similarly by the interviewer and the participant. The other part of the model involves the background and social roles of both the interviewer and the participant which influences their objectives and approaches for the interview. These

factors in turn affect the power struggle over the course of the interview between the interviewer and the participant (Wengraf 2001).

Summary

Generally speaking, the nature of knowledge in the measurement of QoL is based on concept-indicator theory. The theoretical concept of QoL is operationalised through empirical indicators such as questionnaires. However, the current approach to the measurement of QoL does not correspond to the dynamic nature of QoL. The lack of in-depth qualitative methods in the measurement of QoL can put the validity of QoL measures in jeopardy. Despite great concern about validity and its assessment, most current methods that are used to validate qualitative research are based in positivist paradigm. In narrative interviewing as opposed to survey interviewing meanings are constructed contextually and interactionally. Such characteristics have made the role of interviewers and their relationship with the participants more significant. In other words, stories change when they are produced in different contexts and in relation to different audience. Of interest here is the meaningless application of methodological considerations that seek to reproduce the same or similar data through providing full description of a qualitative research. The problematic issue of representation including transcription has raised questions regarding the link between the written text and the lived experience and to what extent a text can portray an experience. The use of computer-aided programmes in qualitative research inhibits researchers to limited analytical methods, particularly in respect to the dilemma of representation. In the light of the flaws associated with written texts, researchers examine various ways of representing their data other than texts.

3.7. Methods

This study examines the congruence between patients' expectations of outcome from hip replacement related to QoL and data collected with three standardised measures (Appendix 3).

- The UK SF-36 (Jenkinson, et al. 1996), a generic instrument recommended as the generic core in disease-specific batteries of health related QoL.
- The disease-specific Oxford Hip Score (Dawson et al. 1996a).

These measures apply pre-defined concepts to patients. Taking account of individuals' perspective and concern requires measures that are sensitive to the effects of hip replacement on individual QoL. So called individualised measures give patients an opportunity to show a preference for domains of concern. For this reason, they may have high content validity (Fitzpatrick 1998a).

- An individualised measure, the Patient Generated Index (PGI) (Ruta et al. 1999).

This project is related to the Exeter study, a country-wide project collecting data from THR patients, which has previously received ethical approval (Hamer/NS99 3 446). Post-operative patients were purposively sampled (Patton 1990). The arthroplasty nurse specialist in the assessment clinic who collected the SF-36 and Oxford Hip Score was asked to select patients who were able to explore their experiences and express them verbally (Table 3.1.). Apart from being a minimum of one year and a maximum of two years post operative, no criterion (e.g age, gender) was specified. It might be argued that the sample was self-selected, which would open the findings to bias if data had been grouped or aggregated for statistical manipulation. However, these participants provided personal individual data and were never considered or treated as a representative group.

Data from five participants were not included in the analysis. The first interviews with two of the participants were conducted at the presence of their partners. The participants' partners were also involved in the generation of the data. One participant was admitted to the hospital at the time of the interview and the interviews with the other two participants did not produced narrative text. These five accounts can be considered as deviant cases in relation to the method used in the study and can be analysed for further study within a comprehensive data analysis approach (Silverman 2001). As a result the participant group consisted of thirteen women and seven men aged 44-83 years, with a range of 39 and a median age of 68.

	Gender	Age	Marital status	Employment
C	Female	64	Married	Retired (PE teacher)
T	Male	51	Single	Employed
E	Female	62	Married	Retired (News agent)
V	Male	69	Married	Retired (bus driver)
W	Female	79	Married	Retired (housewife)
O	Male	73	Married	Retired (policeman)
M	Male	50	Married	Business
F	Male	67	Married	Retired
Q	Female	83	Widow	Retired (housewife)
I	Female	44	Married	Employed
D	Female	50	Married	Teacher
H	Female	75	Widow	Retired (hairdresser)
L	Female	79	Widow	Retired (housewife)
U	Male	61	Married	Retired
R	Female	60	Married	Housewife
X	Female	77	Widow	Retired (shopkeeper)
S	Female	71	Widow	Retired (housewife)
P	Female	74	Married	Retired (housewife)
Y	Female	69	Married	Retired (hospital worker)
K	Male	49	Married	Mechanic

Table 3.1. Characteristics of the participants

Therefore, narrative interviews and QoL measures in the form of disease-specific, generic and individualised formed the data sources.

The first interviews were conducted in a hospital environment with patients who had undergone THR surgery and had attended the reassessment clinic one or two years post operation. As the first interviews were conducted in a clinical setting, the participants expected a medical encounter that routinely seeks to evaluate patients' physical and functional performance. Before the interview, the participants were given the UK SF-36 (Jenkinson, et al. 1996) and the Oxford Hip Score (Dawson et al. 1996a) by the arthroplasty nurse specialist as generic and disease-specific outcome measures in the form of self-administered questionnaires. In addition, in this study the PGI (Ruta et al. 1999) was used as a facilitative tool before the narrative interview by the permission of the author (Appendix 2). It gave the participants a relatively familiar picture of the interview. The same approach was used in a study by McMurray and colleagues (1999) in which they used the Oxford Hip Score as a prompt for collecting qualitative data.

The UK SF-36 is a self-administered questionnaire that takes 5-10 minutes to complete. Slight changes of wording in the original SF-36 were made to make it suitable for use in the UK (Jenkinson, et al. 1996). Its single multi-item scale measures eight dimensions:

1. Physical functioning
2. Role limitations because of physical health problems
3. Bodily pain
4. Social functioning
5. General mental health
6. Role limitations because of emotional problems
7. Vitality (energy/fatigue)
8. General health perception

There is also an unsealed transfer question asking respondents about health change over the past year. Scores for each of the dimensions are summed and scale scores have a range of 0-100 from 'poor health' to 'good health' (Jenkinson, et al. 1996).

The Oxford Hip Score is a 12-item questionnaire that is administered by practitioners to patients having THR. The items are summed to produce a single score with lower score reflecting a higher level of QoL (Dawson et al. 1996a).

Ruta and colleagues (1994) developed the PGI to investigate patients own definitions of HRQoL. They are asked to nominate the five most important areas of life affected by their medical condition and then to rate them on a scale of 0-100, with 0 representing the worst they can imagine for themselves. They are finally asked to "spend" 60 points across one or more areas to representing the relative importance of potential improvements. Assessors generate an index by some multiplication.

A new version of the PGI (Ruta, et al. 1999) is easier for users to complete, particularly when self-administered. The new PGI is completed the same as the original PGI and only in stage two the patients are asked to rate their condition on a scale of 0-10 and stage three asks patients to spend 14 imaginary points to show which areas they would most like to see improve.

The design of the initial interview question was taken from (Wengraf 2001, Fischer-Rosenthal 2000). The first interview started with the initial single question aimed at inducing narrative: "Please tell me about your experience of your hip condition and the treatment you received for it and how things happened up to now. Start wherever you

like and take the time you need". The initial question focused on a special topic of the hip condition. Wengraf (2001) defines a narrative question as one which "aims to induce a narrative response and to discourage a non-narrative response, such as the production of a theory, an argument, an unhistorical description, a justification, a declaration of official values, an expression of felt emotions, etc." (Wengraf 2001, p. 127).

The participants were not given any direction to the interview. However, verbal and non-verbal supports were given to encourage a narrative response. My aim was to take them back to their experience of hip condition. Verbal supports included questions such as: What was that? Why? How come? Or phrases such as: That's interesting. Please tell me more about it. Non-verbal communications constitute of supportive and attentive body language. According to Mehrabian (1971, cited by Pease 1997) a communication consists of only seven percent words, the rest includes 38 percent tone of voice and sounds, and 55 percent of a communication is carried out non-verbally.

Acknowledging the inadequacy of verbal communication and viewing the non-verbal part as important as the words, I conducted the narrative interviews by paying attention to my body language during the course of the interviews. My hands, arms, body, and legs gestures were associated with positive and honest attitudes and were consistent with my verbal communication (Pease 1997). As open palms indicate an open and positive attitude I avoided positions such as clenching hands. My palms were open or sometimes in a vertical position showing my confidence in what I was doing. Similarly, as folded and cross arms show a negative, nervous and defensive manner, to get a positive message across, I positioned my arms on the arm rests or I used a vertical position of both hands and arms. With respect to my legs, my legs and ankles were not

crossed, only one leg slightly forward, because cross-leg gestures are signals of making barriers and defensive attitude, particularly a 4 shape position indicates an argumentative attitude. For my body, I sat down slightly leaning forward and my neck in a neutral position. On the whole, my attempt was to use a gesture cluster to send open, honest and positive attitudes and to avoid power imbalance between the participant and myself (Pease 1997). By doing this, the dominant role of the interviewer in traditional research interviewing is reformed and the focus is pointed toward sharing more power with the participant (Mishler 1986). All these positive body language (Pease 1997) is what Wengraf (2001, p.128) calls "an attentive listening posture". I also maintained a good level of eye contact as "the social gaze" with the participants during the interviews. It means that by looking at the participant's face below the eye level between the eyes and the mouth an impression for a social interaction is built up (Pease 1997).

The second interviews were conducted with nine participants who agreed to take part in a second follow-up interview. To elicit more narrative, the follow-up interviews, which took place in participants' homes started with this question: Would like to tell me more about your experience of hip condition or add anything else to what you told me before? Following the first question I asked the participants two different kinds of questions with two main purposes:

1. To encourage them to tell more about the themes that were raised in the first interview.
2. To explore the participant's values by asking questions to get at evaluation (Rowe 1988).

By means of evaluation questions the interviewee's standards and values can be revealed and to what extent these standards and values have changed over the course of a disease can be examined (Sprangers and Schwartz, 1999). As a result, I did not have a

set of predefined questions as an interview schedule in advance. Instead, my attempt was to elaborate on themes and subjects which were raised by the participants and ask about their topics of interest.

The research questions based on my theoretical perspectives were formulated before the interviews. The research questions, however, were not asked in the same wording as appeared in a text. Although aspects of life such as values, feelings, choices, job, attitudes, relationships, activities and appearance were explored during the interviews, the questions were not verbalised previously, because central to my argument is that meanings are constructed within the context. Questions on interview schedules allow participants to categorise only those answers that are indicators of the researcher's theoretical views (Mishler 1986).

Rapport was established during the first interviews and was developed during the follow-up interviews. With the type of the initial question as narrative-induced and open ended, I provided a calming context in which the participants were able to talk about their experiences. In the same way that predefined questions can get in the way of constructing meanings in narrative interviews, so also can the objective, out of context responses from the interviewer lead the participants in the direction of researcher's theoretical perspectives. So instead of prompting them with my own words, I either sought to elaborate on their personal language or communicate through a positive body language and active listening techniques. I used this approach as a way of addressing apprehension in the process of rapport (DiCicco-Bloom and Crabtree, 2006). In other words, rapport was established more effectively when the participants received contextually dependent responses. Advanced stages of rapport such as exploration, co-operation and participation (DiCicco-Bloom and Crabtree, 2006) were developed

mostly in follow-up interviews when the participants were engaged in the telling of their stories. It was through these stages that a range of activities including obtaining information, exploring the raised topics, sharing and understanding experiences took place (Rubin and Rubin, 1995). By establishing a "rapport-talk"/"private speaking" rather than a "report-talk"/"public speaking" (Tannen 1990, pp. 76-77) meanings were constructed within a particular context and in relation to two persons. The interview sessions were ended by the participants with expressions such as "that's it really", though I made sure the endings are genuine by my last question as "Is there anything else you'd like to talk about"? Long pauses and silences were not treated as signals to end the sessions (Wengraf 2001), but rather as opportunities for the participants to talk (Mishler 1997).

In terms of its basic paradigm, the types of methods used for data collection and data analysis, the role of researcher and the participants and the extent of individuals' participation (Zarb 1992), the study is a halfway research project between a participatory inquiry which involves the full involvement of participants in the study including the research design (Heron and Reason, 1997) and standardised approach to interviewing that impose pre-defined proposals to participants. The aim of the study was to renovate the traditional roles of interviewers and interviewees (Mishler 1986). Although participatory research involves a wide range of approaches, according to Cornwall and Jewkes (1995) it is based on the attitudes of the researchers rather than the methods that has a great impact on the balance of power through a research process. This is in accordance with the fifth wave of public health intervention, which as a balanced movement will be based on participation, care and compassion resulting in empowering the individuals (Lyon 2003).

The use of strict and firm methods can lead to power imbalance between researchers and participants and results in participants' exploitation (French, et al. 2001). According to Zarb (1992) the ideology of objectivity can create a positivist or quasi-positivist perspective out of individuals' own accounts of a concept through the methods that are used to collect, analyse and present data.

Studies with a participatory nature can act as facilitators for emancipatory research. Empowerment of individuals including their involvement in research is a "prerequisite to emancipatory research...also...is only a step on the way towards the development of a paradigm for emancipatory research" (Zarb 1992, pp.128, 129). The outcome of emancipatory research is about more fundamental changes in society including participants' liberation of social obstacles and inequalities (French, et al. 2001). The elements of emancipatory research are central to the social model of disability. In contrast with the dominant individual model, the social model is grounding the roots of impairment and disability and their imposed limitations on individuals within a variety of social origins such as attitudes and the power relations (French and Swain, 2002). On the whole, knowledge generated in standardised research interviewing as the conventional approach to the measurement of QoL is grounded in biopsychosocial model (Engle 1977), while participatory research and emancipatory research are subsumed under holistic model and social model of disability, respectively (Figure 3.1).

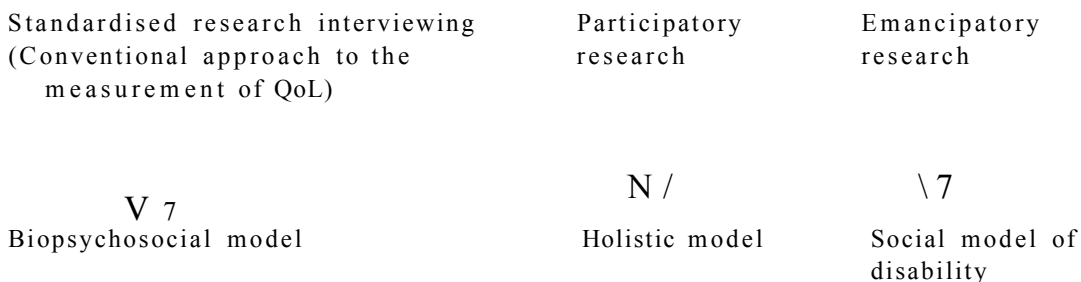


Figure 3.1. Models underpinning different research approach

After each interview, my experience of the interview in terms of observations, feelings and thoughts were put into words. In other words, I made debriefing notes (Wengraf 2001) or field-notes (Sanjek 1990) (Appendix 4).

The interviews were tape-recorded and transcribed (Appendix 5). Hearing the interviews for the first time triggered some memories and ideas that result in reflecting on the interviews. I put in writing my perceptions of the interviews as I was prompted by hearing and re-hearing of the interviews (Wengraf 2001). There is no clear way of representing a lived experience. For example, the so-called relation between written text and oral narrative has created representation problems (Denzin 1994). As a result, I used different methods to produce a transcript (Appendix 6), "because there is no universal form of transcription that is adequate for all research questions and settings, the criteria for choice are theoretical concerns and practical constraints" (Mishler 1986, p. 49). The transcriptions were sent back to the participants to check their comments on the accuracy of narrative accounts (Seale 1999).

3.7.1. Content and framework analysis, (De- and re-conceptualisation)

Wengraf (2001) distinguishes the theory language used in research questions from the interview language used in interview questions. This distinction has its roots in instrumentation theory introduced by Rose (1982), which is based on concept-indicator relationship. The revised model of instrumentation as Rose-Wengraf model (Wengraf 2001) involves theoretical concepts in the form of research questions to be assessed by practical indicators such as interview schedules and interview questions. The measurable variables are defined through the methodology, methods of data collection and data analyses. In other words, they are described through the process of operationalisation.

It seems that the instrumentation theory (Rose 1982) also dominates the coding and interpretation process in qualitative analysis. For example, the coding approach employed by Coffey and Atkinson (1996) follows the same process, however, in an opposite direction. It means that we start with identifying the themes related to the original data (interview themes) and connect them with wider systematic concepts (theoretical themes). I applied Coffey and Atkinson's (1996) model of coding to summarise the interview accounts, segment the data and code the segmented data. By using this approach, I was able to compare themes at the theoretical level and examine similarities and contrasts between the accounts.

First I identified themes that were specific to a particular interview account. The generated categories were related to the interview language of the participant (de-contextualisation). Examining the interview accounts systematically, I compared the accounts in terms of similarities and differences. This resulted in producing categories that were related to the research or theoretical language of the study. The theoretical categories implied general topics concerned with the conceptual framework and the research questions. New contexts were introduced to the interviews by the theoretical categories and moved the interviews to the broader analytical prospects (re-contextualisation). The chunks of data were displayed under theoretical categories.

Other than attending to the technical process of transcriptions such as pauses, repetitions and tones (Riessman 1993), I used a linguistic approach (Gee 1991) to represent the interviews and subsequently analyse them. I applied this approach to two interview accounts as case studies and related it to the rest of the narrative accounts. The case study as a method of analysis is supported by Karl Popper's notion of "falsification" (Popper 2002). What characterises the case study is "falsification" rather than

verification. The logic underpinning the "falsification" test is that if an observation does not fit with a scientific proposal, the proposal loses its validity and needs more examination. The reductionist approach of standardised measures loses the rich variety of individuals, whereas the two participants who were selected for the case study had maximum variation in terms of gender, background, and the life circumstances. The type and number of coping strategies employed by these two participants were also different. As a result, they were well suited for obtaining important and diverse information.

Choosing spoken discourse rather than text, Gee (1991) applied a linguistic approach to the analysis of narrative. Gee (1991) defines the basic unit of analysis as "stanza". "A stanza is a group of lines about a single topic, each stanza captures a single vignette. Each stanza is a particular take on a character, action, event, claim or piece of information, and each involves a shift of focal participants, focal event, or a change in the time or framing of events from the preceding stanza" (Gee 1991, p.23). Stanzas are separated from each other by "topic chaining" or returning to the main discourse topic and rhythmic or semantic patterns of words such as repetitions and dysfluency (Gee 1991). Table 3.2 shows the transcription principles applied to the interview accounts (Silverman 2001, Gee 1991, Riessman 2002).

Symbols

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CAPITAL LETTERS

Stanzas

Definitions

Participant

The interviewer and the prime researcher

Overlapping talks

Author's descriptions

Inaudible words

Loud voice tone

Snap shots (scenes) distinguished by changing characters, action, event, claim, piece of information, time or framing of events, dysfluency, repetition (Gee 1991)

Table 3.2. Transcription principles

I arranged the stanzas as separable snap shots into different scenes (Riessman 2002). I organised the narrative account into different episodes. For example, for the participant S, the interview includes seven episodes, each telling a story and a separate section named off main line of plot. The off main line of plot includes states, repeated events, habitual events and generic events (Gee 1991). Gee's (1991) strategy of transcription prepared the ground for my chosen method of narrative analysis as performance.

3.7.2. Performance analysis of narrative

Analysis of narrative as a "performance" challenges "static conceptions of identity ... that assume the unity of an inner self" (Riessman 2002) against the concept of identity as a "performative struggle over the meanings of experience" (Langellier 2001). By focusing on two theoretical approaches, narrative positioning (Bamberg 1997) and the use of grammar of helplessness and abnormality (Capps and Ochs, 1995), Riessman (2002) analyses personal narratives as the performance of identity. As Bamberg (1997) points out: "People position themselves in relation to one another in ways that traditionally have been defined as roles. More importantly, in doing so, people produce one another and themselves situationally as social being" (Bamberg 1997, p.336). To apply the concept of positioning to the analysis of narrative, we need to answer the questions that attempt to clarify the position of characters in relation to one another and to the narrator, the position of the narrator to herself or himself and the position of the narrator to the listeners or audience (Bamberg 1997). In doing narrative positioning approach, linguistic features employed in the narrative play a crucial role to see how the story characters perform their preferred identities (Langellier 2001). Therefore, this requires careful consideration of how the narrator grammatically constructs each part of the story in terms of the word structures, the words relation in a sentence and how the words are said regarding their sound (Capps and Ochs, 1995).

Validity of the study

Three methods were used to test the validity of the study: methodological triangulation (Denzin 1978), member validation (Seale 1999), and using tabulation (Silverman 2001). Methodological triangulation involved quantitative methods as well as qualitative methods with the latter as the main method of data collection. The participants were given the SF-36, the Oxford hip score and the patient generated index. Member validation, the weak version, consisted of participants' remarks on the interview transcripts. Finally, simple descriptive statistics were used to represent large amount of narrative accounts.

Summary

The study takes on the standardised approach to interviewing, which underpins the measurement of QoL. Standardised questionnaires in the form of generic measure of QoL, disease-specific measure and individualised measure were administered to the patients who had undergone THR surgery. The instruments were compared with each other and with the data generated from narrative interviews in terms of the structure and the meaning. The study examines the major difference between standardised instruments and narrative interviews regarding meaning and context. Pre-defined list of items on standardised questionnaires give participants an opportunity to select categorised answers that correspond to the researcher's theoretical perspective. The same or similar process occurs when participants are encountered with questions on interview schedules. The researcher's theoretical views are also entered into the study through the coding process in which new contexts are created. The new introduced contexts are defined through the researcher's cultural and theoretical background.

The narrative interviews were conducted at two different points in time. The initial question was designed to induce narrative. Although different aspects of participants' life including values, feelings, job, attitudes and relationships were explored during the interview, the study's theoretical framework in the form of research questions was not tested by pre-determined interview questions. In other words, the interviews were not guided by an interview schedule, because the major argument of the study focuses on narrative analysis as a way of constructing meanings contextually and interactionally and the implications of these concepts on the measurement of QoL over time. As non-verbal communication is as important as verbal communication, supportive and attentive body language was maintained during the course of the interviews.

The interviews were transcribed and the narrative accounts were summarised. The interview themes and the theoretical themes were identified based on the instrumentation theory and data segments were displayed under theoretical categories.

Knowing the inadequacy of written texts for representing lived experience, I applied Gee's linguistic model to represent a narrative account. Moreover, as there is a fundamental difference between oral stories and written stories, I applied "positioning theory" to analyse the narrative account as the "performance of identity".

Chapter Four

Findings and discussion

4.1. Introduction

Our understanding of knowledge and its validation differs as we move from positivist paradigm to "post"paradigms including post-positivist and post-modernist (Polkinghorne 1997). My approach to reporting the research reflects a certain epistemological standpoint through which the nature of knowledge is understood and is validated. Choosing a narrative format for reporting the research, I challenge the fixed methods within a positivist paradigm in which the validity of research is detached from the researcher, the researched and the audience to whom the research is presented (Polkinghorne 1997). Polkinghorne (1997) argues the diachronic nature of narrative reporting. From a diachronic perspective, a research project is a series of temporally ordered human actions that are related to each other and are the product of the researcher's actions, decisions and interactions with participants over the course of the research. By reporting the research process in a narrative format, the generated knowledge and its meaning would be the outcome of the actions undertaken in the research process over time. "By changing their voice to storyteller, researchers will also change the way in which the voices of their subjects or participants can be heard" (Polkinghorne 1997, p.3).

In presenting the research report, I have three roles as the author of the text (Tierney 1997):

1. The interviewer: my role is more significant than my individuality as a person.
2. The narrator: as a first person narrator my involvement in the creation of the text is indicated.
3. The participant: I am involved in the research as a human being with all the emotions, thoughts and interests.

These roles are in proportion to the concept of linear time in producing research reports in which the text has a chronological order corresponding with how the author is presented in the text (Tierney 1997). However, within a conventional format the author with an omniscient voice collects and presents the data without having a role in creating the reality, while disregarding the temporal order of the research process (Tierney 1997).

My approach in presenting the research report reflects the attitudes towards the project audiences. Lincoln (1997) refers to the audiences of research projects as "stakeholders", in order to identify them more easily. These include the participants in the study, those who may or may not benefit from the research, the researcher, and those who provide funding for the study. The potential "stakeholders" guide us to particular audiences. This study is a self-funded project. Therefore, the main stakeholders and subsequently the main audiences of the research are the researcher, the supervisors, the examiners and the participants and the study is the result of meaning construction between them. Accordingly, I was not afraid to demonstrate my personal self in the text in terms of my feelings, changes in my feelings, thoughts and my interests (Lincoln 1997).

Other than a narrative format for representing the research, I also presented the research findings in a more definitive and typical format to establish a relationship with research and clinical audiences who are interested in more pragmatic outcomes. Challenging the standardised outcome measures as constructs of researchers and clinicians' perceptions, I could not get away without proposing an alternative measure, which is a construct of patients' perceptions. Despite categorising the themes and relating them together to make an instrument as typical practice of "paradigmatic" or "logico-scientific" mode of thinking (Bruner 1986, p. 13), I did not follow the "hypothetical-deductive" process of generating knowledge in the positivist paradigm (Polkinghorne 1997). The adapted

presentation formats consist of a classic format and a narrative format that serve the process of discovery rather than the process of justification over the course of the research (Polkinghorne 1997). Participants' perception of hip condition and THR was also examined by the standard approach of patient-based outcome measures. The availability of the narrative data made the in-depth study of the standardised data possible.

4.2. Content and framework analysis

Introduction

The interview accounts of participants were examined carefully and empirical themes in the language of the participants emerged. The themes were supported by extracts from longer narrative accounts, which were created by verbatim transcript. As a result, grammar errors have not been edited and any errors in quotations are deliberate. The interview themes were related to the research questions and thus the theoretical categories were generated. The theoretical categories were observed in all interview accounts (Fig. 4.1.).

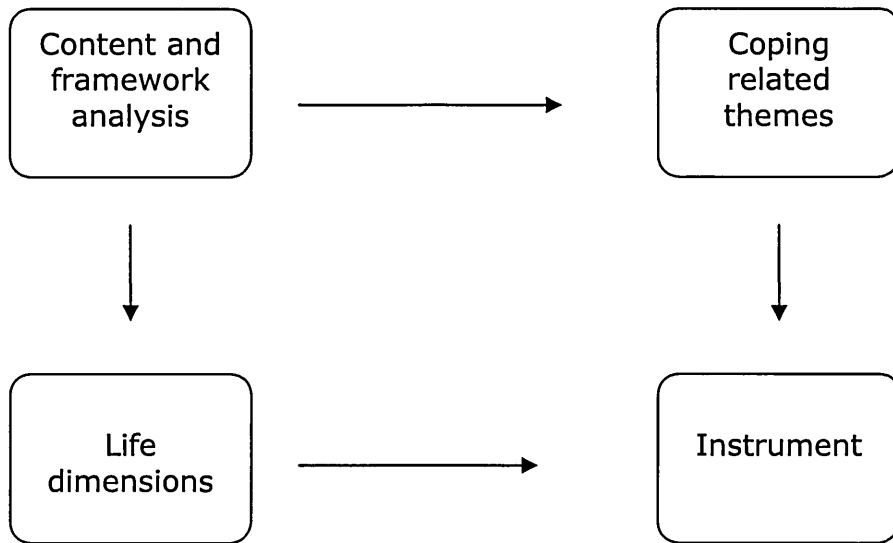


Figure 4.1. Content and framework analysis

Categories

Generally from the participants' narrative accounts two major themes emerged, which are different characteristically. There are themes that show how the condition has affected participants' life domains in different ways. There are also coping-related themes that are related to coping strategies used by the participants sometime during the course of the disease, from the onset of the condition through the diagnosis, the operation and after the operation. The common characteristic among the themes was that they were overlapping and integrating, which makes it difficult to code and relate them to a certain piece of data. The information given by the participants was obtained through conducting narrative induced questions in an indirect way. A part of the information mostly on various life domains can be translated into topics or questions within the construct of an instrument. The instrument can then be introduced as an alternative way of measuring the patients' perception. However, some information related to participants used coping methods cannot be put together to construct a topic or a question, because the great bulk of the data on coping strategies were compiled through indirect narrative questions, for example, data on emotion-focused coping, spiritual coping and comparative coping.

All the participants provided narrative comparing their current situations with the past before they had the hip operation done. Fifteen out of 20 participants (75%) stated that they had problems other than their hip condition. The most common health condition mentioned by the participants was arthritis. Other conditions were problems with the eyesight, varicose veins, oesophagitis, stomach pain, problems with platelets and haemoglobin, thyroid dysfunction, anaemia, asthma, hernia and skin cancer.

Nine out of 15 participants (60%) with multiple health problems related their present health condition and their physical limitations to problems other than with their hips. They stated explicitly that the hip was not the cause of their post-op concerns and in fact,

the non-hip problems were jeopardising their QoL and well-being. One participant declared:

... since the hip operation, my life's took a better turn, but you know as I say I can't really walk, it's not because of my hip, it's because of my arthritis in general you know....now I'm on painkiller for the for me arthritis not for me hip. I don't need anything for that, that's been absolutely great, fantastic. (P. U)

Another woman with multiple health problems said:

I can walk for about a mile and a half before I think I need to rest and I think it is to do with laziness, because I got out of habit of walking, but also my thyroid condition makes me very tired, so I'm never sure what is the real cause of the tiredness, whether is the thyroid or is the hip condition. So I'm usually a little foggy with that. I'm never sure what is the real cause really. (P. C)

4.2.1. Coping strategies

We can gather from the narrative interviews that the participants were coping long before the operation, through the operation and after they had the hip replacement done. Five coping strategies were compiled, which were used by the participants at some point during the course of the disease (Tables 4.1 and 4.2.).

No. of strategies	of coping	Participants (%)	Multiple problems C%	Single problem (%)
1		(10) 2/20	(13) 2/15	
2		(25) 5/20	(27) 4/15	(20) 1/5
3		(45) 9/20	(40) 6/15	(60) 3/5
4		(10) 2/20	(13) 2/15	
5		(10) 2/20	(7) 1/15	(20) 1/5
Total		(100) 20/20	(100) 15/15	(100) 5/5

Table 4.1.Number of coping strategies

Coping strategies	Participants (%)	Multiple health problems
Spiritual coping	(10) 2/20	(7) 1/15
Self-oriented coping	(35) 7/20	(27) 4/15
Problem-focused coping	(70) 14/20	(73) 11/15
Emotion-focused coping	(70) 14/20	(67) 10/15
Comparative coping	(100) 20/20	(100) 15/15
Total	(100) 20/20	(100) 15/15

Table 4.2.Type of coping strategies

These coping strategies were self-oriented coping, problem-focused coping, emotion-focused coping, spiritual coping and comparative coping. All participants used at least one coping strategy to help them manage the new imposed situation. Two participants (10%) used one coping strategy, five participants (25%) used two methods of coping, nine (45%) used three methods of coping, two (10%) used four methods of coping and two (10%) used five methods of coping. The relation between having multiple health problems and the number of used coping strategies was two participants with multiple health problems (13%) used one method of coping, four (27%) used two methods of coping, six (40%) used three methods of coping, two (13%) used four methods of coping and one (7%) used five methods of coping. Participants with single health problem (hip condition) one (20%) used two methods of coping, three (60%) used three methods of coping and one (20%) used five methods of coping.

Seven participants (35%) used self-oriented coping, 14 (70%) used problem-focused coping, 14 (70%) used emotion-focused coping, two (10%) spiritual coping and all the participants used at least one form of comparative coping.

It seems that there is not a positive relation between having multiple health problems and the number of used coping strategies, because while one participant with multiple health problems used only one method of coping, another participant with single health problem used all five identified coping methods. On the other hand, two participants one with multiple health problems and the other with single health problem used all five methods of coping.

Spiritual coping

Engaging in a spiritual strategy in both direct and indirect ways was an important part of the narrative account of 10% of the participants in the study. They frequently provided some form of implicit spiritual engagement in their accounts and stressed the presence of some outside forces that helped them to get through the disease process and rewarded them luck and fortune. They constructed a narrative dominated by outside forces with emphasis on the importance of meanings and themes, as well as employing grammar of helplessness (Capps and Ochs, 1995). The following statement illustrates this:

"I felt that the way things had worked out, it somehow been towards a plan, but it wasn't a plan. I think I was looked after there." (P. S)

They also presented explicit spiritual practice, stating their faith and belief in a direct way as it was stated by one participant:

Um, well I go to church and things like that you know, and thank God for bringing me through and you know making my life again really, you know. It's been lovely....I really mean that yes. I feel that I really truly there is a God and urn has got me through anything you know, through operations and through my husband's dying and anything that way (P. X)

Self-oriented coping

The participants declared some degree of scepticism and resistance towards having the operation. They were concerned what would happen to them. In fact, many of the participants coped for many years before having the operation done. In some cases the pain, which gradually got worse, and in others the functional limitations and physical restrictions made them seek medical help in the first place. Before being recognised as having a hip problem, the participants attempted to deal with pain and functional limitations by talking to someone, e.g, their GP or a friend and they tried more conservative interventions such as physiotherapy or individual modalities like swimming. One participant referred to the benefit from reading leaflets and information packs produced by the Arthritis Research Council. However, she said:

Um, I did get quite a lot of benefit in reading the leaflets which are produced by the Arthritis Research Council, but having said that trying to get through to the helpline, because I would've liked to have been able to talk to somebody on to a one to one basis about the problems and really was this normal in my condition. ...So it's not being able to have somebody really to talk to, I think that probably isolated me, in that sense. So that was probably the hardest part.
(P.E)

The finding of a study by Malkin (2000) showed that orthopaedic patients including patients undergoing hip replacement, valued factual information as well as information provided within the context of an individual patient. It supports the ideas that patients wish the written information to be validated through communication with health professionals.

The use of natural coping mechanisms was acknowledged by Sharpe and Gilbert (1998) in a study to answer to the re-test effect. Based on this study, when subjects are administered a test for the first time, they will become aware of their conditions and try to cope with the situation using informal intervention, such as communicating with friends, or using personal intervention. This will result in observing fewer negative states at the follow-up assessment, which can be a real threat to the validity of longitudinal studies conducted to evaluate the effectiveness of medical interventions (Arrindell 2001). The participants in this study tried to use natural coping mechanisms as a mean of alleviating their target condition. However, their attempt in using their own coping mechanisms does not seem to succeed. As it is evident in the grammatical rhetoric of one of the informant:

... I made sure that I did everything I could um I went to a physiotherapist who taught me the exercises that would keep me as mobile as I could within what I had wrong with me I used all the health remedies I could and did everything I could and also I tried to keep very positive about the whole thing. Once I'd come to terms with the fact that there was nothing I could do or anybody else could do to alter the situation, that I would possibly have to have this operation um I think I determinedly then tried to keep positive about it... (P. E)

Problem-focused coping

Some of the participants used a form of coping that allowed them to accommodate to the demands imposed by the hip condition. The underlying goals for using this kind of coping may vary, but those participants who used problem-focused strategies concentrated on the limiting hip-related dimensions, which were out of their control. The sudden realisation of losing his independency, one participant relied a great deal on mobility aides to make life a little bit easier and gives him a measure of independency.

As it was expressed by him:

... I have a mobility car, and I've also I got an electronic scooter. So uh I've also got a stair lift at home, so all these things makes life just a little bit better, just gives you a measure of independency. ... I can buzz around on it, so in that respect yes, I've sort of come to terms of being determined, I'm not going to become house bound and trapped and not going. (P. V)

Problem-focused coping refers to strategies useful to control or solve distress-making problems that hamper goals (Lazarus and Folkman, 1984). Problem-focused coping strategies can be effective by helping individuals to experience some control over rather uncontrollable situations and to get some sense of fulfilment, resulting in more positive psychological states (Folkman 1997).

Emotion-focused coping

Seventy percent of the participants used an emotion-focused coping strategy. Coping refers to "efforts to master conditions of harm, threat, or challenge when a routine or automatic response is not readily available. Here, environmental demands must be met with new behavioural solutions or old ones must be adapted to meet the current stress" (Monat and Lazarus 1977: p. 8). As mentioned earlier, this concept can be explained by two different kind of coping. Problem-focused coping, in which a person attempts to change external environmental problematic factors, and emotion-focused coping which includes actions to protect internal feelings (Lazarus and Folkman 1984).

The participants used a number of emotion-focused strategies to help them with hip condition and the problems imposed by it. These strategies are illustrated by quotations from the participants:

- goal rearranging, shifting the goals or reframing expectations

Now I can't drive, you see and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden. I can sit in which I wouldn't settle without it. (P. S)

- positive reappraisal

... when you get over 60 you're going to slow down, you're going to do rest, so you have to adjust a bit really, which I think I'm doing quite well (laughs). In fact, I'm enjoying it. I used to think (short pause) at first I shouldn't be paying this money out to somebody to do this job, but now I'm thinking well, WHYNOT? It's their job, they get a job out of it and I get the pleasure of somebody else doing the hard work (laughs), so that's how I've changed (laughs). (P. C)

- focus on preferred self

... people with (long pause) some kind of aim or faiths I think benefit it. I think it gives someone (short pause) comfort and peace quite honestly, uh (short pause) and for me it helps me. It does. I do feel it helps me. (P. S)

... when I attended the pre-admission clinic um (short pause) something was mentioned about pain and I openly admitted that in fact mine was more discomfort than actual pain at that stage. Yes, it was enormously uncomfortable, but I wouldn't class it as I was in absolute agony ... I didn't necessarily think that those people going with me were in more pain than I was, but I think it just depends you know how you are going to let ruin your life or not ruin your life ... I think it's mentally. I think because I'm happy um, my circumstances, my life, my everything, I think that I had it all right... (P. E)

- accepting life and re-learn it, adjusting to the new situation, getting on with life and make the best of what is there

Uh (short pause) well, to take life as it as it comes, don't start planning a lot of things in future, because there is no guarantee that you'll be able to fulfil them plans ... as I say just got to take life as it comes, accept what comes and make the best of it, not not get withdrawn ... uh but at the same time don't build your expectations high ... you just got to accept what life brings you. (P. V)

- carrying on as usual or as normal

So I suppose like a lot of people make life for myself easier, I MADE things easy for myself ((referring to the use of mobility aids)) and carrying on like normal. Two little things, I can't climb and I don't get on the floor, so that's about it (laughs). (P. P)

- positive thinking and being optimistic, looking at the benefits from the operation

Um while I was waiting eventually for the hip replacement I felt it was much more the discomfort the limitation to my life as opposed to enormous pain which I heard other people saying about having them. So I felt fortunate from that point of view. I tried to be as optimistic as I could about the whole thing, which I think does help the physical well-being. I think being mentally positive, it minimizes some of the physical discomforts that you're going through. (P. E)

"I'm not a morbid sort of person actually, you know. I'm trying to look on the benefits that I've had from it and how much better I am." (P. H)

- relating real health problems to other things like laziness

"I can walk for about a mile and a half before I think I need to rest and I think it is to do with laziness, because I got out of habit of walking..." (P. C)

Yeah, it's not nice really when you are not really active, yeah. Mind you some days I feel a bit more active than other, but I used to get up early in the morning and get all me work done, but now I don't feel if I've got any energy in the morning. I have to do it in the afternoon when I could you know, gather me ways, yeah. So (laughs) it's laziness I think. (P. R)

- keeping mind active and occupied

So you know, but it's this that hurts that I can't I can't walk myself ... Um (short pause) yes, um I'm getting better, you know. I read a lot and I do puzzles. You know puzzle books and I read a lot and I don't watch telly that much. (P. Q)

- using comparative coping strategy

Interviewer: What did you do to be positive and stay mentally positive?

I think that I looked at people who were very much worse off than I was ... so I compared my situation which wasn't like that at least thank goodness I've got a lovely husband and I've got a nice family and so if I wanted to go out somewhere I could go out somewhere, it it was just more difficult... (P. E)

- belief in fate

I always think everybody's ends determined from the minute they're born and no matter what you do and where you put yourself when your end comes, time and circumstances put you to this. You don't have to worry about it. ...so you know as I say the fate take take what comes that's all you can do(P. V)

Comparative coping

All participants used at least one form of comparative coping. A definition that is shared among most researchers refers to social comparison "as the process of thinking about information about one or more other people in relation to the self" (Wood 1996, p: 520). The demand for self-assessment in the absence of objective information as the main characteristic of social comparison theory (Festinger 1954) can explain why people increase the level of their engagement in social comparison when they encounter health problems. Uncertainty is an essential prerequisite for social comparison (Wills and Suls, 1991) and health problems create vague and doubtful situations that increase the desire for social comparison (Gibbons 1999). We need to consider the location of social comparison process and whether it meets the criteria for inclusion in coping-oriented mechanisms. According to Lazarus and Folkman (1984), there are two forms of coping: problem-focused coping is focused on managing or altering the problem causing distress and emotion-focused coping is conducted for handling emotional reactions to the problem. Although coping in this theory has an effortful and conscious nature, they referred to effortless positive comparison as emotion-focused coping.

The theory of downward comparison suggested by Wills (1981) refers to the situations when people in a negative status compare themselves with people who are worse off in order to maintain or improve their subjective well-being. Wills (1997) suggests that when active cognitive strategies that require effort and seeking information are not available, people will undertake downward comparison to enhance their negative mood.

Therefore, downward comparison can represent an emotion-focused coping or avoidant coping mechanism in which people do not actively face the problem but rather try to feel better by avoiding it. However, Taylor and Lobel (1989) argued that this kind of downward comparison is alarming if people expect that they may deteriorate on the dimension of comparison. Therefore, they questioned Will's downward comparison theory by proposing upward comparison involving seeking contact and information with better off others that can be supporting and reinforcing. To reach a compromise between the two above mentioned theories, Wood and VanderZee (1997) argued the critical determinant underlying the selection of downward and upward comparisons. They suggested that if people have little fear of getting worse on the dimension of interest then downward comparison can be self-enhancing. This type of downward comparison was overlooked by Taylor and Lobel (1989). Similarly, an upward comparison can have an inspiring effect when an individual wishes to progress on the dimension of comparison. When people feel rather stable and certain on a dimension, they go for downward comparison. At the same time, they may seek information and engage in upward comparison on a dimension that is under threat and they have hope of improving it.

In the narrative accounts of participants in this study different types of social comparison emerged. These involved intra-personal and inter-personal comparisons (Gibbons 1999). In intra-personal comparison, people used times before and after their health problem and the operation as a baseline or in other words temporal comparison. Temporal comparison may be downward, comparing their present situation with past difficult days. As expressed by one participant:

Before I had the operation, I'm forty years old, before I had the operation I walked with two sticks, like somebody in eighty or ninety years old. The operation and the treatment I received was good and successful and it just transformed my life and I'm very grateful for that. (P. K)

Almost all participants engaged in upward temporal comparison when they were providing life narrative accounts before developing hip condition. One participant recalled what her life was like prior to developing hip condition after being prompted by a narrative induced question:

Interviewer: Do you remember how life was before you developed your hip condition?

Um, I used to, when I was a young man I was very much more active, because I was a police officer in in East Africa and I was twentyfive years in East Africa and I quite was very mobile then, and I was walking a lot then, and that when I was very young man. I'm seventy three years old now and I could never do that sort of things again. (P. O)

The targets of temporal social comparisons included some aspects of life such as age, pain and physical abilities. The comparisons also involved inter-personal comparisons including comparing one's own situation with specific others who are experiencing similar problems or with general referents with whom the participant had no personal contact. Inter-personal comparison can also be either downward or upward. When the participants compared themselves with others, they referred to both individual and aggregate social comparison information (Buckingham and Alicke, 2002). In individual social comparison, the participants evaluate their circumstances and their life quality by comparing their status with someone they know. For example, a woman referring to her son's mother-in-law used upward social comparison and said:

She is seventy nine and she's all right, you know. She can get about you know (short pause). She's on her own, but she's got a son lives there and his wife and grand children, so (short pause), but when they come we always got a full house (laughs). (P. L)

She was providing narrative on her understanding of family and relationships. Her family was the most important part of her account, as she provided detailed narrative on the concept. The longing for living close to her children who live abroad was described meaningfully, as well as, by engaging in individual upward social comparison, describing the abilities and status of a specific individual on the dimension of comparison. Individual downward comparison is observed in the narrative account of another woman:

I knew somebody that I worked with and who wasn't very much difference in me age and she's now living down in Kent in a beautiful part of the country with the first time they own their own bungalow and everything should be going for her, but because of arthritis she is now in wheelchair ... so I think I looked at people like that ... so I compared my situation which wasn't like that at least thank goodness I've got a lovely husband and I've got a nice family and so if I wanted to go out somewhere I could go out somewhere, it it was just more difficult... (P. E)

However, aggregate social comparison in an implicit way was used more often by the participants. The following statements provided by the participants show their engagement in aggregate downward social comparison:

I FEEL I AM LUCKY to live where I live with nice neighbours and the people round about are nice, but we just I just feel fortunate in that respect ... very fortunate, neighbours either side is a caring community ... yeah, yeah, I'm very fortunate really (short pause). I'VE GOT NOTHING TO COMPLAIN ABOUT REALLY, nothing and (long pause). I'm probably the wrong person to ask about. (P.H)

... I think I have strong faith in God. ... um I feel sorry for people, I think you do need (short pause) I think I think people would have an empty life (short pause) miss out you know something... I'm very very lucky with my family and friends ... I'm very fortunate in a lot of ways, because I mix a lot with the younger people as well... (P. S)

In some cases the participants' engagements in aggregate upward comparison was identified:

... becoming frustrated sometimes you know, when you look around uh you see people and they don't deserve to have a good life, some of the things they get up to it, some of the things they don't, and then you see people really come to do the life, done the best and they are struggling and you think you know what's fair in life, why is that? (P. V)

Age was the target of social comparisons in many participants:

"Well, I'm sixty one now uh but I think that contributes to me problems you know arthritis." (P. U)

4.2.2., Dimensions of life

The participants identified a number of concepts as their life dimensions that were affected by the health condition before the operation and compared them with their post-op status and situations. Areas of life pointed out by the participants were mostly: physical, emotional/mental, pain, social, family/relationship, job, appearance and the use of medications/painkillers as well as the effects of hospital care and long term care on participants' health (Table 4.3.).

Themes	Participants (%)
Multiple health problems	(75) 15/20
• Non-hip physical limitations	(60) 9/15
Physical	(100) 20/20
• Persistent physical limitations after the op	(53) 11/20
• Non-hip limitations	(73) 8/11
Pain	(85) 17/20
• Pain after the op	(23) 4/17
• Non-hip pain	(18) 3/17
Pain effect over a long period	(40) 8/20
No benefit from mobility point of view	(30) 6/20
Emotional	(50) 10/20
Social	(75) 15/20
• Continuing effect on post-op life	(53) 8/15
Family	(70) 14/20
• Active role	(28) 4/14
• Passive role	(71) 10/14
Job	(85) 17/20
• Retired	(29) 5/17
• Housewife/retired	(60) 10/20
• Back to work	(12) 2/17
• Work-related health problem	(18) 3/17
Appearance	(15) 3/20
Medications/painkillers	(20) 4/20
Hospital care	(80) 16/20
Long-term care	(50) 10/20

Table 4.3. Summary of different life domains

4.2.3. Applying the identified themes in an instrument: Developing the instrument

I put together a construct of participants' perceptions to develop a questionnaire or an interview schedule where the interviewer needs to ask certain questions in her/his own way (Figure 4.2.).

- Have you used any kind of mobility aids or have you changed your living environment to adjust to your hip problem?
- Have you had any health problems other than your hip problem?
- Do you have a previous experience of arthritis in your family?
- Do you think your hip condition and the treatments you received for it either medications or the surgery has caused you other health problems? (After the operation)
- » Please describe your physical abilities and your functional performance.
- What causes your physical limitations, hip or other health problems?
- Is your life affected by pain? Please explain about it.
- What causes the pain? Is it hip or other health problems?
- How long have you been suffering from the pain? (Before the operation)
- The pain severity and its impact on participant's waiting time for the operation. (Before the operation)
- How do you feel about your health condition?
- Is social aspect of your life affected by your health condition?
- Is your post-operative social life affected by your health condition? (After the operation)
- Can you explain the impact of family or any relationships in your life and how you describe your role in relation to your family?
- What do you do? Has your health condition had an impact on your job? How?
- Do you see any relationship between your hip problem and your job?
- What has been the impact of hip condition on your professional life?
- Does your hip condition affect your appearance and how important it is to you?
- Do you take medications/painkillers? What do you need painkillers for?
- Have the medications caused you other health problems?
- How did you come to terms with your decision to have the hip replacement done? (Before the operation)
- What is your perception of the total hip replacement surgery? How do you see your post-operative life? Can you put the post-operative long-term care in some perspectives? (Before the operation)
- Please explain your experience of the operation and hospital care. (After the operation)
- How satisfied are you with post-operative care (long-term care)? (After the operation)
- What is your perception of the total hip replacement and can you compare it with your perception before the operation? (After the operation)

Figure 4.2.The instrument

- **Have you used any kind of mobility aids or have you changed your living environment to adjust to your hip problem?**

Seventy percent of the participants used a form of coping that allowed them to accommodate to the physical demands imposed by the hip condition. As it was expressed by one participant:

... I had a large seated car in those days and now I've changed my car, a high seat car, so I don't have to push it up all the time and the bed is a high bed and things like that made life easier ... Well, I've changed the furniture and the car, that's the major things and they've been absolutely wonderful. (P. C)

- **Have you had any health problems other than your hip problem?**
- **Do you have a previous experience of arthritis in your family?**
- **Do you think your hip condition and the treatments you received for it either medications or the surgery has caused you other health problems? (After the operation)**

Seventy five percent of the participants stated that they had problems (self-defined) other than their hip condition. For example the non-hip problems were a barrier to change internal standard in one participant:

... uh because of the double disability you see, if I could be doing my painting and my reading and sewing, I don't mind not going out. It isn't that I want to go and do anything uh (short pause) you know uh just normal things ... (P. S)

Another participant describes her double health problem like this:

... I can do most of the things that I used to enjoy doing. I don't go for long walks anymore, um (short pause) that is not necessary to do with hip, because my thyroid is disappearing and I get very tired ... so you know I have these two things to be considered all the time, my hip really is my tremendous business. The thyroid won't get better until it disappears all together, which will do in about next year. (P. C)

Forty percent of the participants expressed that their hip condition and the treatments they received for it caused them some worries and even other health problems. One woman said:

... *When I had this I had to use sticks a lot, put more pressure on which affected my shoulders, which I had to have injections in the arms, because I couldn't move the arms (shortpause), uh it was very very bad really...* (P. Y)

■ **Please describe your physical abilities and your functional performance.**

■ **What causes your physical limitations, hip or other health problems?**

All the participants discussed the impact of their health condition on physical aspect of their lives. To do this, they either were engaged in downward temporal comparison or simply described their functional disabilities before the operation. In the process of social comparison, they recalled days before the operation that were associated with physical and functional limitations and compared those difficult days with their post-op situations, which seemed to be less affected by their limiting physical circumstances.

For example one participant stated:

Before I had it done, I could walk about two-hundred yards before my hip was locked, so I couldn't really continue and I daren't go anywhere in case I couldn't get back. That was quite frightening really ... since I have it done, I can walk for about a mile and a half before I think I need to rest. (P. C)

Another participant described her physical limitations before the operation without engaging in down-ward temporal comparison:

" ... I really got problems for so long getting in and out of the chair and I couldn't do a lot of work in the house." (P. S)

Eleven out of 20 subjects (53%) felt that the physical and functional limitations were persistent after the operation, although eight of these participants (73%) related their physical restrictions to problems other than hip as part of their multiple health problems such as arthritis. Referring to the pre-operative knowledge of the outcome of the operation, one participant said:

What they told me that the biggest advantage I got from it was to get rid of a lot of the pain from the arthritis condition, but I wouldn't get a lot from the mobility point of view, which is true. That's exactly what they told me. (P. V)

Showalter and colleagues (2000) suggest that patients undergoing total joint arthroplasty, can benefit from information that reflects "best case-worst case scenarios" (p.49). Providing patients with this kind of information, they are able to develop realistic expectations in the process of recovery and transition.

Another participant related his physical limitations to arthritis developed in both his ankles and regarding how far he could walk remarked:

"Well, if it wasn't for my arthritis and my ankles I would be able to walk considerable distances, but ...it isn't the hip that restricting it, it's the arthritis."
(P. O)

- **Is your life affected by pain? Please explain about it.**
- **What causes the pain? Is it hip or other health problems?**
- **How long have you been suffering from the pain?**

Seventeen out of 20 subjects (85%) declared that their lives were affected by pain seriously before the operation. One participant said:

"Um, before I got me hip done, I was in constant pain, virtually twenty four hours a day, a bit of pain when I had it done, after that pain's gone till there was nothing."
(P. T)

Four of them (23%) expressed that they had still been suffering from pain after the operation, of which three (18%) declared that the pain had caused by other problems like arthritis. One participant declared:

The hip doesn't restrict me, it's just the arthritis that restricts me you know. The ankles when they uh they can get very painful sometimes you know....the hip is not painful, not as it was before. It was really painful, but as I say if it wasn't for my arthritis in general I think I would be fine. I mean with the hip I don't get any pain. (P. U)

Eight participants (40%) referred to the effect of pain over a long period of time. They acknowledged how getting rid of pain altered their post-operative lives substantially.

The following exemplify this:

...that pain and when you've got pain like that you sort of mentally hit you you see, because you see your mind's constantly on this pain, so therefore you've got more interest in life and that's right, it's like living again, because you've got different life all together. (P. X)

So basically I had pain. I've lived with pain, always um and gradually got worse, but because you're used to living with pain, you don't know how much you're expected to put up with ... so you just get on with life...but it's lovely to be pain free, so it's been well worth it. (P. D)

A pain like that that you've got all the time, it wears you down, it tires you out, even you don't realise it you know. Just grinds you down, but now it's totally different. It feels marvellous now. (P. K)

Despite the fact that six out of 20 (30%) participants had not benefited a great deal from a mobility point of view after the operation, relief from the pain was rewarding enough for them in order to evaluate the outcome of the operation worthwhile. This is evident in the following statement from one participant:

...when I'm walking, it gets me irritated and I know it, because I can't walk very far uh, but I think really on the whole it's not been bad at all, so I haven't got the pain that I had and that's the main thing and I have got a better life. ...I can't do things I would like to do, but I say otherwise the pain's gone and that's THAT IS ONE BONUS REALLY. (P. H)

■ **The pain severity and its impact on participant's waiting time for the operation.
(Before the operation)**

... Yes, it was enormously uncomfortable, but I wouldn't class it as I was in absolute agony and the nurse more or less said to me if you could say that to the consultant then you won't be an emergency case. Well, I mean I waited 18 months, you know, so how much more really I can't, but she was more or less saying you don't get the operation...but I think she ((the nurse)) felt that I should've been in absolute agony to have the operation ... (P. E)

■ **How do you feel about your health condition?**

Fifty percent of the participants referred to the emotional aspect of their lives and expressed their feelings regarding their health condition. For example negative feelings of disappointment, fear, frustration, guilt, anger, depression, getting upset and anxiousness vs. positive experience of happiness, satisfaction and feeling younger.

".../ used to paint my own house, decorate, but I can't now. ... / don't like it, I get depressed, because I've always been so active ..." (P. R)

"...I quite well looked after yes, but it's just that I get frustrated, because I can't do things for myself Um, it's my own feelings. I think when you've been so active, you've got to relearn your life kinda things, so I'm trying." (P. Q)

"... when I had it done after that pain's gone till there was nothing. Uh, uh as I say I feel I'm 50 and I feel I'm 25 years old. I just feel great." (P. T)

- **Is social aspect of your life affected by your health condition?**
- **Is your post-operative social life affected by your health condition? (After the operation)**

Social dimension of life was mentioned by 15 out of 20 participants (75%) during their interviews. With regard to this, some aspects of life such as playing sports, travelling, attending fairs, going on holidays, visiting family and friends and dancing were described by the participants. These aspects of life were affected by their health condition. Eight out of 15 participants (53%) who recognised the effect of their health condition on their social life before the operation, acknowledged its continuing negative effect on their post-operative life as well. Three of the participants could not play sports after the operation and this had negative impact on their overall QoL. The social burdens imposed by the condition after the operation were also acknowledged by three other participants. Yet, family and friends played a significant role in their lives so that they could overcome those burdens and therefore, rate the social dimension favourably. Extensive use of artificial mobility aids by one participant who was also very dependent on his wife from a mobility point of view, made him view his social life rather promising. No improvement in social life was identified in narrative account of one woman after the operation, because she felt she had been restricted in terms of social activities such as dancing, which she used to enjoy.

- **Can you explain the impact of family or any relationships in your life and how you describe your role in relation to your family?**

Fourteen out of 20 (70%) of the participants provided narrative regarding their QoL in relation to concepts of family/relationship, which can give a measure of their independency. Among 14 participants who talked about their relationships with their family only four of them (28%) gave themselves an active role in relation to other members of the family. Therefore, as an active agent, they needed to control the condition-specific related domains. Referring to the most important things in his life, one participant said:

"I've got two grandchildren, both ten and nine years old, so at the moment that's the only important thing going on in my life at the moment, looking after them two." (P, T)

The rest of the participants (71%) had a passive role in the family and were either physically dependent on their family members or just had enough independence to look after themselves. One participant explained his position with respect to his wife:

...I've led a very active life, I've been in control. ... and then suddenly came to a situation when you can't get about, you dependent on other people to help you. In other words, you lost your independency. I couldn't live on my own now. I know that and I'm relying on my wife to help me with things.... (P, V)

- **What do you do? Has your health condition had an impact on your job? How?**
- **Do you see any relationship between your hip problem and your job?**
- **What has been the impact of hip condition on your professional life?**

A number of participants, 17 out of 20 (85%) referred to the concept of job regardless of not being in a job at the time of the interview. Among those participants who talked about their jobs, five were retired (29%), ten were housewives and or retired, (60%) and two were back at work after the operation (12%). Ninety percent of the participants who talked about their jobs were engaged in downward temporal comparison. Following a narrative induced question, which attempted to create narrative response, they recalled those days before they had developed a hip condition. They described themselves as active or very active before being recognised as having hip problem. One man stated:

Well, I was very active uh I used to go walking uh I played football... I was very active I used to work lots of hours you know as I say before I came off with me hip, I was working 12 hrs 13 hrs nights. I worked for 3 years like that you know ... (P. U)

One housewife said:

Oh, before I had my hip, oh marvellous, working, cleaning, decorating, everything, but that ((the hip)) put stop to everything, yeah well it still has, because I mean I used to paint my own house, decorate, but I can't now....I mean I've been active. I could clean all through my house and go to my mother's and same day do hers, just look at me now ... (P. R.)

Three out of 17 participants (18%) related their current health problems to the jobs they carried out in the past and considered their present health condition as a work-related one. As expressed by one man:

...and working on public transport, driving buses and things like that wasn't a good idea you know. It's a wrong job to do, because ... you're wearing and tearing the joints you know, the actions you do and that's you don't wanna do if you're gonna develop something like that... but I can't turn the clock back, I've done it. ...and I think we are paying the price for um possibly the end of the era of manual work, if you want to put it that way, not to try to deny the present one... (P. V)

In replying to a question, which sought to explore the importance of independence all through her life, one participant mentioned:

...I've always been the person who looked after other people...I think probably that part of the problem with my back now is I used to get my mother in and out of the bath, I used to get my husband in and out of the bath and I used to get them hang around my neck you know to sort of lift them up and I think that's what's happening to me now. (P. H)

With reference to the concept of job, the participants accepted the retirement and related it to the factor of age, using age comparison to adapt to the new situation. One participant stated:

"...and decided I have to give my job up, because I realised I couldn't even go out any more. I had to stay in the house ...so I gave my job up and was nearly 67, so it was time that I did... " (P. S)

This approach to retirement sometimes was used with more negative perception of the whole situation. One woman remarked specifically to the impact of retirement on her pre-operative time:

If for instance was a newsagent which is very heavy, difficult job ... and I was at an age I could retire, I was over 60, but at the same time I hadn't anticipated my retirement as being then. It was only that hip really didn't allow me to carry on and it is very daunting. ...so your whole life changes and I do mean your whole life, because you you had to give up the job, so you become retired really against your wishes and instead of going into a retirement when you can go out and enjoying yourself, you had to come to terms with limitations of waiting for the hip replacement and that time is daunting. (P. E)

Resuming routine function, such as returning to work, was perceptible in the narrative account of only two participants who had gone back to employment as a criterion for evaluating the QoL after the hip replacement. The validity of this criterion, i.e., the relation between participants' routine functions and their functional limitations, seems to be called into question in the narrative account of one participant who had both his hip joints replaced within a few years:

"The previous hip replacement was a little more of a problem. At the time I was at work and I had to get up and go to work every morning, whereas on this one I was retired when it was done." (P. O)

■ **Does your hip condition affect your appearance and how important it is to you?**

Three out of 20 participants (15%) brought up the subject that their hip condition had an impact on their appearance and they provided accounts from a cosmetic point of view.

You don't like to think that you've got to use a walking stick, um psychologically you don't like to think that you're aged by a walking stick and also the inability to do more things that you could easily do before ... And so so it does seem to be a theme with women that they do feel you know it is a sign of aging. Um, so it's much better not to have to PROBABLY IT'S MUCH it's much better to limp (clears throat), excuse me, than to be seen on a stick. (P. E)

First I couldn't walk very far, constant pain all the time and I came and had my replacement. First twelve weeks was torture, but now I'm getting on fine really. But only one problem, I've got one leg a bit longer than the other one, so I've attached wedges to my shoes, apart from that I don't admit having it done. (P. I)

- **Do you take medications/painkillers? What do you need painkillers for?**
- **Have the medications caused you other health problems?**

Four participants (20%) stated that they had been taking medications/analgesics at some point during the course of the hip condition for their hip or their other health problems. They had all taken medications including anti-inflammatory and analgesics before the operation. Two of them continued using analgesics after the operation for their arthritis.

... I had been on anti-inflammatory drugs for about five years ((up to the operation)) ... ((now)) I've lost movement for bending and getting down to things and I had to get in a car in a certain way and there are loads of things in the house I just can't do anymore and I can't get down. That um it's not bothered me. I mean you just adjust and I think well, it's no big deal. I'm just relieved that I am on no painkillers ... (P. S)

... / had to wait quite a long time before I got the operation, but uh I had lots of pain. I used to uh I had tablets actually that's what caused my problem, which made my stomach bleed and that's what caused my platelet... so uh I've been off that so now I'm on painkillers for the for me arthritis not for me hip. (P. U)

- **How did you come to terms with your decision to have the hip replacement done?**

(Before the operation)

- **What is your perception of the total hip replacement surgery? How do you see your post-operative life? Can you put the post-operative long-term care in some perspectives? (Before the operation)**

Thirty five percent of the participants acknowledged implicitly and explicitly that they had tried everything to avoid the operation and after they had been confident that nothing could be done to alter the situation, they decided to have the operation. They emphasised meanings and repeated use of some thematic structures that demonstrate their reluctance for the operation (Riessman 2002). They also employed particular linguistic features in their accounts and used the grammar of vulnerability such as negative and modal verbs to show their passive role in relation to the operation (Capps and Ochs, 1995). This is evident in the following account:

I coped for a number of years really and um then I started to have, I couldn't get in and out of chairs, it took me ages and I was having problems and I went to the doctor and um I had an x-ray and when I saw him, he he said: well, it needs a hip operation straight away and I've known the doctor for a long time and I said: well, if you were me what would you do and he said: well, try physiotherapy, but if the hip's gone too far, it means it had to be done ... Um, but I did persevere and I went every morning with a friend and tried to do the swimming, thinking that it would do me good. (P. S)

This evidence suggests that the existence of a negative perception of hip replacement before the operation caused the participants to use natural coping strategies to adapt to the requirements imposed by their negative perception of it. The participants in this study tried to use natural coping mechanisms as a means of alleviating their target condition. Having a negative perception of hip replacement had an effect on participants' decision for having the operation. They put off the operation and coped for many years until they were absolutely certain that attempts for finding alternative interventions had failed. Moreover, the burdens of pain and physical limitations got so heavy that finally they took on board the fact that they had to have the operation. When they were inclined to have the operation, they got on the waiting list. Therefore, there was the time they needed to make the decision to have the operation, which could be very long, and there was further delay due to being on the waiting list.

■ **Please explain your experience of the operation and hospital care. (After the operation)**

Sixteen participants (80%) referred to their experience of the hip operation and hospital care during the interview. One woman narrated her experience of the hip operation:

... Dr. X came to see me. Anyway, he said: We're going to operate on you and then I got a nasty surprise. They took me down, they didn't tell me whether I'm going to have an anaesthetic or anything else. And two big women got me on a bag of beans or whatever it is, bean bags and tried to push a needle in my back and I said: Don't do that... he ((the surgeon)) means well, I mean they all do. This is just these things that come and to try it on, aren't they? (P. W)

- **How satisfied are you with post-operative care (long-term care)? (After the operation)**

Ten participants (50%) provided detailed narrative regarding the post-operative care, which involved their partners, families, friends, neighbours, social care support and community care. Seventy percent of them with similar preceding circumstances were satisfied with post-operative long-term care regardless of their active or passive roles in relation to their family. They all had partners or a very close member of the family like a daughter or a son lived with them or visited them daily. One man said:

I couldn't live on my own now. I know that and I'm relying on my wife to help me with things like fastening buttons, you know generally getting dressed. Sometimes at night arthritis getting that bad I've had difficulty turning over ... I owe a lot to my wife obviously. If it wasn't for her I don't know what I should do. I depend on her enormously right now, you know ... Uh well, I rather not, putting it that way, I'm comfortable with it now. First I found it awkward, but you know she says she understands it... (P. V)

Thirty percent of all those who were dissatisfied with post-operative care were widows and lived by their own whose families either lived far away or were very busy. One woman who lived on her own and had no close family near her expressed her expectations from the health service:

... the only thing as far as care would concern, I did feel when I came out of hospital that should've could've been a better follow-up from the community care, you know. I mean I couldn't get in the bath or anything like that, because I hadn't had a shower. They said: nobody could come and help me, so I just used to um first week my neighbour used to come and fill the wash bowl and put it on the bath room floor and I washed myself down the bath ... I was on my own you know. I mean it's probably all right I haven't children of my own, so it is um um it would've been help from to just have somebody to follow, give me a hand with things. (P. H)

- **What is your perception of the total hip replacement and can you compare it with your perception before the operation? (After the operation)**

Despite his scepticism about the operation in pre-operative period, one married man agreed that he had not changed his perception of the operation after he had the operation done:

"What they told me that the biggest advantage I got from it was to get rid of a lot of the pain from the arthritis condition, but I wouldn't get a lot from the mobility point of view, which is true. That's exactly what they told me". (P. V)

Another widow expressed her surprise after the operation:

Um, the thing I wasn't prepared for was how little I could do. That was the shock to me after the operation ... I am a widow. I've been a widow now it's fourteen years. Um, if I lost a crutch I wasn't allowed to get down. Living on my own it was difficult, um and getting um I couldn't stretch to one side. I thought I was prepared, but it was an awful shock how little I could actually do, because I realised if I wasn't careful, it could dislocate and um that took a lot of adjusting to for me and living on my own you know the home help's came in a little bit, but they don't get a lot of time and once or twice I got in a mess um and I felt a bit frightened, if I couldn't do this, often I wouldn't. What I am going to do ... (P. S)

Summary

The findings of the content and framework analysis revealed a wide range of themes that were categorised into two major components, coping-related themes and themes related to different life dimensions affected by the health problem. The coping strategies extracted from the participants' accounts were self-oriented coping, problem-focused coping, emotion-focused coping, spiritual coping, and comparative coping strategies. The coping strategies were used through the course of the disease to ease the burdens of the health condition. The participants used the coping strategies to adapt themselves to the demands imposed by the stressful situation, in order to improve or maintain their level of QoL. In addition, a number of life dimensions affected by the health condition were identified by the participants including: physical, emotional, pain, social, family, job, appearance, and medications. Each theme represents statements expressed by the participants that have a common core concept linking the expressions together. As a result, the concepts were put together to develop an instrument, which represents participants' perspective of hip condition. It challenges the standardised outcome measures as constructs of researchers and clinicians' perceptions.

4.3. Standard measure of health-related QoL, the SF-36, Oxford Hip Score and the PGI: Case studies

Introduction

Patients' perceptions of illness and health care interventions are evaluated by standardised instruments in the form of questionnaires and interview schedules. Generic measures, disease-specific measures and individualised measures are three major standardised instruments. Their aim is to address patients' concerns and interests in order to evaluate illness and treatments (Fitzpatrick, et al. 1998a). The items of a standardised instrument are normally summed based on the developer's scoring system to produce a score of level of functioning and QoL.

Case study 1: Participant S

Helen (a pseudonym) is a 71 year old woman who lives on her own in a flat in a beautiful area. She had THR surgery done on both her hips within two years. She used to be an active person, running an after school club. Helen lost her husband 9 years ago owing to a heart condition. She looked after her husband, her in-laws and her mother till the day they died. She has two sons who are married and live on their own. She welcomed the idea of the interview warmly and was reluctant to fill in the PGI, so we went straight to the narrative interview. Medical professionals were her main audience through the interview and I was a mediator through whom her voice could be heard. The operation itself formed a major part of her story and her experience with post-op care in hospital was important to her. She compared the two operations and the care she had received during the operations. I felt that I was talking to different characters. She changed her position through the interview from a passive recipient of a medical intervention to an active agent who looked after many people in the past. Within a medical world she was passive and had no control over her life, but within a real world she was an active agent whom many people were dependent on. Having multiple health problems, she beautifully portrayed how she was dealt with within a dualistic medical

model. She is suffering from a degeneration disease which ultimately will affect her vision. The longing for being able to walk and doing other physical activities while she has got her vision intact is a cry for being perceived as a whole person. Her physical problems are intensified partly because she is a widow and lives on her own.

Helen completed the SF-36 pre-operatively and one year post-operatively. For each subscale of the SF-36 the raw scores were calculated based on the scoring system for the UK SF-36 (Jenkinson, et al. 1996) (Table 4.4).

Pat	Gender	Age	Marital status	Empl.	PF1	RP1	RE1	GH1	VT1	SF1	BP1	MH1
					PF2	RP2	RE2	GH2	VT2	SF2	BP2	MH2
S	Female	71	Widow	Retired	45	0	0	85	45	37	33	76
					0	0	0	70	20	62	22	84

Table 4.4: Case 1, scores on eight dimensions of the SF-36 ranging from 0 (worst possible) to 100 (best possible).

The data shows deterioration in Helen's physical functioning (PF), general health perception (GHP), vitality (VT) and bodily pain (BP) and no change in her role limitation owing to physical problems (RP) and emotional problems (RE). Improvements are seen in social functioning (SF) and mental health (MH) dimensions. The Oxford Hip Score showed a change of score from 31 to 36 indicating a slight decline in Helen's health condition. Despite lower scores in most dimensions of the SF-36 reflecting a lower level of QoL as well as worsening health shown by the Oxford Hip Score, the transfer question of the SF-36 did not detect any change in Helen's health during the past year. Her health stayed about the same compared to one year before.

Case study 2: Participant V

Michael (a pseudonym) is a retired bus driver in his early 70s. He was quite willing to take part in the interview and was happy to complete the PGI in which he focused only on physical areas of his life. Michael lives with his wife as his main carer in their own house. His son and daughters live on their own and help him when he needs, but he is dependent on his wife a great deal. As an active and independent person in the past, he has found it difficult to come to terms with the functional limitations of the hip condition. Over the course of the narrative event, he pictured himself as an active person who is in control of the narrated event. Nonetheless, he positioned himself differently as he chose to talk to different audience. For example, when the audience of his speech was his wife, he gave himself a passive and dependent position. He also relied on mobility aids and believed that they could give him a "measure of independency".

Michael showed improvements in most dimensions of the SF-36, apart from no change in role and social functioning (Table 4.5.).

Pat.	Gender	Age	Marital status	Emply.	PF1	RP1	RE1	GH1	VT1	SF1	BP1	MH1
					PF2	RP2	RE2	GH2	VT2	SF2	BP2	MH2
V	Male	69	Married	Retired (driver)	5 10	0 0	33 66	50 60	35 40	37 37	22 44	76 80

Table 4.5: Case 2, scores on eight dimensions of the SF-36 ranging from 0 (worst possible) to 100 (best possible).

Improvement in Michael's health was also confirmed by the scores on the Oxford Hip Score from 51 in pre-operative assessment to 35 in follow-up evaluation. Similar to Helen's case, the transfer question of the SF-36 could not detect change in Michael's general health over time. The incapability of the SF-36 transfer question in revealing health change over time is also of importance in those who show improvements in physical functioning and pain approved by the SF-36 as well as the Oxford Hip Score

(Appendix 7). Observing no change over time in general health of patients who showed improvements in their physical functioning and pain as well as those with functional and pain deterioration raises serious doubts about the validity of standardised outcome measures. Applying measures of central tendency, Widar and colleagues (2004) have also noted that the transition question of the SF-36 did not uncover any change in patients' health over time.

Michael completed the PGI with my assistance. Difficulties were observed in relation to different factors including steps two and three of the PGI, scoring each area and spending points on them and also problems around his ability to write down the answers due to the arthritis in both hands. Following the PGI scoring system (Ruta, et al. 1999), a final score of 38 was summed for him. He identified the three most important areas of his life that were affected by his hip condition. These areas were limited mobility, difficulty with gardening and inability to walk. To show how badly each area is affected, he gave 4 on a scale of 0-10 to limited mobility, indicating his mobility between poor and fair. He also gave 4 to gardening and a score of 2 was given to walking in order to specify a very poor but not the worst status for his walking. He showed areas of his life affected by other health problems as very poor and non-health areas of life as good but not how he would like to be. To demonstrate how important each area is to him, he gave 6 points out of 14 imaginary points to mobility and a point of 2 to each other areas of life.

Administered to all the participants, the PGI could capture and specify pain, physical and functional limitations, social dimension, emotional dimension, and multiple health problems (Appendix 7). The PGI, however, asks participants to rate and give points to

"Areas affected by other health problems" and "All other non-health areas of life", without asking them to nominate each area.

Reflection on the standardised measures

During the narrative interview with Helen, five coping strategies were identified. She used self-oriented, problem-focused, emotion-focused, comparative and spiritual coping strategies to adapt herself to the new situation imposed by her health condition and its burdens. Michael also used the same strategies, except the spiritual coping. By engaging in these psychological mechanisms, the response shift is induced (Sprangers and Schwartz, 1999). Over the course of the disease, Helen engages in social comparison including age and temporal comparisons. She gave up her job at the age of 67, which she believed was time that she did, and compares her current situation with difficult past days before the operation. By using these mechanisms she changes the scale by which she decides about her physical performance and her functional abilities. In other words, beta change in a recalibrated scale has occurred (Allison, et al. 1997). Likewise, by engaging in spiritual coping, rearranging goals, reframing expectations and positive reappraisal of the stressful situation (Folkman 1997), she modifies her understanding of QoL and redefines its meaning through gamma change (Allison, et al. 1997). Michael engages in downward social comparison. By comparing himself to worse-off people in many aspects of life, he tries to maintain his level of QoL. Furthermore, his engagement in emotion-focused and problem-focused coping strategies leads him to experience a similar or even better level of QoL compared with one he had experienced before the condition.

The SF-36 reports patients' responses to their disease and the treatments they received for it. The instrument like any standardised measure is not affected by patients' experience and understanding during the course of a disease. Hence, its intervals remain

stable for an individual over time as well as for different individuals at a point in time. It aims to measure conventional change pre-and post intervention. Nonetheless, it overlooks the fact that patients' perception of a disease, its treatment and the meaning of the whole experience can change, leading to a reinterpretation of that experience.

Helen and Michael provided narrative regarding their multiple health problems. However, with a reductionist and dualistic view of patients, their multiple health problems were not addressed by the SF-36. It was not able to measure their QoL as a whole and could not measure their perception of hip replacement prior to the surgery. Evidence brought together from their narrative accounts shows their reluctance and scepticism about the hip replacement before the operation. In other words, the SF-36 could not measure their negative perception of hip replacement. The negative perception brought about a set-back in their initiations for the operation, which in turn has negative impact on the cost and care.

Summary

Participants' perception of hip condition and total hip replacement surgery was evaluated by standardised measures. The participants were given the SF-36 and the Oxford Hip Score before and after the operation. The PGI was administered to the participants after the operation as a prompt for conducting narrative interviews. The data obtained from the standardised questionnaires were examined in detail for two participants. The inadequacy of the standardised measures in depicting patients' understanding of a health experience can be shown by the data obtained from the measures. In the case of participant S, deterioration is observed in most dimensions of life measured by the SF-36 as well as the Oxford Hip Score. Nevertheless, no change in the participant's health was detected over time by the transfer question of the SF-36. Likewise, despite improvements in most dimensions of the SF-36, which was also confirmed by the Oxford Hip Score, the transfer question of the SF-36 failed to reveal any change in health in the case of the participant V. Raising question about the validity of the standardised measures, I concluded that the standardised measures overlook the psychological mechanisms used by the participants over a disease trajectory to accommodate to the disease. By engaging in different coping strategies their understanding of the measure and the experience change over time. Therefore, physical and functional abilities and pain are interpreted in the light of their new understanding of the situation. Moreover, flaws in addressing multiple health problems underline the dualistic and reductionist nature of the standardised measures.

4.4. Content analysis: Case studies

Detailed examination of Helen and Michael's cases allows deeper understanding of their perception of hip condition and the treatment they received for it. The content analysis is based on their interview accounts and the personal language they used to explain their perception.

Case study I:

Helen sought different coping strategies before and after the operation. She used natural coping mechanisms to resist the operation as much as possible. These mechanisms include self-motivated activities such as personal, informal and conservative interventions to help either avoid the operation or contribute with the result of the operation. For example, after talking to her doctor, whom she had known for a long time, and friends, she tried physiotherapy and swimming, assuming that these treatments would be effective.

She was engaged in social comparison and used different types of this coping strategy. She used age as the target of her comparative method. The burdens of the hip condition and the fact that she could not go out of the house any more, forced her to give her job up. Yet, she justified her decision within the logic of relativism and comparison "... so I gave my job up and was nearly 67, so it was time that I did ..."

She used temporal comparison to compare her physical and functional abilities at different points in time. Temporal upward comparison was used to give a picture of her life, particularly her physical functioning before the hip condition. In answering to my question asking if she remembered how life was before she developed the hip condition, she said:

'7 have to say I was extremely active...I was physically very strong and I have done a lot work...so I mean really I did a man's work..."

Temporal downward comparison was a mechanism to elaborate on physical limitations before the operation.

" ... it wasn't the pain that made me ((undergo the operation)), the hip gave way ... I really got problems for so long getting in and out of the chair and I couldn't do a lot of work in the house."

All participants used intra-individual comparison over time to explain their main problems at different points in time.

Helen used spiritual practice extensively for expressing her understanding of hip condition. I sensed an unspoken faith in Helen's first interview. She constructs her narrative with a feeling that she is watched over. In the follow-up interview, I asked her how her faith helped her. She clearly depicted her belief and referred to it directly as a coping strategy.

I think my faith does help me. I think if you I have strong faith in God and I really feel, when you pray, I DON'T MEAN I'M GOING OVER THE TOP AND SILLY OR ANYTHING LIKE THAT, but I do think if you feel that God loves you and he's in control and you can pray to him and ask for help and strength to get well (short pause), I do THINK IT HELPS and you do feel alone, you know if you pray you can pour out. Um I don't ask him for materials 'cause I think I'm very well blessed. I'll ask for help with my problems and for the strength to cope with them and somehow you get through and I think I think God does help me to cope.

She applied her faith as a self-advantage point to compare herself with those who do not have faith.

Um I feel sorry for people, I think you do need (short pause) I think I think people would have an empty life (short pause) miss out (low voice), you know. Sometimes people think if you uh if you have a faith in God, perhaps you're stuffy or you miss out on (short pause) pleasures. I don't think I think they are the ones that miss out... I do think people with (long pause) some kind of aim or faith I think benefit. I think it gives someone (short pause) comfort and peace quite honestly, uh (short pause) and for me it helps me. It does.

She broke up her talk a number of times which indicate her difficulty in creating the talk as well as the significance of the talk (Riessman 1990).

During the process of member validation-verifying the transcript by the participant-, Helen reiterated concern over her double disability and its effects on her overall QoL. She had made it clear that how desperate she was to be mobile, before she got partially sighted. She had also added some lines wishing that she could still drive, an activity that has been affected by her visual problem and not the hip. After the operation, Helen got little benefit from a mobility point of view, as it was shown by her physical functioning scores on the SF-36 (45-0) and the Oxford Hip Score (31-36). However, she realises how badly she had got used to the pain over time and says:

"... there is loads of things in the house I just can't do anymore and can't get down. That um it's not bothered me. I mean you just adjust and I think well, it's no big deal. I'm just relieved, that I am on no painkillers ..."

However, the bodily pain score on the SF-36 does not show an improvement in Helen's condition (33-22).

Despite decline in Helen's physical functioning and pain and no improvement in role limitation owing to physical problems, her social functioning score on the SF-36 has improved from 37 to 62. In fact, social functioning and mental health dimensions of the SF-36 are the only aspects of life that show improvements after the operation. In her interview, Helen explains that because of her physical limitations she had to move into a beautiful flat with a lovely garden and a view. Helen believes that moving house, which took place between two operations, is the best thing she has ever done. As she has no control on her health-related limitations, she reframes her expectations. Satisfied with moving into a new house with a beautiful garden, she lessens the impact of her double disability. She says:

"... it is the best thing I have ever done. Now I can't drive, you see and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden. I can sit in which I wouldn't ve settled without it."

In addition to reframing expectations, positive reappraisal has an important role in Helen's improved social functioning and mental health. She creates a narrative about how she looked after her family, particularly her ill husband in the past. At the same time she vividly makes a positive picture of the stressful past situation. By doing this she describes a positive finding about her characteristic:

... and in a strange kind of way, when you've got someone who was in that state (short pause) um you get closer, you made the most of what you've got and I still think I have that in me, because if anyone asks me I go and if I can do anything I do and I have many friends.

In her follow-up interview, she elaborates more on her positive gain which has led her to have more friends.

... and I have people that come and ask me out and always pop in that I wouldn't have and because and I've got somebody could ring up if I needed them. I don't put on them, but um they ring me, are you all right? And I think they gain a lot from me.

Having friends and family is the target of downward social comparison in her follow-up interview. She puts it this way:

I'd rather do my own work, never bothered me doing it, but I can't, I can't, so I'm very very lucky with my family and friends. I've got some very very good friends for years and um (short pause) you see these my friends their children are my friends and then they bring their children, do you know what I mean?

Helen's attempt was to maintain her level of QoL by seeking different coping strategies before and after the operation including natural coping, spiritual coping, positive reappraisal, goal rearranging, reframing expectations, and social comparison. Engagement in different coping mechanisms can explain why Helen's social functioning and mental health improved despite her worsening physical functioning, pain, general health, and vitality shown on the SF-36 as well as her lower score on the Oxford Hip Score.

Case study 2:

Michael constructs his narrative by using different coping strategies. Although he does not talk about personal, informal and conservative interventions before the operation, he openly expresses his scepticism and reluctance towards the operation. He relies greatly on problem-focused coping strategy within a broad spectrum, from obtaining information to using various mobility aides. The use of problem-focused coping strategies helps him to remain independent as much as possible. In his narrative, Michael tells us a great deal about the loss of independency and control in his life after the operation. In making sense of the post-operative trauma, he explains:

Apparently what I'm told one of the basic cause of it I mean I've led a very active life, at one time I had people I was in charge of things like that, so I've led a very active life, I've been in control. I've worked without supervision for a greater part of my life, and then suddenly came to a situation when you can't get about, you dependent on other people to help you. In another word, you lost your independency.

He incorporates social comparison and problem-coping strategies and interprets the independency this way:

"I am fortunate. I have a mobility car and I've also I got an electric scooter. So uh I've got a stair lift at home, so all these things makes life just a little bit better, just gives you a measure of independency."

Michael employs social comparison in aggregate and individual forms. Engaging in downward comparison, he compares himself with less fortunate people:

My family is good, you know. My daughter and all out there always help me. My son lives in Somerset, I go down there, because it's so nice down there, I stay with them for two weeks, a time, but yeah (short pause) I just make the best of it and carry on. I mean there are people worse-off than me, so I thought I should be thankful, I can at least keep going about, in that way, you know using my scooter and things ... we have our own house. We live comfortably, so in that respect we've got our independency there, so we're fortunate ...

Michael's account, however, suggests that he has some feelings of anger and frustration.

These feelings are demonstrated by engaging in upward comparison:

Sometimes you know, you get up in the morning, you think why me? Why has this happened? What have I done to deserve this? You know. I mean I'm an honest person, I worked hard all my life, I've never caused people trouble and

then you know you see people've been absolute criminals, been in prison and they got a healthy life, why me? What I have done to deserve this? But that's life. It don't work as you think, does it? You know. Uh the people who you think well, you don't think anybody deserves this, but the people who you think might get punished for the way of life, don't seem to. Those who seem trying to be as good as they can in the life seem to be punished for it. I don't know. Maybe one day I'll find out (laughs), yes. I don't know.

Emotional-coping strategy is also used by Michael in a number of times. After each description of a problem, he concludes with the expression "that's life". Having difficulty in changing his standards related to his physical limitations, he says:

"so I thought I should be thankful, I can at least keep going about, in that way, you know using my scooter and things, but I would rather be able to walk about like anybody else does (laughs). That's life, isn't it?"

Speaking of his anger and confusion about his health, he concludes with the same expression:

"... why me? What I have done to deserve this? But that's life. It don't work as you think, does it? You know."

He clearly depicts what is missing in his relationship with his wife and ends his description with sentences which indicate his engagement in emotional coping.

I owe a lot to my wife obviously. If it wasn't for her I don't know what I should do. I depend on her enormously right now, you know. I mean uh you feel selfish, don't you? Because you feel you're the one who should be doing things for her and I'm dependent on her more than anything... so yeah, I've come to terms with it ((depending on his wife)) now more or less. It's just one of them things, isn't it? You don't know what's coming to you in life.

Michael's scores on most dimensions of the SF-36 improved after the operation. Role limitation owing to physical problems and social functioning do not change and the physical functioning shows a slight improvement from 5 to 10. His hip condition has improved according to score change on the Oxford Hip Score from 51-35. He also scores 38 on the PGI one year after the operation.

Examining the items of the Oxford Hip Score in detail and relating them to Michael's account, gives more insight into the nature of the questionnaire. Six questions out of 12 items of the Score ask about pain. They aim to represent different aspects of pain and its magnitude in different contexts. Michael began his narrative by describing his feelings towards the operation and continues to explain what he expected from the operation based on medical information. He says:

"... and um what they told me that the biggest advantage I got from it was to get rid of a lot of the pain from the arthritis condition, but I wouldn't gain a lot from the mobility point of view, which is true. That's exactly what they told me."

It is not surprising that his ratings on six items relating to the experience of pain have improved after the operation. An improvement is seen on item 3 and item 5 asking about having any trouble getting in and out of a car and doing household shopping on his own, respectively. Michael's account shows how he makes life easier by using mobility aides. By engaging in problem-focused coping strategy, he defines himself as self-advantaged as a result of having an electronic scooter, mobility car, and a stair lift. Improvements on item 4 relating to putting on socks can be explained by Michael's dependency on his wife. He relies on his wife a great deal for daily general activities like getting dressed. As a result, the higher score on the Oxford Hip Score at one year follow-up cannot be attributed solely to assessing pain and function of the hip in relation to different daily activities. Michael answers each question in the context of other circumstances. By engaging in different coping strategies he changes his internal standards, values and re-defines his QoL (Sprangers and Schwartz, 1999) in a new context which makes the ground for assessing hip-related problems.

The identified areas of life on the PGI reflected Michael's physical and functional limitations related to the hip condition. As it was confirmed by the previous studies (Lintern, et al. 2001) the PGI is more likely to reflect negative changes corresponding to

a person's physical abilities rather than showing positive or constant abilities. The PGI is also less likely to represent emotional well-being. The PGI provides spaces for areas of life affected by other health problems and also non-health areas of life. These areas can be rated and given points. However, participants are not given an opportunity to specifically identify these areas. It is only through the narrative interview that Michael connects the hip-related physical limitations to other life events and re-interprets the health experience in the light of the new created context. For example, he reduces the negative impact of his functional limitations by drawing attention to his family, his artificial mobility aides, his house and his full pension through downward social comparison.

Summary

The impact of the reinterpretation of the disease experience over time on patient health outcomes can be demonstrated to some degree by the participants' accounts and their personal language. Moreover, score change on different sub-scales of the SF-36 and the Oxford Hip Score is justified by gaining more insights into the participants' accounts. For example, Helen showed improvement in social functioning and mental health dimensions of the SF-36, despite decline in her physical functioning, role functioning and pain. In her narrative interview she shows that she has no control on her health-related limitations, so she reframes her expectations to lessen the negative impact of her disability. Also by positive reappraisal of the stressful situations, she discovers a positive character for herself which becomes the target of many downward social comparisons. Michael's improvement on most dimensions of the SF-36 as well as his higher score on the Oxford Hip Score at one year follow-up is not only assigned to the evaluation of pain and functional ability of the hip. Improvements on some items of the Oxford Hip Score are related to his preference for problem-focused coping strategies such as using mobility aides. His dependency on his wife for daily general activities can also explain his improved score on the item related to getting dressed. As a result, he maintains his level of vitality, role emotional, mental health and general health through problem-focused coping strategies and downward social comparison. His family, his artificial mobility aides, his house and his full pension are the targets of the comparison.

4.5. Performance analysis

The approach I undertook in the analysis of narrative is grounded in a new social sciences paradigm in which "positioning" and "roles" are the main contrasting concepts. The dynamic concept of positioning rather than the static concept of role is used by people to handle a situation (van Langenhove and Harre, 1999). Davies and Harre (1999) define "positioning" as a "discursive process whereby people are located in conversations as observably and subjectively coherent participants in jointly produced storylines"(p.37). They identify two forms of positioning: "interactive positioning in which what one person says positions another and...reflective positioning in which one positions oneself (Davies and Harre, 1999, p.37). Bamberg (1997, p.337) in a similar move identifies three different levels for positioning in the form of three separate questions:

1. "How are the characters positioned in relation to one another within the reported events"?
2. "How does the speaker position him or herself to the audience"?
3. "How do narrators position themselves to themselves"?

When people talk or write about their experiences they are less aware of their personal identity as a stable individual over a life course. However, they have more knowledge of their social identity as the product of their interactions in different contexts (Goffman 1959, cited in Harre and van Langenhove, 1999). Therefore, the self as a stable unique entity and the selves with characteristics of multiplicity and changeability are the focus of positioning theory in the analysis of narrative (Harre and van Langenhove, 1999). The notion of self has features similar to the characteristics of oral stories. Oral stories change because they are product of an interaction between a narrator and a particular audience in a specific context. They are told in accordance with the audience's requirements and interests. The written stories, however, lack the dynamic properties of oral stories as well as the self(Harre and van Langenhove, 1999).

Sabat and Harre (1999) use the methods of constructionist psychology to analyse discourse accounts. The significance of language in creating social identity and the importance of linguistic skills in managing thought and experience underpin the constructionist theory (Sabat and Harre 1999). Applying the analytical methods of the theory to the interview account of an Alzheimer's disease (AD) sufferer, they illustrated two kinds of "self" in his account:

1. A stable personal "self" whose character remains unchanged over the course of the disease.
2. A changeable self or selves created as the result of social interactions and not the disease, and how the disease sufferer is perceived by others.

They showed how the AD sufferer constructs his story grammatically and uses the indexicals "I", "me", and "my" that indicates an intact self. In other words, he does not use the grammar of helplessness (Capps and Ochs, 1995), instead he positions himself as an active agent through the interview. Stressing the importance of meanings and themes, Sabat and Harre (1999) also demonstrated variable selves in the AD sufferer's account, such as a family burden and a scientific collaborator in the study. For example, given his background as an academic, he preferred to be identified as the study's collaborator rather than a subject. A new study (Scarmeas, et al. 2006) examining the relationship between education and rate of decline show that AD patients with higher education lose their cognitive ability faster than patients with lower education. The positive association between education and rate of cognitive decline shows the vulnerability of social identity in social interactions. The social identity of highly educated patients is influenced significantly by the way other people understand and see them.

Case studies

The following interviews with Participant S and Participant V were the first interviews with them which were conducted in a hospital environment.

Case study 1:

Episode one: the first pre-operation period

Nasrin: Please tell me about your experience of hip condition and how things happened up to now? Start wherever you like and take all your time you need.

Helen: Do you mean with the way it started or since I had the operations?

Nasrin: Um, wherever you like to start, since it started or [

Narrative lines	Scenes
Helen: Yes, well, um with my right hip,um I thought I'd strained some muscles in the groins and I went to the doctor and he said he thought it was a hip problem and um but, I coped for a number of years really	1 2
and um then I started to have, I I couldn't get in and out of chairs, it took me ages and I I was having problems	3
and I went to the doctor and um I had an x-ray and when I saw him, he he said: well, it needs a hip operation straight away AND I'VE KNOWN THE DOCTOR FOR A LONG TIME and I said: well, if you were me what would you do and he said: well, try physiotherapy, but if the hip's gone too far, it means it had to be done.	4
Before I had the operation I thought I would try and swim and when I went to the swimming bath I realised how the movement'd gone. Um, you know it is amazing that I hadn't been swimming for a while and I realised that the hip just wouldn't do it.	5
Um, but I did persevere and I went every morning with a friend and tried to do the swimming, thinking that it would done me good.	6
Um then I had the the operation.	7
I was working, um running an after school club,	8
and um my biggest problem was that the hip used to give way without any warning. Um, it wasn't the pain that made me, the hip give way. Um, it was if I was on an uneven surface or on a step and suddenly I was down	9
and I had a nasty fall down on a friend's stairs, very very lucky really and I had a nasty haematoma in my arm.	10
The house I used to live the stairs um, you came down five steps and then on a little bit that you walked on and then another five.	11
The number of times I fell down the second bit, I don't know why, fortunately I didn't fall far, but it was amazing, I didn't really injure myself.	12
When I came in in the car and I stopped at the top of the drive and I got out of the car, I couldn't move, it was a pain from top to bottom like severe cramp and I had to wait a minute and it kind of cleared and I went to open the garage door, drove in then when I got out of the car, the same thing	13
and I really got problems for so long getting in and out of the chair and I couldn't do a lot of work in the house.	14
I've been I've been employing a gardener and a cleaner for floor for a number of years, um because I couldn't cope	15
and I was waiting 18 months for the hip	16
and decided I have to give my job up, because I realised I couldn't even go out anymore. I had to stay in the house	17

My open and temporally limited question introduces a specific topic for Helen that is her experience of THR intervention. I did not give her any direction and she was left to provide her preferable account of hip experience.

I analyse Helen's account as well as the next following case as the performance of identity (Riessman 2002) by focusing on two theoretical approaches: narrative

positioning (Bamberg 1997) and the use of grammar, grammar of helplessness and grammar of abnormality (Capps and Ochs, 1995).

Helen begins by constructing a story during the time before the hip operation and positions herself as the central character who has active role in making decision in the pre-operation time (Bamberg 1997). The use of active verbs in the sentences in the pre-operation story indicates an active role, particularly in relation to the other character within the story that is Helen's doctor.

In her communication with the doctor, she gives herself a speaking role and tries to strengthen the experience by using reported speech (Scene 4):

I saw him, he he said: well, it needs a hip operation straight away and I've known the doctor for a long time and I said: well, if you were me what would you do and he said: well, try physiotherapy, but if the hip's gone too far, it means it had to be done.

The quoted direct speech may not been the original remarks, but they are not used simply to add information to her account. They describe how Helen prefers her coping strategies before the operation to be approved by an appropriate person who has the authority and would express evaluation of the interventions she seeks pre-operatively (Sawin 1992). "... and I've known the doctor for a long time" also stresses how important it is for her to be evaluated by a person who she finds acceptable. She does not position herself passively in her interaction with the doctor. Harre and van Langenhove (1999) differentiate between reporting an event and narrating it. The direct speech Helen used refers to the time and space of the narrated event and shows a personal and self-positioning act, while being the subject of mere reporting lacks the characteristics of a lively narrative. Using a direct speech in the narrative event with me,

Helen shows her dedication to the narrative experience (Harre and van Langenhove, 1999).

In scene 5 the use of mental verb “think” constructs an interaction that Helen conducts with herself. The listener in a narrative interview is not limited to the interviewer. Interviewer, story teller and others who are not present, e.g, health professionals, comprise an audience that participates in the interaction (Langellier 2001). Helen engages in a conversation with herself in scene 5 “...*I thought I would try and swim ...*” and in scene 6 “...*and tried to do the swimming, thinking that it would done me good.*” In her communication with herself shown by the use of verb “*to think*” she pictures herself as vulnerable and lowers her active role by frequent use of the verb “*to try*” which “implies that the attempt (by an agent) was unsuccessful” (Capps and Ochs, 1995).

Her active positioning in the story is overshadowed by the presence of some paranormal forces that are evident all through the interview. She locates herself in a world that rewards her luck and fate (Bamberg 1997). In scene 10 she talks about her pain and functional limitations and how the hip keeps on giving way, but at the end of the day she is always favoured by a value:

*“I had a nasty fall down on a friend's stairs, **VERY, VERY LUCKY REALLY.**”*

or in scene 12:

*“The number of times I fell down the second bit, I don't know why, fortunately I didn't fall far, **BUT IT WAS AMAZING**, I didn't really injure myself.”*

Although Helen is the subject of most utterances and pictures herself as the core agent in the story, she uses some grammatical features to lessen this role. She uses negative verbs to give herself a vulnerable and weak position, for example in scene 3 “... *II couldn't get in and out of chairs ...*” She also intensifies the presence of some forces that

are acting upon her. In scenes 10 and 12 she amplifies these forces with even amazement, using the word *"really"*.

Analysing scenes 10 and 12 by applying "narrative positioning" and through the use of "grammar" indicates how Helen is subordinated by unknown dominant forces that reward her luck and fortune. In scene 11 Helen uses the pronoun *"you"* to pull the listener(s) closer to the scene she has experienced (Tannen 1989).

She describes her vulnerability before the operation by using the grammatical modal verbs that "indicate that someone undertakes an action out of obligation or ... necessity or that someone does not undertake an action because it is impossible" (Capps and Ochs, 1995). In scene 13:

"I couldn't move, it was a pain from top to bottom like severe cramp and I had to wait a minute and it kind of cleared and I went to open the garage door ..."

She also de-intensifies her experience of pain by using the form *"kind of"*, showing that she manages to perform the act.

She starts her story by raising how much she has coped through years and strengthens it by using intensifies in the form of *"really"* (scene 2). Helen continues her story of hip condition, diminishing her agentive role by frequent use of negations as she develops her experience of hip condition before the operation, while reinforces outside forces by the grammatical form *"really"*. She positions herself in a situation that is beyond her control half way through the story when she uses adverbial phrase *"suddenly"* in scene 9. "These adverbial phrases are abnormalizing devices in that they mark a transition from a normal to an abnormal condition" (Capps and Ochs, 1995). She describes her character helplessly when she says:

" ... my biggest problem was that the hip used to give way without any warning, um it wasn't the pain that made me, the hip gave way."

The grammatical phrase *"without any warning"* and the verb *"made"* assign Helen in a position with little control and autonomy. When she eventually reaches the end of the pre-operation story she emphasises her vulnerability strongly by double use of negation and modal verbs in scene 17:

"... and decided I have to give my job up, because I realised I couldn't even go out anymore. I had to stay in the house."

Campbell (1968) describes illness as a journey with a departure that begins with a call. The call is in fact the symptom of the illness and is often resisted by the person, as the ill person is aware of pain and misery associated with the illness. In the pre-operation period Helen seeks different coping strategies to reject a possible hip operation, though she has already coped for a number of years. She tries alternative, conservative and more informal interventions after consulting her trusting doctor who recommends physiotherapy. She also initiates self-motivated activities to help her avoid the operation. She tries swimming as a personal intervention and despite significant loss of hip functioning she would not give up on it. In scene 6:

"Um, but I did persevere and I went every morning with a friend and tried to do the swimming, thinking that it would done me good."

The pre-operation story is organised into two main sections separated by scene 7

"Um then I had the the operation" echoing Helen's resistance to the hip condition and her main physical problems before the surgery.

Before scene 7 Helen engages in various coping strategies to hinder a possible operation, nevertheless, the burden of the symptoms, constructed in scene 8 and onwards, are so limiting that they cannot be refused any longer. After years of coping and resistance, she eventually had the operation done. From this point, she constructs scenes in which she justifies why she had the operation. Pain and functional limitations which had great

adverse effects on her personal and social life are described in detailed narrative to give a clear picture of how life was before the operation. Despite being an active person, she had no choice but employing a cleaner and a gardener, because she could not cope any longer. She quit her job, because she could not even go out anymore.

Episode two: The first operation

Narrative lines	Scenes
and Christmas and on Christmas Eve I got the letter to say that my hip...appointment was 2nd Jan. So I gave my job up and was nearly 67, so it was time that I did	1
and then when I was waiting outside the theatre, Mr. S. came and said the other hip was as bad. Well, I wasn't really aware of that. It may sound strange um, but I said to him: well, I'm fine. I'm not aware of any problems	2
but I had been on anti-inflammatory drugs for about five years	3
and (short pause) when I had I had an epidural for the operation. I have to say I couldn't understand I thought I would be frightened, but I wasn't. I don't know why I think I was just relieved	4
and um I had an epidural which went a dream, the operation went well	5
and when I came out of the anaesthetic I felt I'm on a high, because the pain was so much better. I can't... you get used to pain and it wasn't there	6
and the operation just seemed fine. I know I sound strange, but that is how I felt and I was just laughing and chatting and I thought well this is just wonderful	7
Um when I came I asked Mr. S. then if I could do with the other hip while I was in, because he said it was bad and he said no, because he hadn't put I think it was cement as much in, because with my age he thought, there was only perhaps 10 years it would be last and therefore it may have to be redone, so he couldn't do the other hip.	8

At the beginning of the first operation story, she is dominated again by the power of her faith when she mentions Christmas Eve as the date she receives her hospital appointment for the operation. This is not just a simple coincidence, but has a profound meaning for her. She is being safeguarded by outside forces which seem strange, unknown and confusing at some points. Receiving the hospital letter on Christmas Eve is one of those occasions, which she feels lucky and rewarded by her faith. This value is also reinforced by her voice tone and her gestures. After the appointment is confirmed, she immediately concludes that *"So I gave my job up and was nearly 67, so it was time that I did..."* As an agentive character, using an active verb, she quits the job. However,

she engages in social comparison in the form of age comparison to possibly maintain her level of satisfaction with QoL (Gibbons 1999). Before using this kind of coping mechanism, she gives herself a relatively minor role in the pre-operation story in scene 17 when she uses a modal verb plus negation to explain how and why she gives her job up.

The operation story starts on Christmas Eve, when she receives the hospital letter. She constructs scenes outside the theatre before the operation, during the operation and after the operation. Helen's position and the salience of the story are similar to the pre-operation story. She is still at the centre of the story, but the use of negation, mental verbs, and intensifiers diminish her active role and demonstrate her vulnerable position in the story. She uses direct and indirect speeches to narrate her communications with her doctor. She reflects on her experience and describes her feelings to herself and the interviewer. As she performs the story she unfolds the positive feelings associated with the operation. She does not alter the tense of the initial quotation after the mental verb and express it as a direct speech "... I thought well this is just wonderful." Somewhere else when she represents her intentional action in the narration event, using a modal verb, she again addresses herself to feeling of fear, which turned out to be false, leaving her in confusion and amazement again "*I have to say I couldn't understand I thought I would be frightened, but I wasn't*" In scene 2 she claims the familiar unknown phenomenon when she says "*It may sound strange um, but I said to him: well, I'm fine. I'm not aware of any problems ...*" and the same claim in scene 5:

"I know I sound strange, but that is how I felt and I was just laughing and chatting and I thought well this is just wonderful."

She brings the audience closer to the experience by using the pronoun "you" to deliver her message of pain suffering and how it feels when pain is gone and does not exist

anymore. She positions herself in a passive situation in relation to pain "... *I had been on anti-inflammatory drugs for about five years ...*" Yet, when pain is not there anymore she casts herself as the active character:

"... I felt I'm on a high, because the pain was so much better I know I sound strange, but that is how I felt and I was just laughing and chatting..."

Episode three: The first post-operation period

Narrative lines	Scenes
Um, the thing I wasn't prepared for was how little I could do. That was a shock to me after the operation. You know, you can sit in a chair, you've got to keep the 90 degrees, you can't go forward.	1
I am a widow. I've been a widow now it's fourteen years.	2
Um, if I lost a crutch I wasn't allowed to get down.	3
Living on my own it was difficult,	4
um and getting um I couldn't stretch to one side. I thought I was prepared,	5
but it was an awful shock how little I could actually do, because I realised if I wasn't careful, it could dislocate and um that took a lot of adjusting for me	6
and living on my own you know the home help's came in a little bit, but they don't get a lot of time	7
and once or twice I got in a mess um and I felt a bit frightened of the stairs, you know I thought I don't know what I am going to do,	8
but um then I've done very well with the first hip.	9
I've lost, Mr. S. said: I've lost movement for bending and getting down to things	10
and I had to get in a car in a certain way and there is loads of things in the house I just can't do anymore and I can't get down.	11
That um it's not bothered me. I mean you just adjust and I think well, it's no big deal. I'm just relieved, that I am on no pain killers,	12
I can walk about and I could walk very very well which was wonderful and I thought well if I could do that, I haven't been doing that for so long.	13

Helen starts the post-operation story by constructing a passive and subordinated position for herself. She attracts the interviewer's attention towards the experience by using the pronoun "you" instead of "I" and then pictures herself vulnerable by multiple uses of the grammatical structures, which indicate helplessness, such as applying modal verbs, negation, passive verbs, mental verbs, and preserving the tense of the quotations (Capps and Ochs, 1995).

In replacing the pronoun "I" to "you", Helen shows her perception of self at the time. The use of the distant "you" indicates the isolated self soon after the operation (Riessman 1990). She says:

"That was a shock to me after the operation, you know. You can sit in a chair, you've got to keep the 90 degrees, you can't go forward"

The change from the individual "I" to the universal "you" is observed throughout her narrative. For instance, when she describes her experience of pain in the first operation story: *"I can't ... you get used to pain and it wasn't there"* or when she talks about adjusting to the limitations she was experiencing after the first operation, she describes a different self from what she wishes herself to be: *"I mean you just adjust ... "* (Riessman 1990).

In the post-operation story she minimises the significance of her agentive role through the use of particular grammatical structures and repetition of thematic structures such as *"a shock"* and *"an awful shock"*, which shows her sensitive and defenceless character against the hip related problems. She also amplifies the level of difficulties arising from the hip when she says *"... 'cause I am a widow"* and *"Living on my own it was difficult..."* and reiterates it a few lines later: *"... and living on my own you know ... "* Nevertheless, at the end of the story she prefers a more active persona for herself by using more active verbs. From a psychological perspective, she engages in intra-personal temporal social comparison (Gibbons 1999). She is relieved that she is not on painkillers anymore and can walk which she has not been able to do before. She engages in social comparison which is demonstrated by internal conversations with herself by using the mental verb *"think"*. She draws the interviewer closer to the incident *"you just adjust"* and employs a mental verb to disclose her thoughts.

Episode four: The second pre-operation period

Narrative lines	Scenes
Then the other hip was playing up, well I did realise that then I did have a lot of pain and had to keep on with the tablets	1
and when I saw Mr. S. I went on the waiting list	2
and um (short pause), but there again I didn't have pain and I wasn't in the mess with the second hip as with the first as much, but um the hip was bad	3

She does not give detailed narrative in the second pre-operation story. Only by describing physical limitations and pain, she moves to the next story without scrutinising any feelings and meaning involved in the second pre-operation story. Having experience with the first hip, she compares her situation with the first pre-operation time. The lack of narrative detail in this story decreases the importance of second pre-operation experience (Riessman 2002).

Episode five: The second operation

Narrative lines	Scenes
and when I actually did come in after about 15 months to have it done, Mr. E. did it and he said it had deteriorated a lot and that	1
um when I had the operation done, it was a longer op. than the other. I have to say as far as the op. was concerned and the epidural, it seemed totally different. It did bother me the epidural and I wasn't worried about it.	2
I was expecting the same as the last time and it wasn't the the lady who went in to my back, I don't know whether she hit a nerve twice, but I nearly hit the roof.	3
It was strange, because I felt I was in a dispensary and everyone was round me, I wasn't aware of that with the first time at all and um I was aware of the feeling in my legs going which was odd. They packed me for the op with like bean bags or something,	4
all very strange to me, because I don't know why I wasn't aware of that with the first,	5
but I did feel very ill after the op in the recovery room. I couldn't... felt dreadful. I couldn't stop shivering and I think I was in there for a long time. I really felt quite ill.	6
Um, when I came out I still didn't feel myself at all and then I don't know what it was in the end, I couldn't spend a penny	7
and um (short pause) um I felt shivering again as I was going to ... just shiver and they sent for a doctor and I think he increased the drip and the flow was very quick, because I could feel it coming in me cold and he said	8
....and also I did have a problem which I've always had all my life with a very low blood pressure which I have to be careful about standing up after an op and I think that had dropped very low,	9
but when he came back he said he was very pleased, because he said the numbers and figures were a lot better.	10
After that I did very well, I did very well.	11

In the second operation story she represents herself as the target of other characters surrounding her in a hospital environment. She gives herself a passive role by selecting verbs and themes. She is the object of medical professionals' actions and the actions are being performed upon her (Scene 4):

"They packed me for the op with like bean bags or something, all very strange to me..."

The nature of this type of outside force is different from the force which rewards her time to time. Helen keeps on comparing her situation in the second operation with her situation in the first operation story, she did the same comparison between the first and second pre-operation stories. She states clearly her negative experience of the second operation compared to the first one. It is not clear to what extent this comparison has impact on Helen's judgement of the second operation. What is clear is that in both stories she prefers a vulnerable role in relation to other characters, though both incidents seem important to her as she provides narrative details. However, in the first operation story she is more likely to be rewarded by the outside forces, while in the second operation story she is helplessly being controlled by the force (Bamberg 1997).

Finally she repeats her last sentence twice and finishes the story: *"After that I did very well, I did very well."* At this point of the interview, she makes an effort to carry on with the narrative, so she uses repetition in her conversation before she could decide what to say next (Tannen 1989). At the end of her long story by "exit talks" she signals that she is ready to proceed with a new question (Riessman 2002).

and is that. Is there anything you want me to [

Nasrin: [No, go on.

Helen: I'm not chatting too much, am I?

Nasrin: No, you're not.

Helen: I'm just trying to say how things were um in between the operations when I had the first operation I realised ... well I had had strange problems, which do you want to know of it?

Interviewer: Yeah, yeah sure.

Helen: Nothing to do really with the op.

Episode six: The rat story

Narrative lines	Scenes
Um, I came home, I got the home help. I didn't live at home two weeks after my op. the first hip. I found I thought somebody's trying to get into the house at night.	1
Um, (short pause) and I was up all night and when the house help came she said: I think you've got mice, but to cut the story short I had rats.	2
Don't ask me where they came from, I think while I've been absent, I found out after wards the detached house next door had had them for months and they hadn't had the people in it and so how they got in, I had no idea	3
and the man who came said he thought I would be as well moving out, or other wise I had to seal the doors and it wasn't hygienic in the kitchen and I think really they were all over which was horrifying. I can't I felt awful. Can you imagine how I felt?	4
Nasrin: Yeah.	
And so um I thought well I have to find somewhere to go and um my daughter-in-law said: well, you have to ring the home help, they would come in, in the morning and would wonder where you are and think you had fallen in the house.	5
So when I phoned up her and I said: I don't know where I'm going to go and what I'm going to do, she said: leave it with me	6
and they phoned back in half an hour and had got me into an old people's home um which did me the biggest favour in my life,	7
because I went to 0. which was um run by church organisation, because I go to church and I have my faith and the atmosphere suited me down to the ground. I was spoiled. I thought if this is an old people's home, I have nothing but praise and I felt it was like a fortnight of CONVALESCENCE	8
and because it was on the flat outside, which my own home wasn't, I could practise walking with crutches and I used to go a little way, come back to the home. I didn't go long way and that fortnight put me on my feet, isn't it strange?	9
and when the house was clear I paid someone a lot of money to clean and they cleared the cupboards, they did everything, because I didn't know where they had been and I had to be clean	10
and it cost me a lot of money that, a lot of money, because the kitchen carpet was in shreds, um they chew wires, I couldn't believe it, would you?	11
So with the home and I did get a 100 pounds for each week from the social service, which I didn't expect, but I had to buy new carpets and all sorts	12
...My son came to help ((interruption)).	13
When I came home, my son had got the house nice and warm and when I got in I thought oh I'm going chilly. I'm going to bed. The boiler was gone, the central heating, boiler.	
So there many problems that were very big problems to me, that was sorted out.	14
	(coda)

When Helen, at the end of the second operation story, repeats herself "*After that I did very well, I did very well.*" in fact she signals a change of scene and diverts the story to a

new event (Gee 1991). However, before she proceeds with the new story, she wants to be prompted by asking *"Is there anything you want me to ..."*? My resistance to provoke her to a new subject encourages her to provide a detailed narrative on a story, which is different from the rest of the account. So far Helen has constructed different stories with various characters alongside herself. These characters are all health professionals including her doctor, the surgeons, the anaesthetic specialist, nurses and theatre nurses. In the rat story Helen introduces new characters the man (worker), her daughter-in-law, the home help and her son.

The rat story is significant for Helen for different reasons: First, she constructs the story in narrative detail and describes her feelings about the incident and its subsequent events. Second, she talks about her belief in an explicit way for the first time. Unlike the first operation story in which she presents some implicit faith and belief, while the listener(s) are left to draw conclusion, in the rat story she clearly states that *"... I go to church and I have my faith ..."*. Furthermore, she tries to raise and enhance the story by including the linguistic device of reported speech. In her conversations with her daughter-in-law and the home help she reports direct speech. Reported speech creates a distance between the narrator and the message she intends to deliver. By using reported speech, the narrator represents herself in a way that is in accordance with her values and standards, while ensuring that the audience receives her message, otherwise the audience would never hear it from her directly (Sawin 1992).

In scenes 5 and 6 Helen constructs a narrative in which she is the object of other characters' actions with a minor role for herself. Before reporting her conversation with her daughter-in-law, she engages in an internal dialogue with herself, reflecting on her experience. The mental verb *"to think"* and the modal verb *"have to"* are good evidence

of her vulnerability. She gives significant weight to her daughter-in-law's point of view about ringing the home help. She also reports her conversation with the home help in direct speech, giving special importance to her opinion. When she says "... *I said: I don't know where I'm going to go and what I'm going to do, she ((the home help)) said: leave it with me ...* " she constructs a narrative in which she is helpless and has no responsibility. Later on in her account, when she reaches to the narrative's sensitive point of faith and belief, the importance of the above mentioned characters' opinions becomes apparent. It sounds that an outside force was acting upon her to get her to an old people's house, which was run by church. This outside force implements its act via these two characters. She stays in the house for a fortnight, a fortnight of "CONVALESCENCE "that" ... *put me on my feet, isn't it strange?*" Helen reiterates her amazement, a familiar performance in her narrative.

She positions herself in two different atmospheres: a church-like atmosphere which "... *suiting me down to the ground* and home atmosphere. When talking about the church-like atmosphere she initiates an internal conversation with herself through the verb "*to think*". She recreates her feelings about the old people's home as she is experiencing them in the narrative event, because she preserves the present tenses of the reported verbs "*I thought if this is an old people's home, I have nothing but praise ...*" The same pattern can be observed when she constructs narrative on her arrival home "... *when I got in I thought oh, I'm going chilly. I'm going to bed*" However, the meaning and thematic differences between these reconstructed feelings delivers different messages.

A narrative plot consists of two distinctive materials: main line of plot and off main line of plot (Hopper and Thompson, 1980). The main line materials are normally

characterised by the past tense and sometimes by the conversational historical present, a change from past tense to present tense, as a reinforcement tactic to enhance the narrative plot (Wolfson 1978). The off main line of plot includes states, repeated events, habitual events and generic events (Gee 1991).

She provides narrative detail for some stories, showing that these stories are noteworthy to talk about. The second pre and post operation stories are those events that Helen does not talk about them in detail and therefore are not significant for her. The only narrative she provides for the second post-operation story is that "*After that ((the second operation)) I did very well, I did very welly*" At this point, she changes topics and talks a great deal about an experience, which I call "the rat story". She finishes "the rat story" by a concluding section or coda and returns to the overall topic of the story "*strange, big problems*" (Gee 1991). After "the rat story" we cannot see any major narrative. Therefore, I organised non-narrative chunk of the text under off-main line of the plot where she stops the narrative. She returns to the narrative when she talks about her move into a new flat between two operations and how hard this has been for her. Nevertheless, she manages to do it as the best thing she has ever done.

Off-main line of plot

The second hip was a dream for recovery.

The second hip, the recovery was cemented in and all I can say is you would probably know what hip has had.

The second is so much better from the first. I hardly know I've had it done and you see how I've got a problem with the right hip the first one and to be perfectly honest I feel I'm back to where I was before (laughs) I had it done.

So I don't know ...I know they don't want me to have it redone and trying to force me, keep it as long as possible,

um but as far as I'm concerned I have to be mobile, because I've got macular degeneration and anytime, I don't know how long it will be I'll be registered partially sighted and that would more or less be it.

I think it's no good giving me another hip later, I want it now and I want to be mobile now, while I have my sight. I want my quality of life now and I want to know the score and I am really going to be quite firm today, because I think I could understand. I really must... I feel... I'm disappointed that I'm not seeing Mr. S.,

., because um there is something going on that is not right and if I've got to be on severe pain killers, I'll be very limited.

Um, I don't know whether you can have three hips done and they're perhaps thinking of 70, 10 years there may be another op and I don't know whether they do three, but for me ... I'm probably going to be house bound in any case with my eyes. I feel I'd rather be mobile now and that's I think that's it. I don't want it you know, yeah

I think Mr. S.'s marvellous, I think he must get satisfaction from seeing the difference he makes, because he certainly made a difference and I'm certainly not complaining, because this hasn't lasted and I'm not complaining at all. I'm very very grateful and they are very clever men

and (short pause) if I have to say anything and I really don't like saying this, but the difference in the nursing care between the first hip and the second. It was bad for the second and it's that that frightens me, if I had to have another op.

Narrative lines	Scenes
I've moved between the two ops into a flat, because I realised I have to do which has been wonderful.	1
I've got the most beautiful flat, um not very big, but to me. It's got a lovely garden and a view which makes it for me which you can make your own home nice.	2
So all that has done which has been hard.	3 (coda)
I thought I was rushing between the two hips and it was it was a lot of it took some doing, but it is the best thing I have ever done.	4
Now I can't drive, you see and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden. I can sit in which I wouldn't ve settled without it, because...um so yeah all I know um (short pause). I've done that which was needed to be done,	5 6 (coda)
because where I lived before I realised it was steps, steep hills, couldn't get to shops, um just wasn't suitable anymore.	7

The narrative structure of Helen's story can be characterised by Campbell's notion of journey of illness (1968). He describes illness as a journey in three stages: First is the departure, begimiing with a call as the disease's symptoms which are resisted by the patient. A multilateral approach to analysis of the first pre-operation story shows despite the fact that Helen has been helpless and vulnerable in the pre-operation time, she tries to turn down a hip operation when she says "*Um but I did persevere ...*" Finally, the physical, emotional and social burden of hip condition led Helen to resign herself to the operation.

The second stage is initiation or as Campbell calls it "the road of trials" (Campbell 1968, p.97). It involves all the sufferings a patient experiences during a disease trajectory. Helen narrates in details her experience of hip condition in the operation and post-operation stories. She not only describes her experience of pain and misery, but also she talks about her feelings of ease and relief. As a result, it is not only adversity that the patient faces along "the road of trials", but encountering pain is accomplished in the light of some senses of alleviation and relief

In the first post-operation story, in scenes 12 and 13 she returns as a person who has been affected by the illness, but is relieved to some extent that the illness is not there any more (Campbell 1968). Also, from a psychological perspective, she compares her present situation with the difficult days before the operation, which were associated with pain and functional limitations. This temporal downward social comparison can result in more promising level of QoL for Helen.

After concluding "the rat story" in which Helen engages in some sort of spiritual coping mechanism, she returns to her body, to her illness and to her problems. She performs the off-main line of plot to an audience of mostly medical professionals. Unlike her previous stories in which she performs a dialogue with herself and reflects on her experience using mental verb *"to think"*, in this part of her account she clearly talks to medical practitioners as her audience. She casts them as the agentic characters who *"... don't want me to have it ((hip operation)) redone and trying to force me keep it as long as possible..."*

Helen moves between her body and the advantages she is blessed with. She has got a beautiful flat with its lovely garden as a positive result of the hip operation. She moves to this flat between the two operations, because her previous house was not suitable for her anymore. Moving to the new flat which *"... has been hard... "* and *" ... a lot of it took some doing, but it is the best thing I have ever done."* In fact, despite the fact that her problem with the right hip still exists and *"... to be perfectly honest I feel I'm back to where I was before (laughs) I had it done."* she focuses on domains of life that make her seem more dominated (Schulz and Decker, 1985). In other words, a beautiful flat can cushion the burden of her physical disability (Gibbons 1999).

As it is noted from Helen's account she suffers from multiple disability, the functional disability resulted from hip problem and the visual disability as a consequence of macular degeneration, which leads her to be partially sighted. As she says:

"Now I can't drive, you see and I've got a beautiful view and if I'm going to be housebound, at least I can I've got a lovely garden I can sit in, which I wouldn't ve settled without it... "

She directs her focus from disease related problems to the primacy of the comfort of her home. She uses the adverb *"at least"*, which is defined as "at all events, anyway, even if there is doubt about a more extended statement" (The concise Oxford dictionary 1990). While she is in doubt about the possibility of a bigger assertion related to her physical ability and functional performance, she presents some form of implicit superiority, which is having a beautiful flat with its lovely garden.

Episode seven: The pre-condition period

Nasrin: Do you remember how life was before you developed your hip condition?

Narrative lines	Scenes
Helen: I have to say I was extremely active and you see I had a husband who had heart condition most of his life, and um really it was high blood pressure which he was born with it, he didn't develop it	1
and he had his first severe heart attack at 38,	2
um at 31 he was in hospital with heart failure, just the high blood pressure hadn't been controlled,	3
so I did all the heavy work which didn't bother me at all,	4
because I was I mean ... I was physically very strong and I have done a lot work,	5
because David's parents, David's father had a hip operation done, it wasn't successful, so he was more or less in a wheelchair. His mum had heart trouble, we moved them near us, so I loved looking after them in their own home,	6
looked after ...David worked he managed to work, you know. He gave up his business. He had his own business, plumbing and heating.	7
He gave that up, but he had a job estimating. Um and they were wonderful to him, thought the world of him really, but his health was dodgy and if he couldn't go to work in the Winter, they brought the work to him and he did the estimates at home, not many companies wouldn't done that,	8
and he got about 50 and he had three heart attack in 18 months and they just couldn't stop them and they said they wanted to do a by pass not for the normal reasons, they didn't know whether there would be any benefit actually.	9
Um when they operate, they said to me the heart was badly damaged and they never thought he'd pull through the op, but he did and with 4-5 good years after, um but they told me that the heart really was so badly damaged they wouldn't even actually done the op if they had known him and because he died	10
and but I was doing all the garden, the work, when there was David's parents, I looked after David's parents right up to the end, you know they were just down the road. When David's mum, her heart was quite bad and she was in a bit of mess, we brought them to my home for a while and they lived with me, then they went back home and	11
then my parents weren't well, so when David's parents died, we moved them into the home again. You just ... If you walk it's five minutes and in the end I had to keep my father. My mother died and I had to. It was all tough really, hard work,	12
,um because my mum was in hospital with the cancer op, on the same day, the day as David was in NG for his by pass, see you can imagine how I felt.	13
Um, but my brothers took over and they gave me a room at the NG, and I stayed there until he was out of intensive care,	
but David was lovely and cheerful and we didn't have a miserable life	14
and I did all the heavy work, all the gardening and looked after David's mum and dad, and it was rather sad, because my dad got two months off hundred and I looked after him and he died and I started with my own problems, didn't I? It's 8 and half years and and so I mean really I did a man's work,	15
but I can't... I liked decorating. I liked the garden,	16 (coda)
but David wasn't miserable, my parents were nice, David parents were nice, we just ...yeah we were all right.	17
mean, I mean I don't say... It sounds gloom and doom, but quite honest it wasn't, you know. We were ... David was cheerful and optimistic and he worked quite up to the day he died. He died at his desk	18
and that was a tough time after, a tough time after, because you know we were very close and in a strange kind of way, when you've got someone who was in that state (short pause) um you get closer, you made the most of what you've got and I still think I have that in me, because if anyone asks me I go and if I can do anything I do, and I have many friends.	19
	20

So is that any good? ((she laughs)).

Nasrin: Yeah, yeah. Thank you. I really appreciate your willingness to express your feelings.

Narrative lines	Scenes
I do think you can give up. Um, I got down a fortnight ago, because I really really thought I'm going to stuck in this house and	1
but um I can't... I can't get a plastic bag on the back seat, get my legs up, even get in a car.	2
Um, I just ...I can't, I don't know, I just can't do it, any way.	3

Nasrin: Thank you very much.

Helen provides her account chronologically starting with the first pre-operation time, because I introduced the hip experience topic in my first question. The pre-condition story is narrated at the end of the interview following another narrative-inducing question which tries to take the informant back to those days before the hip condition. She constructs a narrative plot with several characters beside herself, her husband, her parents, her in-laws, her brothers and the medical professionals.

In previous stories Helen's identity has shifted with reference to two different relationships, one is her relationship with medical professionals in a medical dominated world. In this world she is passively the object of medical characters that perform actions upon her, despite the fact that she is often the main character in most utterances and clauses. She uses various grammatical structures to demonstrate her passive and vulnerable position in relation to medical characters in her stories. The other is her position within a world dominated by outside forces in which she is blessed with luck and favour. To show her position within this world, Helen puts emphasise on the importance of meanings and themes, as well as, employing grammar of helplessness. Unlike these two worlds in which Helen has a passive role, in the pre-condition story she is the central character who acts upon others. She is the subject of many sentences, which are constructed with active verbs showing the narrator's intended actions:

" ... so I did all the heavy work which didn't bother me at all... I was doing all the garden, the work... I looked after David's parents ... "

Sometimes she shares the agentive position and the responsibility with her husband when she used the pronoun "we": " ... *we moved them near us ...* " Before developing hip problem, she constructs a narrative of her family life where she has a major role as the main character. A person who does all the heavy jobs, the gardening, decorating, looking after the husband who has heart problem, looking after her in-laws who are also ill and looking after her own parent till the day they die. After that she starts with her own problems.

By selection of active grammar and choices about positioning, she proposes the preferred identity (Riessman 2002) "*an extremely active*" person who "*... did all the heavy work...*" and "*... did a man's work...*" She interprets her past life in the light of her present circumstances and perceives her identity and her true "self" (Frank 1995). She realises that she has always been a hard working, physically active person who has loved looking after others.

Similar to what happened in off-main line of plot, at the end of the pre-condition story Helen returns to her body with its physical and functional limitations. The pre-condition story is mostly about Helen's husband's illness. She ends her ill husband's story totally different from hers. As a carer she accompanies her husband in his illness journey and when she returns at the end of the journey she had been given a gift by the experience, a new vision and perception (Frank 1995), which has remained with her. The repeated use of pronoun "*you*" in scene 20 once again emphasises the change of her understanding of the self in the past from her perception of the self at present (Riessman 1990).

From a psychological point of view, Helen reframes the stressful situation and makes a positive picture of it through the cognitive strategy of positive reappraisal, which results in a positive psychological state (Folkman 1997).

However, at the end of her own illness story, she returns to her body. Helen draws me close to what she feels in her present situation by using the pronoun "you". The general "you" makes a distinction between a real self and a self she is now experiencing (Riessman 1990). She uses the intensifiers "really" twice to expand on her current life experience. Then she employs the verb "thought" to reflect on her feelings in a conversation with herself, particularly when she gets very close to the experience by preserving the tense of the original sentence. Excessive use of negations, repetitions, pauses, lack of control and confusion are seen in her last sentences as well as elaboration on the limitation of functional performance.

Case study 2:

Michael: You want to know about the the operation the attitude for the operation?

Nasrin: The experience you had of hip condition and how things happened up to now.

Start wherever you like.

Narrative

Scenes

Michael: The hip condition started really about from being about 60 and uh before I reached retirement 64 I finished up falling on my face really and I had to be help to get back home and that's when I had to stop work three months before my 65 birthday.	1
Uh, the doctors told me as much as they could, but it was obvious I had to have the operation.	2
I had never been in hospital in MY LIFE for any long period or even day surgery,	3
so I weren't frightened, but I was very you know sceptical as to what was going to happen to me.	4
But as I said the whole thing went well.	5
Uh I would honestly say I would never be frightened to go for an operation again you know	6
and um what they told me that the biggest advantage I got from it was to get rid of a lot of the pain from the arthritic condition, but I wouldn't gain a lot from the mobility point of view, which is true. That's exactly what they told me.	7
The only thing HAVE to say was this post-operative trauma. I've never had anything like that in my life before and it came on a month or two after.	8
Uh I couldn't come to terms with it at first you see, like going in an aircraft as I said. When the door shut you're trapped you can't get out, not the fear of flight,	9
but it's the fear of being in a situation that I have no control, but now being what would it be over a year more down the line I managed to get control of it to the point I've never flown. I won't be able to be on an aeroplane till now but at least I can get on a lift. Uh I got that.	10

Nasrin: Can you explain a bit more about this experience?

Michael: The trauma?

Nasrin: Yes.

Narrative lines	Scenes
Apparently what I'm told one of the basic cause of it I mean I've led a very active life, at one time I had people I was in charge of, things like that	11
so I've led a very active life I've been in control. I've worked without supervision for a greater part of my life	12
and then suddenly came to a situation when you can't get about, you dependent on other people to help you. In another words, you lost your independency.	13
I couldn't live on my own now. I know that and I'm relying on my wife to help me with things like fastening buttons, you know generally getting dressed, sometimes at night arthritis getting that bad I've had difficulty turning over.	14
Uh these are things and all that in your mind that's what affects you. The sudden realisation that you've lost your independency, you know. You've got to rely on other people to help you	15
and I am coming to terms with it now like my own doctor which I am fortunate I've got a brilliant GP, I owe him a lot uh and he helped me, he explained it all to me and he gave me a special leaflet for use to read on it, and now you know I've got a more positive attitude to it.	16
I do occasionally feel uncomfortable uh even going on a lift now the time I get off it I'm sweating a bit, but I can control it. That's been one of the worse after effects, you know.	17
You see the other thing that's in my mind now if I have to go in a hospital again to have any other joints done, would I? I said to the wife if it was life threatening if somebody said you either have this operation or you die, then I would, because you have no choice (laughs), have you?	18
But if it's not a life threatening operation I don't know I should have it. I have to have a long think about it whether I want to go through with that,	19
because the experience after, the trauma was far worse than the operation. Operation I've got no problem (short pause). That was the worst experience this post-operative trauma	20
and I never knew that such a thing existed. I've never had anything like that in my life before, you know.	21

Nasrin: Do you think that you need to change things that are important to you after the operation?

Narrative lines	Scenes
Well, yes. You have to change your life.	22
I mean uh the one thing that I was determined that I wasn't going to be trapped in the house.	23
I am fortunate. I have a mobility car and I've also I got an electric scooter. So uh I've also got a stair lift at home, so all these things makes life just a little bit better, just gives you a measure of independency.	24
It was with the electric scooter I said to the wife, I don't want no body pushing me in a wheelchair, if I couldn't avoid it.	25
All that gives me independency, that electric scooter. I can buzz around on it,	26
so in that respect yes, I've sort of come to terms of being determined, I'm not going to become house bound and trapped	27
I mean I've just been down to Cornwall. I've been to see my son in Somerset. Well, it's only because I've got that little electric scooter I can get about on, you see.	28
So that has made a big difference in my life and it is a big change in my life now yeah so uh (long pause). I don't know what other things I can say. I owe a lot to my wife obviously. If it wasn't for her I don't know what I should do.	29
I depend on her enormously right now to what, you know I mean.Uh you feel selfish, don't you? Because you feel you're the one who should be doing things for her (laughs) and I depend on her more than anything.	30 31
Uh well, I rather not, putting it that way, I'm comfortable with it now,	32
first I found it awkward, but you know she says she understands it. It's not to be awkward.	33
You've got to realise the situation, because if you start how can I put it? If you start getting upset, show bad temper about it, you're not going to make it better. It won't go away, will it?	34
So yeah, I've come to terms with it ((depending on his wife)) now more or less. It's just one of them things, isn't it? You don't know what's coming to you in life.	35
I mean I worked from being 14. Fortunate or unfortunate either way you want to look at it, I've never been unemployed for even a short period of time,	36
virtually I worked all my life. I served in the forces, you look forward to retirement, what you're going to do, where you're going to go and the whole lot falls down	37
so you just you just can't plan for your retirement really.Uh the only thing you can open bridge when you come to retirement is that you can have good health, a good health makes a big difference, dramatically difference, it does. Two most important things in your life are obviously: mobility, being able to get about you know and keeping your mental faculties and if you lose any of those your mobility or your mental faculties obviously then your life is affected, isn't it?	38
My biggest loss ah ah touch wood up to now I have not lost my mental faculties. I can't remember things as good as I used to do, but my biggest loss is my mobility, not being able to do what I want to.	39
I can't think of anything else to say (short pause).	40
My family is good, you know. My daughter and all out there always help me. My son lives in Somerset, I go down there, because it's so nice down there, I stay with them for two weeks, a time, but yeah (short pause) I just make the best of it and carry on.	
I mean there are people worse-off than me, so I thought I should be thankful, I can at least keep going about, in that way, you know using my scooter and things, but I would rather be able to walk about like anybody else does (laughs).	41
That's life, isn't it? So I don't know what else to say really. You just got to take life as it comes (short pause).	42

Nasrin: Do you think you're trying to accept life as it comes?

You're trying to accept life as it comes, yeah, yeah. Sometimes you know, you get up in the morning, you think why me? Why has this happened? What have I done to deserve this? You know. I mean I'm an honest person, I worked hard all me life, I've never caused people trouble and then you know you see people've been absolute criminals, been in prison and they got a healthy life,

why me? What I have done to deserve this? But that's life. It don't work as you think, does it? You know.

Uh the people who you think well, you don't think anybody deserves this, but the people who you think might get punished for the way of life, don't seem to. Those who seem trying to be as good as they can in the life seem to be punished for it.

I don't know. Maybe one day I'll find out (both laugh), yes. I don't know. We have our own house. We don't live in council house or anything like that. We live comfortably, so in that respect we've got our independency there, so we're fortunate (short pause),

but still that's life. 47

Nasrin: Yes, thank you, thank you very much for your time.

Michael: You're welcome (laughs).

After I was introduced to Michael by the specialist nurse, we had a little talk about the interview procedure, so when I turned on the tape recorder, he was trying to get prompted by his question about the operation and shift the interview towards a medical interaction. My narrative-induced question, however, diverts him from the medical world and places him in the real world. Unlike Helen who creates her stories in a temporal sequence such as pre and post operative periods, Michael organises his account more thematically. Nevertheless, the topics he chooses to elaborate on are grounded in time, the time of his independency and the time when he is dependent on others, particularly his wife. He does not provide detailed narrative regarding his limitations before the operation and the operation itself, indicating that the experiences are trivial for him (Riessman 2002). Instead he introduces a topic, the post-operative trauma. As he described meanings and emotions related to the trauma (scene 9), my next question focused on the trauma experience, which prompted him to raise the topics of dependency/independency and expand upon them. He compares himself before and after the hip condition. Before the hip condition as an active person he is in control of

life situations. After the hip condition, however, he is a dependent person who can not live on his own. He makes a relationship between the unexpected loss of independency and the post-operative trauma, which leads him to hypothesise the loss of independency as the cause of the trauma. Before the hip condition, he gives himself an active role (Riessman 2002), which is evident grammatically (scenes 11, 12). After the hip condition, he shows his vulnerability by the use of negative verbs (scenes 13, 14). In scene 13 the adverbial phrase "*suddenly*" also shows a change towards abnormality in Michael's situation (Capps and Ochs, 1995). The significance of the experience for Michael is clear as he draws my attention closer to the scene by using the pronoun "*you*" (Tannen 1989). He reiterates his active role when he expresses his feelings regarding his dependency on his wife (scenes 35, 36).

Michael's attitude towards expressing his feelings and his emotions and not being silent about them indicates that he is inclined to change his standards and values (Riessman 2002). From a psychological perspective, he uses social comparison (Gibbons 1999) and emotional coping (Lazarus and Folkman 1984) to maintain his level of well-being (Sprangers and Schwartz, 1999). He changes his values so that meanings in his life now cluster around his new values.

Summary

What counts as performance analysis of narrative is to understand how people position themselves to one another in their interactions in different contexts. Oral stories as the manifestations of social identities change in relation to the audience's requirements and interests. The narrative account derived from the interview with Helen (participant S) had a temporal order and was organised into seven episodes, each episode representing a particular period of her life. Helen's narrative was analysed using narrative positioning and grammar of abnormality and helplessness. In her story that deals with her experience of hip condition, Helen establishes different relations with her audiences by giving herself various positions. For example, she gives herself a passive role when she is the object of medical professionals' actions. However, she is the central character in relation to her family in the pre-condition story. Helen departs her ill journey with showing some resistance to the symptoms of the disease in the pre-operation period. Then, she describes her experience along "the road of trials", experience of suffering as well as some experience of ease and relief. This was also evident from a psychological point of view as she was engaged in temporal downward comparison. She ends her story by incorporating her ill journey with what she had experienced as a carer in her husband's journey. The effects of physical and functional limitations imposed by the hip condition are minimised by the reward she had gained while accompanying her husband in his journey. Similarly, she demonstrates this fact psychologically by positive reappraisal of the stressful situation.

Michael (participant V) organises his account based on the topics of independency/dependency and compares himself as an active person who is in control of life before the operation with a dependent person who cannot live on his own after the operation. He clearly expresses his feelings and emotions. From a psychological point of view, he employs social comparison and emotional coping strategies a great deal to maintain his level of QoL.

Narrative models

We reinterpret our understandings of past events in the light of our current situations, a concept that is in accordance with the narrative time model and a challenge to the clock model of time (Mishler 2005, Personal communication). Unlike the clock model of time, which is based on a match between temporal order of events in real life and their appearance in the narrative (Labov and Waletzky, 1997)), the narrative model of time allows individuals to make sense of their past experiences in the light of their later circumstances. Through this event, they change their understanding of self and create a new identity for themselves (Mishler 2005, Personal communication). Therefore, the narrative time model underlines the importance of "ending" in stories and how "the ends beget beginnings" (Mishler 2005, Personal communication, p. 9).

The continuous process of changing life stories and how identities are changed over time is best exemplified by looking at turning points when the narrator implies a major change in the likely course of his/her life. This change leads to different interpretations of past experiences (Mishler 2005, Personal communication). Expressions such as "this is it" shows the narrator's unforeseen decision in the course of the life (Riessman 2002).

In my research on outcome of THR surgery, the narrative accounts of some participants include evidence suggesting their retrospective realisation of turning points. The pain and limitations resulted from the hip condition and in many cases resulted from multiple health problems that interfered with their personal, professional and social life. Despite all these problems, it was not without some reservations that the participants decided to undergo the hip operation. In fact, the process of coping started way back before the operation in the pre-operation period. They were engaged in some kind of coping strategies to deal with their hip problem in conservative, personal and informal ways. They talked to their friends and sought information from medical agencies like their

GPs. The participants' scepticism about the operation was the main reason for referring them for more conservative interventions like physiotherapy, in the hope to keep them mobile as much as possible. They tried personal remedies such as swimming and did persevere in order to hold back the hip operation. In addition to using these coping mechanisms, their emphasis on meanings and repeated use of some thematic structures demonstrates their reluctance to undergo the operation. They also employed particular linguistic features in their accounts and used the grammar of vulnerability such as negative and modal verbs (Capps and Ochs, 1995) to show their passive role in relation to the operation. They seemed uncertain about the future and what was going to happen to them. Although the benefits of having a hip operation was discussed with them as part of an information seeking process before the operation, many of the participants still remained sceptical about the operation. The biggest beneficial effect from the operation was getting rid of a lot of pain. However, from a mobility point of view they were told that they would not get as much advantage as they would for pain relief. The facts about the hip operation and the extent of getting benefit from it would put their post-operative life in a more realistic perspective. From this perspective, their independency and their control over life would be in jeopardy and they would need to be dependent on others.

Thirty five percent of the participants acknowledged implicitly and explicitly that they had tried every thing to avoid the operation and after they had been confident that nothing could be done to alter the situation, they decided to have the operation. This evidence suggests that many participants had a negative perception of hip replacement before the operation. Therefore, they used a form of coping strategy to adapt to the requirements imposed by their negative perception. Having a negative perception of hip replacement as a common experience among many participants had an effect on their

decision to have the operation. They put off the operation and coped for a number of years until they were absolutely certain that attempts for finding alternative interventions had failed. Moreover, for many of them the burdens of pain and physical limitations got so heavy that finally they took on board the fact that they had to have the operation. When they were inclined to have the operation, they got on the waiting list. Therefore, there was the time they needed to take to decide to have the operation and it could be very long and there was also the delay in the wake of being on the waiting list. To sum up, the decision to have the hip replacement done was a measured process with uncertainty for some participants. This indecisiveness is brought to an end by a moment when the narrator implies a significant change in the course of actions as turning point (Riessman 2002). In the follow-up interview with Helen, I highlighted a theme related to her faith that she had raised in her first interview. After coping for a number of years and perseverance to find alternative treatments, she receives a letter on Christmas Eve from the hospital stating her appointment for the operation. In response to my question asking if receiving the letter on Christmas Eve means anything particular to her, she said:

Ifelt that the way things had worked out it somehow been towards a plan, but it wasn't a plan. I think I was looked after there, because I had my job which I loved...and then I really couldn't cope any longer. The hip was giving out. I was having falls and I resigned, finished work at Christmas, because I said to a friend I got to stay in my house, I just cannot carry on any more. And I finished with my job and my son came over with his family to be with me over the Christmas and I've done (short pause) all the shopping, came in and the letter was there to say and M. ((her son)) was still up to take me for my assessment and THAT WAS IT.

Looking back at her experience, Helen realises "that was if" (Riessman 2002). This realisation indicates her frustration with the hip and the fact that she could not put up with the burdens of pain and physical limitations any longer. In addition, receiving the letter on Christmas Eve for Helen who has faith, quitting the job she loved at Christmas

and having her family with her all were prerequisites for making a decision to go along with the operation.

However, the lack of turning points in stories of some patients with hip replacement did not stop them to reinterpret their past experiences in terms of their current situation, which involves their health condition.

Types of narrative

The stories of participants in my study have some characteristics of "the quest narrative" (Frank 1995). According to Frank "quest stories meet suffering head on, they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience ... The quest narrative affords the ill person a voice as teller of her own story ... affords the ill their most distinctive voice ... " (Frank 1995, p. 115). Through the quest stories, the patients show how they made personal, social and professional changes in their lives as a result of their illness. They accept illness as a disruption only to make new changes in their lives and to gain new identities (Frank 1995, Mishler 2005, Personal communication). For example, Helen's account has a sequential order and one event is followed by another. When she talks about her husband's illness, she makes a positive evaluation of it. This leads to the creation of an identity for her as a person who is willing to help others. However, at the end of her journey, Helen returns to her ill body with all its problems (Frank 1995). She frequently uses the negative verb "*I can't*" without completing her sentence. She ends her story with "*I don't know*" and "*I can't*" indicating her vulnerability and confusion. The confusion and uncertainty is more prominent in the context of her interaction with medical professionals. She portrays nicely how within the medical model she is divided into two "beings", one "being" with hip condition and the other "being" with a vision disorder. Having functional limitations with her right hip

and knowing the fact that she has to keep the hip as long as possible, she states that she wants her mobility while she has got her vision and that is what she means by "*quality of life*". On the whole, she carries the moral responsibility of a narrator as it is normally seen in the quest narratives. She perceives the event at the time of happening and with a sense of duty and commitment she speaks with other sufferers while she has an opportunity to talk (Frank 1995). For instance, she shares her pain and functional limitations and her struggle to find alternative interventions in pre-operative period. She expresses her disappointment and shock of her continuing functional limitations after the operation. She would not go by without providing more knowledge about the operation itself. What she finds "*very strange*" at the time of operation, she expresses it in the narrative when she has a voice to do so (Frank 1995):

"It was strange, because I felt I was in a dispensary and everyone was round me ... They packed me for the op with like bean bags or something, all very strange to me ... "

Helen accomplishes her responsibility within the realm of medical world, declaring her disappointment, shock and insecurity. On the other hand, she pursues topics in her narrative account that enables other patients to be aware of positive gains during the ill journey. She is concerned and disappointed with her overall health condition. Yet, her attitude towards the whole experience is shaped by appraising the situation positively.

She reorganises her goals and changes her expectations when she states:

"Now I can't drive, you see and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden I can sit in which I wouldn't have settled without it... "

Subsequent to his hip replacement, Michael reinterprets his past and realises what sort of person he has really been:

"... I mean I worked from being 14. Fortunate or unfortunate either way you want to look at it, I've never been unemployed for even a short period of time, virtually I worked all my life. I served in the forces ... "

He also creates a moral identity for himself:

"Uh the people who you think well, you don't think anybody deserves this, but the people who you think might get punished for the way of life, don't seem to. Those who seem trying to be as good as they can in the life seem to be punished for it."

While taking in the illness and its imposed limitations, he reinterprets his past in terms of his current situations and gives himself a decent identity. As a result, the hip condition and the harms associated with it are less significant for him than the gains from the reinterpretation of the past (Frank 1995). The hip condition may not be a turning point in Michael's life, but it has had certain effects on how he reinterprets past events and makes meanings of them. In the follow-up interview, he points to work-related health problems and uses this topic to understand that he has been a victim of *"the era of manual work"*. Michael as *"the storyteller offers his voice to others, not to speak for them, but to speak with them as a fellow-sufferer"* (Frank 1995, p. 132) when he uses the plural pronoun *"we"*:

"... I think we are paying the price for um (short pause) possibly the end of the era of manual work... "

Michael's moral duty is to convince the audience that the narrator understands any mistakes that were made in the past either at an individual level or at a society level (Riessman 1990). He interprets his work-related problem within a bigger picture, which concerns other individuals.

Michael's confusion and how he was not able to understand what has happened to him and why bears a resemblance to chaos narratives (Frank 1995) in which confusion and puzzlement are seen and events are not inevitable (Mishler 2005, Personal communication). Michael has been touched deeply by the loss of control and *"control and chaos exist at opposite ends of a continuum"* (Frank 1995, p. 100). Despite the type

of narrative he creates, he calls attention to his identity as an honest person who does not deserve to be punished by health problems:

... you get up in the morning, you think why me? Why has this happened? What have I done to deserve this? You know. I mean I'm an honest person, I worked hard all me life, I've never caused people trouble and then you know you see people've been absolute criminals, been in prison and they got a healthy life, why me? What I have done to deserve this? But that's life. It don't work as you think, does it? You know.

He tries to understand this confound experience when he declares "*that's life*". In other words, in the absence of normal answers to his questions, he uses emotional coping to adjust to the aftermath of his hip condition (Lazarus and Folkman 1984). He also tries to reach at a shared level of understanding with me by expressing "*you know*".

The lack of clear endings or turning points in stories of some patients with hip replacement reinforces the notion of multiple selves and how the narrator illustrates various selves in different contexts in relation to different audiences (Riessman 2002). Narrators have multiple social identities and perform their preferred identity in a different story corresponding to the social world they found themselves in (Mishler 2005, Personal communication). This feature of narrative supports the notion of narrative time (Ricoeur 1980) and how we revise and retell our stories and create multiple stories in different situations (Mishler 2005, Personal communication). In other words, everyone wants to end their stories that they started to tell, but considering the audiences of the story, the interaction they are involved and the context of the interaction they might refuse to go along with it (Mishler 2005, Personal communication). The way Helen and Michael constructed, developed and ended their stories is specific to their interactions with me and the contexts of their narratives. In each case we created a story that is characterised interactionally and contextually (Mishler 1997).

Narrative forms

The way the participants organised their accounts and created their narratives was different among participants. Helen creates detailed specific stories hoping to provide ground for her audience to experience the past moments with her. Michael, on the other hand, narrates his experience of hip condition generally. Events are repeated continually without highlighting any significant instances. The difference in the form of narrative in two case studies is what Riessman (1990) refers to as story narrative in Helen's case and habitual narrative in Michael's case. Classifying narrative into different forms, Riessman (1990) points out that people make sense of their experiences by the way they construct their narratives. Their understanding of an experience depends on the form of narrative they choose rather than the content of their narratives. According to Riessman (1990), identified themes in interview accounts have a dynamic nature and their meanings are discovered only by examining the ways narrators organise their talks.

Although Michael's account cannot be organised into specific episodes, it has a temporal order as the general characteristic of a narrative. The temporal order is indicated by particular utterances. For example, he remembers his experience of hip condition when he was 60 and the hip had got its worse turn before he reached retirement at 64. Michael creates a narrative by telling his experience in general without re-creating any specific moments. At some points in his narrative, he generates hypothetical narrative to contrast his hopes and expectations with what he experiences as reality (Riessman 1990). He describes his desire this way (scene 37):

"... virtually I worked all my life. I served in the forces, you look forward to retirement, what you're going to do, where you're going to go and the whole lot falls down..."

Of interest here is the use of the general pronoun "you" in his hypothetical narrative for implying the difference between the self as he perceives and the self he would wish to be (Riessman 1990).

The nature of categories

In the process of content analysis, I coded chunks of narrative data based on predefined categories from my theoretical questions. As a result, meanings were attached to the data in the context of the researcher's theoretical understanding (Coffey and Atkinson, 1996). In this way the identified themes are fixed categories (Riessman 1990) that can be applied to the narrative accounts of all participants as I did. For example, the participants' emotional reactions to the hip condition and the treatment they received for it was investigated under psychological mechanisms used by individuals to accommodate to the stressful situation (Sprangers and Schwartz, 1999). However, the way the participants constructed their accounts and related their internal emotions to other life events is dependent on the style and structural design of the narrative (Riessman 1990). By choosing and incorporating different styles into their accounts, the participants assigned meanings to a category. Despite identifying similar themes in the narrative accounts of the participants, the style of the narrative and the meanings attached to a theme by the participant gives an experience a distinctive and lively nature, as Riessman says "interpretation depends on the form of telling, rather than existing solely in the content of what is told" (Riessman 1990, p. 117).

Michael and Helen tell about the actions they take to safeguard them emotionally against the burdens of hip condition. In other words, they engage in emotion-focused coping to adjust to their health condition. Therefore, some chunks of data from their narrative accounts were categorised under "emotion-focused coping" in the process of content analysis. In this manner, the identified themes relating to internal feelings were removed from their empirical context and were introduced to the new context influenced by my theoretical perspectives. The careful examination of their narrative accounts, however, shows how they interpret change in their own ways by using

emotion-focused coping strategies. The assigned meaning to the category emotion-focused coping like any other category is determined by two factors (Riessman 1990):

1. The way the participant chooses to tell her/his story.
2. The context she/he creates for the narrative which varies in different situations and in interactions with different interviewers.

Helen tells about her experience with detailed description of events. She re-creates events by constructing specific stories, stories with temporal sequence. Time, place, characters, objects, special occasions, immediate feelings and thoughts are clear in her stories. By placing importance on specific past moments, she tells her audience of the features of her experience of hip condition and the treatment she has received for it. She also conveys her social situation by telling stories. For example, she converts a social responsibility into a personal problem, when she talks about the difficulties she faces as a result of being a widow (Riessman 1990). Helen emphasises on moments in the past and creates a narrative outlined by episodes to show how significant the experience is to her. Now that she is not able to control disease-related domains of life, she rearranges goals and reframes her expectations to adapt to her new situation. The detailed stories were central to show how Helen encounters the health condition and maintains a sense of meaning in her life. Michael, on the other hand, uses emotion-focused coping within a habitual and hypothetical narrative to relate his experience of hip condition to wider social and philosophical reasoning.

Summary

Performance analysis of narrative reinforces the importance of the narrative/experiential model of time in studies of narrative. Unlike the chronological model, the narrative model of time allows individuals to make sense of their past experiences considering their current situations. By doing this they change their understanding of self and create a new identity for themselves. I examined turning points as excellent examples of reinterpretation of life stories. Helen looks back at her experience and realises how frustrated she had been with pain and physical limitations of hip. The realisation that "this is it" changes the meaning of the concept of age for her, because she uses age as the target of social comparison to give up her job and go along with the operation. Her faith and her family also play significant roles in her understanding of events and re-conceptualisation of the values. The lack of turning points in the stories of some participants including Michael can be inferred that participants create narratives with various styles and organise them differently. Therefore, people's understanding of an experience relies on the structure of narrative they choose rather than the content of their narratives. Helen constructs a narrative with detailed stories temporally. By stressing on significant past moments she sends her voice to the audience. Through her narrative, she shows how her multiple health problems disrupted her life and how she has lost control over domains of life linked to the disease. Nevertheless, through the same narrative she illustrates that she has made changes in her life standards and values to encounter the health condition. She takes in the suffering and distress to show the positive gains of the experience. Michael, on the other hand, constructs a narrative by telling an overall experience without re-creating any specific moments. He is adversely affected by the loss of control which has left him confused. The hip experience and its limitations are less important to him as he does not provide detailed narrative about them. He habitually and hypothetically re-creates a narrative which seeks to highlight the reasons underpinning his experience. In this manner, he creates a moral identity and carries a moral duty to convince and inform his audience what type of person he has been and why this incident happened to him. The habitual style of his narrative broadens his experience from an individual level to a society level.

4.6. Patient-professional communication

Interviews as interactions

The phrase "*That's life*" as an emotional coping strategy is Michael's recurrent line. In scene 42 after hearing the expression "*that's life*" I remained silent at first and then prompted him by a question to encourage him to elaborate on the expression. In scene 44 he repeats the line and because I remain silent and do not carry on with the next question, he signals a search for my understanding and evaluation of his talk by the phrase "*you know*". The expression shows the participant's attempt to reach a mutual understanding of the question and answer with the interviewer (Mishler 1986). After that, my active listening technique encourages him to proceed with his account. Another example of Michael's effort in evaluating the shared understanding of the interaction is illustrated in scene 21. Michael is not interrupted from scene 11 to scene 21 with proceeding questions or my remarks. This leads him to assess our mutual understanding of the interaction in scene 21 with the expression "*you know*".

In narrative meanings are constructed interactionally and contextually (Mishler 1997). These features of narrative are central to what I hope the audiences of my study will get from it. Short and long pauses are seen in my interviews with the participants. Mishler (1997) interprets these "uninterrupted silences" as opportunities put forward by each party for talking (Mishler 1997, p.226). Of interest here is that if the interviewer does not grab the opportunity by asking a question in order to take control of the interview, the participant continues with her/his talk (Mishler 1997). Mishler (1997) compares two medical interviews each was conducted between a physician and a patient named as "facilitated story" and "interrupted story" to show that interviews are joint-production of the interviewer and the participant. I reproduce some parts of the interviews here by the permission of the author (Appendix 2).

Clinical interview: Facilitated story

D: Okay / so you said you had as seizure ... {yesterday?}
P: Uh {Yesterday}
Yesterday about eleven o'clock /yes /
D: Hmm ... At work? [P: hmhm] Okay /
Stanza 1
P: Well I'm not really worried /
Itz same thing you told me 'bout not gettin yaknow upset and aggravated /
Stanza 2
and -I couldn't have ta-uhm my boss get me a car Tuesday / right?
An' I workin on -it was an Audi /
I never did brakes on an Audi before / yaknow front wheel drive? [D: Yeah]
An' it was a problem yaknow /
Stanza 3
and I'm down all day long / ya know w-back like this here/like the car's on a lift / [D:
Yeah]
But it's two bolts ya-know / ya just can't get to em unless you get right up on the caliper /
And ah twis-jus can twist a little bit with a screwdriver /
An' I was going like (gang...)- when ya can see I got a black eye / (laughs)
D: Wha-oh from the seizure/
P: No / from the caliper / one of em fell. to the eye /
D: Oh {I see}
P: {An'} an' it hit me there /

Mishler (1997, pp. 226, 227). The interactional construction of narratives in medical and life-history interviews. In: B-L. Gunnarsson, P. Linell, B. Nordberg, *The Construction of Professional Discourse*. Addison Wesley Longman, London. Reproduced by permission of the author.

According to Mishler (1997), in the facilitated story, the patient starts talking about his work and work-related problems, despite seizure as their agreed topic of discussion. The physician does not interrupt the patient through three stanzas. He gives the patient the chance to develop his story in his preferred context, although the patient's strays from the main topic. At the end of stanza 3 when the physician raises the topic "seizure" again as the cause of the patient's black eye, the patient rejects the idea and continues his story around his chosen topic in his own words (Misher 1997).

Clinical interview: Interrupted story

P: I can hardly drink water / [D: hm hm]
Sometimes it bothers me in-in
Stanza 1
First-remember when it started?
Remember I told you I was in pa-the pains {in my head?}
{D: hm hm}
It must have been startin then / [D: hm hm]
I don't know what it is /
Stanza 2
The doctor looked at it / when I came 'n see Sally /
He said somethin about my glands / [D: hm hm]
Stanza 3

And it's gettin worse now / it's like painin yaknow?
 And it's-uh first it was like-um . well I had some fish/ and I put lemon on it / that's when I
 {noticed-} that's been
 {D: hm hm}
 about five-[D: hm hm] four weeks ago / [D: hm hm]
 Ane now it's-it's just terrible /even coffee hurts it /
 So **I don't know** what it is / [D: hm hm]
 Stanza 4
 (. .) and my sugar's . everywhere doc /
 .hh I don't know /
 I'm doing that finger stickin / . still high /
 (..) .h h [D: ah:m] I don' know /

D: What kinda- Whereabouts approximately on the finger stick have you . been findin it/
 when you do it?
 P: Oh ove the -near there-um 270? [D: hm hm] Yeah / in be-in between there / [D: hm hhm]
 uh huh
 D: Okay / .hh uh . and is that pretty constant? Where it is?
 P: That's where it always is / [D: It is?] yeah / [D: Okay]
 {uh huh}
 D: {ah:h} The last-I was looking in the computer-the last one that I saw in there was about
 three weeks ago / have you had blood drawn in the lab since then? [P: uh:m] Or just {...}
 Stanza 5
 P: {I don't} remember/
 I was comin so regular {ya-konw? / Cause I was comin-}
 {D: Yeah / Yeah / Yeah}
 I know I was seein Sally like one twice a week / [D: Yeah]
 so-I done forgotten that /

D: Okay /Okay / .hh uhm aside form this / how have you been feeling? I know the blood sugar's
 been up / but what-
 [P: Terrible] Yeah /
 Stanza 6
 Tired all the time / that tired feelin again / [D: yeah.]
 An-I don't know /
 I eat and I'm still sick /
 So .hh I don' know /

D: ah:m...hh With respect to this business up here / is that sore if you're not eating?
 [P: Yeah] {or is it only if you take-} {P: yeah / there's pains in it} yes / uh huh
 Stanza 7
 P: Yeah an' it's one-one spot right here / [D; uh huh]
 It's real sore / [D: uh huh]
 But then there's like pains in it /
 Yaknow how -I don't know what it is /

D: uh huh Okay / .hh Fevers or chills?
 P: No/
 D: Okay / ah:h Have you been sick to your stomach / or anything like that?
 P: (Sniffles, crying, 9 second pause) I don't know what's goin on.

Misher (1997, pp. 229-231). The interactional construction of narratives in medical and life-history interviews. In: B-L. Gunnarsson, P. Linell, B. Nordberg, The Construction of Professional Discourse. Addison Wesley Longman, London. Reproduced by permission of the author.

In contrast to the facilitated story, Mishler (1997) believes that in the interrupted story the physician is inattentive to the interview. In making his argument, Mishler refers to the patient's frequent expression of distress related to pain as "I don't know" and how this uncertainty and concern is ignored by the physician. For example, despite

acknowledging negative feelings and insecurity by the patient constantly, at the end of the stanza 5 the physician asks her: "... aside from this (the blood sugar) how have you been feeling?... " The physician reacts actively to the interaction only after the patient brings in a medical topic, which is measuring his blood sugar. From there the physician controls the interview by his questions focusing mainly on physical symptoms, while the patient's main cause of distress as expressed by her are feeling terrible, getting worse, tiredness, and not knowing what is happening to her. Mishler (1997) concludes his discussion by contrasting the "voice of medicine" and the "voice of the lifeworld" and how the physician through the voice of medicine dominates the interaction and shifts the power towards the medical world (Mishler 1997, p. 232). Compassion, listening and time shown by the physician in Mishler's facilitated story (Mishler 1997) represent art as a qualitative approach towards establishing a model of health care (Reilly 2005).

Interruptions are manifestation of power in clinical encounters through which physicians have more opportunity to highlight particular information provided by patients (Epstein 2006). Interruptions are defined based on three criteria (Bechman and Frankel, 1984, Marvel, et al. 1999):

1. Elaborating on patients' stories by making remarks,
2. Repeating patients' last words,
3. Proceeding with a statement or a new question.

Asking a new question particularly in the form of open-ended questions has negative effect on the process of interview, because open-ended questions or interview schedules encourage a mutual discourse and force the patients to an answer (Epstein 2006).

Medical interviews are excellent cases for discussing the nature of knowledge generated in health care research. The inclusion of information derived from the QoL instruments

into the evaluation of the effectiveness of medical interventions is part of a new development in health care called "evidence based patient choice" composed of "evidence based medicine" and "patient centred care" (Hope 1996). Patient centred care can be viewed from different perspectives. For example, from a managerial and clinical perspective, the main focus of the patient-focused care is "to shorten or eliminate process steps in hospitals, ease the administrative burden on staff and limit the number of different staff coming into contact with patients" (Hurst 1996, p.59). By viewing patient focused care as "a hospital-led initiative" (Hurst 1996, p.75), it is believed that the implementation of evidence based care can improve patient care by, for example, reducing time devoted to administrative tasks (Hurst 2005). Patient centred care can also be examined from individuals' point of views. Therefore, to implement successful evidence based patient choice model in health care system essential components such as evidence based information and patients' perspectives including their preferences and their understandings of experience should be provided (Ford, et al. 2003). The patient based outcome measures routinely used in clinical practice, however, are less likely to have an effect on patient centred care (Greenhalgh, et al. 2005).

The Pew-Fetzer Task Force on Advancing Psychological Health Education (1994) recommends relationship centred care as a more encompassing term than patient centred care. Relationship centred care combines both the biomedical and lifeworld perspectives and has five characteristics (Roter 2000):

1. It should be functional from a medical point of view in order to provide basic medical tasks.
2. It should be informative, providing information on different aspects of medical care.
3. It should be facilitative, so that patients could tell their stories of illness and elaborate on their experience, particularly the psychological aspect of the illness.
4. It should be responsive. The professional role in a medical interaction is not limited to being an expert, but they are involved in medical dialogue as

individual persons whom patients can rely on for emotional support and understanding.

5. It should be participatory. There should be a power balance in medical interactions to assist patients in decision making.

The Picker Foundation Survey (2003) identifies eight dimensions of patient centred care:

1. Respect for patient's values, preferences and expressed needs,
2. Coordination and integration of care,
3. Information and education,
4. Physical comfort,
5. Emotional support and alleviation of fear and anxiety,
6. Involvement of family and friends,
7. Transition and continuity,
8. Access to care.

All dimensions except dimension No. 1 have the characteristics of a medically functional and informative care (Roter 2000). They incorporate provision of physical and emotional medical tasks, organisation of care among health professionals, caregivers and services, coordinating series of visits and post-discharge services, and focusing on availability of time and access to care. Patient centred care, however, is a deficient model with respect to being facilitative, responsive and participatory as the main elements of relationship centred care (Roter 2000). These elements highlight the importance of a shared understanding of the patient's problem within a two-way dialogue. Yet, the technicalities of the dialogue and informed clinical decision making are not as important as respect, honesty and expertise for many patients. Those who wish to see the situation under control, particularly by competent doctors (Wright, et al. 2004). Taking into account the significance of communication and partnership as the main domains of the patient centred approach (Little, et al. 2001), Stewart (2001) defines patient centred care as an approach that:

1. Explores the experience of disease from the patient's perspective, considering the patient's feelings, ideas and expectations,
2. Looks for a shared understanding of the whole person and the lifeworld of the patient,
3. Seeks a mutual understanding of the problem and its management,
4. Improves health promotion,
5. Enhances a model of patient centredness by improving the patient-professional relationship.

The relation between patient health outcomes and communication skills in medical encounters is supported by evidence linking physician-patient communication to a range of health outcomes including physical functioning, emotional health, physiological measures and pain control (Stewart 1995). In a systematic review of trials of interventions to alter the interaction between patients and practitioners, Griffin and colleagues (2004) found that interventions had an effect on health-related outcomes whether they are delivered to patient or practitioner or both. Patient health outcomes consisted of objective outcomes such as blood pressure, cholesterol level and subjective outcomes like functional status, pain, well-being, depression, anxiety and QoL. Interventions aimed at patient such as patient activation (Williams, et al. 2005) includes activities like pre-consultation meetings with patients to involve them more in the management of the disease. According to Griffin and colleagues (2004), interventions delivered to patients had a positive effect on health outcomes in 75% of the studies. Interventions delivered via practitioners such as communication skills training showed a positive effect in 82% of the studies. A positive effect on health outcomes was also observed in 86% of the studies in which interventions were directed at both practitioners and patients.

Although studies that show effects of communication on health outcomes are rare, it is through patient-professional communication that we can determine whether outcomes

are perceived valuable by patients. In this way, we can distinguish them from health outcomes defined by the professionals (Epstein, et al. 2005).

Quality of life outcome measures are in the form of questionnaires or structured interview schedules (Fitzpatrick, et al. 1998a). The main characteristics of these questionnaires like any other research questionnaire, are disregarding the background of the patient and presenting a new context defined by the researcher (Mishler 1986). When health outcomes are identified through communication between patients and professionals, the procedure is more likely to be adjusted to the needs of the individual patient and taking account of his/her sociocultural background. This is in accordance with the bi-directional or multidirectional model of communication (Epstein 2006). This model views communication as a two-way process, which is influenced by health professionals, patients, health systems and cultural factors. It involves contributions not only from the patient, but also from other factors including clinicians and health systems (Epstein, et al. 2005). The multidirectional model of communication opposes the common model underpinning research interview practice that regards an interview as a one-way process (Oppenheim 1992). According to this model, an interview is carefully structured to reduce the possibility of biases bringing in to the interview by the interviewer.

Eliciting patient health outcomes within a patient-centred communication model (Epstein, et al. 2005) is similar to obtaining information on health outcomes via in-depth interviewing such as narrative interview. An operational definition of patient-centred communication by Epstein and colleagues (2005) contains features such as understanding the patient's perspective within his or her distinctive psychosocial context and reaching a joint knowledge of the experience with the patient. By understanding the

patient's concerns, feelings, interests, hopes, and thoughts within the context of his or her values, health professionals work toward balancing the power in health care. Mutual understanding of the situation within the context of the patient determines how and to what extent the patient wishes to be involved in care and apply control (Epstein, et al. 2005).

Likewise, deep knowledge obtained from in-depth interviews means that the interviewer has reached a shared understanding with the participant about the experience, particularly in revealing the psychological information related to the experience. In addition to this, the discovery of the interviewer's own feelings and thoughts cannot be ruled out (Johnson 2002). This is in line with the nature of stories constructed in narrative interviews in which meanings are constructed interactionally and contextually (Mishler 1997).

Summary

Context and the interaction process play significant roles in the creation of meanings in narrative interviews. These features of narrative are illustrated in my narrative interviews with the participants as short and long pauses to give participants an opportunity to elaborate on their topic of interest in their preferred context. Interrupting participants by making comments, repeating their words and carrying on with a new question as it is seen in interview schedules and open-ended questionnaires, shifts the power balance in medical encounters towards the professionals. The importance of communication in health care marks a move from patient centred care towards relationship centred care and patient centred communication. In addition to being functional and informative, the new move is concerned with three issues of being responsive, being participatory and being facilitative. The critique of patient centred care has focused on these three issues and has developed an alternative definition for patient centred care while taking into account the importance of communication and partnership. The evaluation of the effectiveness of the medical interventions from patients' perspectives as part of a patient centred care model is influenced by medical communication skills. The link between patients' health outcomes and medical communications gets problematic as the current QoL outcome measures are represented in the form of questionnaires and interview schedules. Quality of life outcome measures yield information through one-way interview process without considering participants' context and background. Identifying health outcomes through multidirectional model of communication is similar to obtaining information on health outcomes via narrative interviews. Both approaches place great importance on context to characterise their understanding of participants' concerns, feelings and thoughts.

4.7. Patients' experience of health conditions

Studies that examine the experience of patients with total joint arthroplasty including THR patients are carried out through three main approaches:

1. Studies employing patient-based outcome measures, such as the Oxford Hip Score (Fitzpatrick, et al. 2000).
2. Studies incorporating patient-based outcome measures in qualitative research such as semi-structured interviews (McMurray, et al. 1999, Heaton, et al. 2000).
3. Studies applying qualitative methods (Showalter, et al. 2000, Montin, et al. 2002, Fielden, et al. 2003, Marcinkowski, et al. 2005).

In studies that use qualitative methods, data analysis is mainly based on the method of content and thematic analysis. Within this process, data derived from participants' accounts are identified into categories. The knowledge generated from this type of qualitative method has an explanatory and descriptive nature. Participants in this study revealed a wide range of coping strategies to manage their hip condition and THR surgery. The information obtained from the content analysis of participants' accounts. At least one comparative coping strategy was used by each participant. The comparative strategies employed by the participants were fitted into different types such as temporal down-ward and up-ward comparison or intra-personal comparison and inter-personal social comparison with different aspects of life used as the targets of comparison. This confirms findings of a study by Bennenbroek, et al. (2002) which examined social comparison among cancer patients. The findings showed the participants' need for social comparison. There was a positive correlation between the need for social comparison and the indicators of low well-being such as depression, anxiety and uncertainty. Moreover, negative evaluation of health was associated with higher need for social comparison. Participants used up-ward comparison for seeking information, but they were unwilling to meet those who were better off. The relation between social comparison and health, illness and disability is well documented. For example, a great

number of studies have been conducted that have investigated Rheumatoid arthritis patients' engagements in social comparison (Tannen and Affleck, 1997).

In the present study, emotion-focused coping strategies included a wide range of expressions and sometimes overlapped other categories such as comparative coping.

Montin and colleagues (2002) categorised experiences of 17 THR patients into physical, psychological, and social aspects. Positive attitude and hopes were ways of emotion-focused coping that were categorised under psychological experiences. "Having attitude" was a form of emotion-focused coping that was used by participants in a study of the patient perspective of total knee joint arthroplasty (Marcinkowski, et al. 2005). The use of emotion-focused coping was shown in a study of the perceptions of HRQoL of patients with coeliac disease (Hallert, et al. 2003). Emotion-coping captured the concept of acceptance as a passive psychological attitude towards the disease.

Focusing on the burdens of hip-related problems, some participants used problem-focused coping to control the physical limitations imposed by the hip condition. The use of problem-focused coping was reported in a study by Small and Lamb (1999) investigating fatigue in chronic illness. Through a semi-structured interview, individuals identified a number of strategies including problem-focused and emotion-focused strategies to cope with their situation. Problem-focused strategies included being active, doing exercises, and taking measures such as rest and relaxation to restore their energy and avoid unnecessary use of energy.

In the present study, self-oriented coping strategies in the form of conservative and informal interventions started before the operation as a way to ease and improve the participants' conditions. The same coping strategy referred to as "seeking comfort" by

Marcinkowski and colleagues (2005). Describing their experience of total knee arthroplasty, the patients managed to lessen their symptoms by using a variety of strategies including medication and alternative therapies (Marcinkowski, et al. 2005).

Implicit and explicit engagements in spiritual coping were observed in the narrative accounts of some participants in this study. In a longitudinal study of the caregivers of men with AIDS, Folkman (1997) showed that the participants had experienced some positive psychological states due to their spiritual beliefs and practices. Spirituality assisted positive reappraisal of their chronic and stressful situations, leading to the experience of positive psychological states.

Using methods of qualitative research to examine the experiences of patients undergoing total joint arthroplasty, Montin and colleagues (2002) describe experiences of THR patients from physical, psychological and social point of views. The participants' experiences of care and the health care system were also described before hospitalisation, in hospital and following discharge. Pain and mobility were their main physical experiences, while positive attitudes, feelings, and dependence were different aspects of their psychological experience. They expressed their social experience in terms of their social roles and their social life. Most aspects of physical, psychological and social experiences improved after the operation. The participants, however, expressed their scepticism and uncertainty about the outcome of the operation and post-operative life. This finding is in accordance with the findings of my study in which the participants underwent THR surgery with some reservations. Their reluctance and hesitation was mainly discussed under self-oriented coping strategy. Describing the patients' experience of care and health care system, Montin and colleagues (2002) stressed the importance of communication in health care as the participants in their

study wanted their own doctor and nurse throughout the course of their disease and treatment. Problems in having their own nurses, lack of adequate time and momentary patient-professional relationships have also been highlighted as potential sources of distortion in patient care in studies of the nature of nursing care in hospitals (Higgins, et al. 1999).

Marcinkowski and co-workers (2005) conducted a study using grounded theory qualitative method to examine the patient perspective of total knee joint arthroplasty. The emerged codes and concepts from the participants' accounts generated three main categories. The "enduring" category described participants' daily lives experiences such as hurting, struggling, and seeking comfort. The category "thinking twice" illustrated the adaptation mechanisms employed by the participants and included concepts such as giving it time, accepting help and avoiding risk. Participants managed to keep going through the arthroplasty experience by getting back to normal, striking barriers, interacting with health professionals and participating in recovery. These concepts formed the category "keeping faith" (Marcinkowski, et al. 2005). The authors concluded that by the tools of enduring, thinking twice and keeping faith, the participants managed the process of "getting back to the future". "Getting back to the future meant getting back to a life without pain and disability, something participants could only do by looking forward" (Marcinkowski, et al. 2005, p.206). Their conclusion based on a grounded theory method, however, contrasts the findings of the present study using performance analysis of narrative accounts.

In this study, the participants had no or limited control on disease-specific domains such as pain and disability. The use of problem-focused coping strategies facilitated a sense of control on these domains. The participants, however, did not remain focused on

controlling disease-related domains. Confronting with the limitations of the hip condition which were not within their control, they sought to engage in alternative coping strategies such as emotion-focused and comparative coping. By using psychological mechanisms they change their focus to other domains resulting in a change in their internal standards, values and redefinition of the meaning of QoL (Sprangers and Schwartz, 1999).

An important concept that reflects the use of psychological mechanisms is "cushioning" the impact of pain and limitations (Gibbons 1999). Many participants reframed their expectations and rearranged their goals to reduce the negative effect of hip-related problems. They also revised their stressful situations positively to create positive psychological states (Folkman 1997). Moreover, the use of various forms of comparative coping by all participants changes the picture of overcoming the hip problem as within their power. The lack of objective assurance in the stressful situation created by the hip condition increases participants needs for social comparison (Wills and Suls, 1991, Gibbons 1999). Social comparison was the method of choice for the participants despite their different perspectives of the outcome of hip replacement. For example, participants whose expectations matched their actual outcomes, employed social comparison as well as those who experienced a discrepancy between their expectations and the reality of the outcome of hip replacement. In both settings, their inability to control important aspects of their lives shifts their focus from hip-related physical limitations to more controllable aspects of life such as family, beliefs, financial assets and resources. Through the process of self-evaluation, the participants used specific others and general public as the social comparison referents. As a result, the participants began their journey (Campbell 1968) with employing self-oriented coping strategies including a range of informal and alternative interventions. This supports the

notion of "resistance" to the health condition as one participant describes how she lived while she waited for the surgery:

I used to do half hour physiotherapy every single night in order to keep me reasonably mobile and free of pain ... you feel YOU FEEL YOU'RE DOING SOMETHING, it's something positive that you're doing, you are taking control by doing that physiotherapy. (P. E)

Continuing with the journey, the participants were engaged in the telling of their experiences that encompassed pain, disability and some degrees of relief. The sense of relief was mainly reflected in their engagement in temporal and inter personal social comparisons. Referring to her pre- and post-operative problems, one participant says:

I was really struggling, um I couldn't go out unless anybody took me ... I was taking anti-inflammatory ... and anything I did unless somebody helped me, I couldn't do it. Um, I can now with difficulty ... I JUST I JUST ACTUALLY FEEL I AM VERY LUCKY TO HAD my hip done and to be out of that pain ... just go for a little walk there and again you see meet people, you talk to people, it's I FEEL I AM LUCKY to live where I live with nice neighbours and the people around me are nice. (P. H)

At the end of the journey, although few participants overcame the hip-related pain and physical limitations, the overall effect of using psychological mechanisms resulted in a positive gain from the disease. They used these coping strategies not to get rid of pain and disability as it was concluded in the study of Marcinkowski and colleagues (2005), but to soften the damaging effects of pain and disability. What viewed as positive gains had far more potential for opening up ways of adjusting to the burdens of hip condition than being merely focused on the hip-specific domains. Grounding the study within a narrative analysis approach, the findings showed that the hip and its limiting problems would not play a central role in how the participants would wish to portray their lives. By revising their lives and re-interpreting the meanings of life events over time, the participants marginalised the hip-specific problems and placed greater value on other aspects of life. One participant puts the re-interpretation process in words very nicely:

"... I get frustrated, because can't do things for myself um it's my own feelings. I think when you've been so active you've got to re-learn your life, kinda things, so I'm trying." (P. Q)

In a comparative study of ten patients with osteoarthritis of hip joint, Oberg and colleagues (2005) compared data obtained by three instruments a generic, a disease-specific and an individual measure with information derived from unstructured interviews. The data were collected before and after hip arthroplasty. They used aggregated data such as means, standard deviations and inferential statistical tests to show the responsiveness of the instruments, but acknowledged that converting different information into one aggregated score obscures the detailed information related to different items of the instruments. They concluded that the three instruments together gave the same information as an unstructured interview. The information included participants' activity and functional status and the ability to detect change over time. The instruments measured the traditional change. In other words, it is assumed that stable dimensions of life are measured by constant calibrated instruments with fixed intervals (Golembiewski, et al. 1976). However, they overlooked the profound change as a result of shifting internal standards, values and redefinition of the concept of QoL over the course of the disease (Sprangers and Schwartz, 1999). Although the instruments capture different dimensions of life that are considered important among a group of patients, they fail to describe the subjectivity of a disease experience and the coping strategies used by patients to adjust to the burdens of the disease over time.

Summary

Central to the analysis of qualitative data obtained from the studies of patients' experiences of health conditions is the method of content and thematic analysis. The generated knowledge from this type of analysis has a descriptive nature. The emerged categories of self-oriented coping, emotion-focused coping, problem-focused coping, comparative coping, and spiritual coping as well as different dimensions of life are in accordance with other studies examining patients' experiences of various health conditions. While most studies focused on burdens of health conditions and elaborated on participants' efforts to overcome those limitations, the findings of this study support the notion of re-interpretation of life experiences through employing psychological mechanisms. The re-interpretation process was illustrated by content analysis and performance analysis of narrative accounts. Participants used different coping strategies not to get rid of pain and physical limitations of hip condition, but to cushion the damaging effects of hip-related problems. Moreover, they brought to light other dimensions of life that they valued more as a result of their disease trajectory.

4.8. Ethical considerations

Ethical decisions in research are made based on two ethical theories. Utilitarian theories evaluate research based on its outcomes, while deontological theories involve commitment to fundamental moral standards (Beauchamp, et al. 1982, p.20, Homan 1991). According to Foster (2001, p.11), two deontological theories can be distinguished. The duty-based approach is related to how the research is carried out and applying rules to prevent harm to participants. Similarly, right-based approach is concerned with participants' autonomy and treats people with respect. Despite different ethical theories, researchers from different background agree on some ethical principles as was identified by Beauchamp and colleagues (1982, pp.18-19). These principles include:

1. The principle of autonomy in which researchers respect participant' decisions about participation in the study and their right to withdraw from research.
2. The principle of nonmaleficence specifies that research must not inflict harm deliberately.
3. The principle of beneficence requires that others should benefit from research.
4. The principle of justice demands that participants must be treated equally.

These ethical principles underpin some ethical codes that are regarded central to ethical practice. Smith (1981, pp.15-19) reviews the ethical codes concerned with research involving human subjects as: informed consent, confidentiality, participant's rights and participant's risk/benefits ratio.

Informed consent

Informed consent focuses on the implication of two factors:

"1) that all pertinent aspects of what is to occur and what might occur are disclosed to the subject, 2) that the subject should be able to comprehend this information" (Homan 1991, p.71). Consent comprises two aspects: "1) that the subject is competent to make a rational and mature judgement, 2) that the agreement to participate should be voluntary,

free from coercion and undue influence" (Homan 1991, p.71). However, applying ethical codes that were initiated by and developed for biomedicine research to social medical research including qualitative research is questionable (Cassell 1982). Owing to specific evolving features of qualitative research, participants are able to have an effect on the context of the research during the process of data collection and data analysis. The participants' influence on the research situation can result in unanticipated phases of data collection and outcome of the research (Cassell 1982, Wiles, et al. 2004a). Therefore, many authors (Wax 1980, Ramcharan and Cutcliffe, 2001, Miller and Bell, 2002) have argued that gaining signed informed consent forms is inadequate for qualitative research and called for informed consent to be considered as a constant process of shared discussion rather than a one-off event. This on-going process of consent is needed to safeguard participants' rights to withdraw from the study at any point. It also shows researchers' awareness and understanding of participants' wishes to pull out of the study (Wiles, et al. 2005). Viewing consent as a process ensures that participants receive adequate information and that they are competent to understand what consent will involve. It also makes sure that the consent is voluntary and participants have sufficient time to decide whether or not they wish to take part in the study (Wiles, et al. 2004a).

Confidentiality

The general idea of who will have access to the research data and how the data will be used is concerned with confidentiality (Wiles, et al. 2004b). People's identities and research locations should be protected and all personal data must be locked or covered. They can only be made public by assuring anonymity. It means that pseudonyms are used to conceal individuals' true identity (Christians 2000). Confidentiality and anonymity are closely related to the balance between risk and benefit directed to the research participants as a result of the research. In quantitative research participants are at

greatest risk during the process of data collection, while in qualitative research the publication of research data poses them greatest threat (Murphy, et al. 1998). It should be borne in mind that qualitative research can also pose harm to participants during the research process as they may create some negative psychological states such as anxiety (Evans, et al. 2002).

4.8.1 Ethical issues in health outcomes measure research

Questionnaire-based research

Examining ethical issues in outcomes research, Kirschner (2001) stresses the importance of measuring the goals of treatment as the goals are perceived by patients, carers, health care professionals and society. Adapting the WHO International Classification of Impairments, Activities and Participation, ICDH-2 (WHO 1999), Kirschner (2001) identifies goals at three levels of impairment, activity limitation and participation restriction. Thus, an ethical concern posed by outcomes measure research is the extent to which patients' perspectives are incorporated into measuring outcomes. Its practical application is whether items of a QoL outcome measure are selected by patients or are predefined by others with different, even, competing interests. Viewing patients' perspectives and preferences as principles of autonomy in ethics reinforces the ethics-laden aspect of patient-based outcome measures (Kirschner 2001). As most outcomes measures reflect researchers' values and interests (O'Boyle 1992), there is the possibility that these measures may cause harm or distress to participants. Questionnaire-based research is an invasive form of research because it involves direct psychological involvement of participants (Fox 2002). A recent study by Evans and colleagues (2002) identified harms that patient-based outcome measures in the form of questionnaires posed to patients with a breast complaint. These harms included increased anxiety in patients with or without clinical diagnosis and unrealistic positive expectations.

In the present study, data were collected with three standardised measures in the form of structured and semi-structured questionnaires. Although not evident from this study, focusing on my experience of the research process, the questionnaires can be the source of social comparison in participants. According to the findings of the study, participants used intra and interpersonal social comparisons to make sense of their experiences. It is more likely that the questionnaires put them in closer touch with issues bearing on self-assessment and expectations while referring to others or themselves over time. I found that the issues of gaining information and making comparison based on obtained information were central to the study. Sitting in the hospital waiting room after an interview, one of my study participants for example said: *"You always see somebody worse than yourself in places like this."* She made this statement while she was completing the standardised questionnaires. Such a statement involves engaging in downward social comparison, which is triggered by observing other patients in a hospital environment as well as being exposed to the content of the questionnaires.

Conversely, an item might initiate upward social comparison. The participants of my study compared their current situations with the past before they had developed hip condition. They recalled days before their hip condition and used those days as a basis to evaluate their present situations. The physical functioning dimension of the SF-36, for example, presents an array of activities including vigorous and moderate activities, which can raise worrying concerns in participants. Although the effects of questionnaires on participants are less troublesome in individualised questionnaires, the PGFs emphasis on identifying affected areas of life and scoring each area highlights negative aspects of life for participants (Lintern, et al. 2001), which can generate harmful psychological states. In answering to step 2 of the PGI, participants should demonstrate how badly affected they are by scoring each area of life out of 10 using a

scale from 0 "the worst you could imagine" to 10 "exactly as you would like to be". The scale has potential to raise some concerns and make them increasingly visible for participants, particularly for those who are affected adversely by their health condition.

Qualitative research

In addition to utilitarian theories and deontological theories used to rationalise ethical principles (Beauchamp, et al. 1982), a third ethical model is suggested by Kvale (1996, p.122) as contextual ethical position. Researchers' values, feelings, skills and logic in interaction with participants and other professionals and in relation to their moral values are fundamental elements in contextual ethics. Definitions of ethical theories need to take into account contextual value added criteria to correspond to the specific characteristics of qualitative research (Shaw 2003). Acknowledging ethical issues caused by qualitative research, Shaw (2003) gets benefit from Lincoln and Guba's view on the ethical implications of different paradigms as a way of addressing the ethical questions not as methodology-related issues but as context-dependent dilemma (Lincoln and Guba, 1989, cited by Shaw 2003). According to Lincoln and Guba, the conventional positivist paradigm is less ethical than other paradigms because the nature of knowledge in positivist paradigm is based on the assumption that there is one single reality. In his critique of Lincoln and Guba's ethical analysis, Shaw (2003) finds answers to ethical issues by focusing on unique features of qualitative research in different contexts and facing the emergent ethical issues in different stages of research as a process. Therefore, according to Shaw (2003) there is no ethical advantage in choosing a research method. However, ethical issues should be tailored according to the nature and requirements of qualitative research.

The present study was approved by the North Sheffield Ethics Committee (Appendix 8).

The participants were provided with information before they decided whether to consent

to the study (Appendix 8). Seeking initial informed consent was carried out in a private place in the presence of the arthroplasty specialist nurse. Involving a practitioner in the research cleared the practitioner-researcher role for the participants and secured their voluntary participation in case they wish to withdraw from the study (Shaw 2003). Moreover, misunderstanding researchers' roles and practitioners' roles by participants can create unrealistic expectations, as the participants try to obtain further information or advice regarding their health and clinical management (Evans, et al. 2002). In the information sheet participants were given contact telephone numbers so they could raise any concerns regarding their current health with the arthroplasty specialist nurse and consultants' secretaries.

Viewing consent as an on-going process with ensuring on-going choice to withdraw (Cutcliffe and Ramcharan, 2002), I sent the transcripts to the participants for verification. It expanded the process of consent beyond the time of data collection and gave the participants an opportunity to amend the transcripts (Wiles, et al. 2005). To assess consent during the interviews and to identify any indication that the participants are reluctant to carry on, I observed verbal as well as non-verbal components of my conversation with the participants including their body language. For example, defensive and negative positions (Pease 1997) made me to reassess participants' understandings and willingness for participation in the study.

In this study narrative interview refers to a research practice as conversation rather than a method of communication based on neutrality and objectivity of information (Teasdale 1993). Supportive of this view, Kvale (1996, pp.36-37) argues that there are three conversational contexts for an interview:

1. Methodological context considers an interview as a technique of obtaining information.
2. Epistemological context in which knowledge is generated within a conversation.
3. Ontological context that "the human world is a conversational reality" (Kvale 1996, p.37).

A fourth context suggested by Fredriksson and Eriksson (2003) as ethical context derives from the fact that ethics constitutes a critical part of a conversation. They develop Ricoeur's definition of the ethical aim within three components of the individual, the interpersonal and the societal (Ricoeur 1992, cited by Fredriksson and Eriksson, 2003). Making a distinction between ethics as the purpose of a good life and morality as the expression of this purpose in norms and rules by Ricoeur, has created a suitable ground for Fredriksson and Eriksson (2003) to examine a caring conversation within an ethical context. According to these authors, an ethical conversation is a conversation in which values of self-esteem, autonomy, and compassion in a health professional, for example a nurse, are redefined as norms of respect, responsibility and reciprocity. In their words "at the normative level in a caring conversation language and words become the medium of reciprocity that enable self-respect and responsibility to unfold ... The patient is able through narrating about suffering to regain gradually the status of agent" (Fredriksson and Eriksson, 2003, p. 146).

Summary

Utilitarian ethical theories evaluate research based on its outcomes, while deontological theories evaluate research with reference to its moral standards. Deontological theories involve duty-based and right-based approaches. Duty-based is related to applying rules that do not hurt participants. Right-based approach is about participants' autonomy and respect. Whatever theory underpins ethical issues, there are some principles that are shared among researchers: principle of autonomy, principle of nonmaleficence, principle of beneficence and principle of justice. These ethical principles support some ethical codes: informed consent, confidentiality, participants' rights and participants' risk/benefit ratio. Informed consent in qualitative research is viewed as an on-going process through which participants' understanding of the research and their wish to withdraw from the research is protected. Health outcome measure research faces ethical issues in the light of applying both questionnaire and qualitative approaches. Questionnaire-based research requires participants to be involved psychologically which can pose harms to them. Ethical issues caused by qualitative research are contextual. It means that in qualitative research ethical issues should be modified according to different contexts and their conditions. In qualitative research, narrative interview as a mode of conversation has four conversational context: methodological, epistemological, ontological, and ethical. According to this argument, an ethical conversation in health care transfers professionals' values of self-esteem, autonomy and compassion to norms of respect, responsibility and reciprocity.

4.9. General discussion

Standardised outcome measures are used to evaluate the outcome of medical interventions such as THR surgery from patients' perspectives. They are used in clinical practice at different points of time including pre- and post- intervention to assess any change in patients' QoL. They explore different domains of life and identify any change in the magnitude, breadth and type of these domains during the course of a disease.

The change assessed by QoL instruments is the traditional notion of change assuming that the fixed dimensions of life are measured by a stable calibrated instrument (Golembiewski, et al. 1976). While the reasoning is true for the measures of biological dimensions, scale recalibration and re-conceptualisation of constructs are likely threats to the validity of self-report measures (Howard, et al. 1979, 1980, Golembiewski, et al. 1976). As patients' conditions and health change over a disease trajectory, the meaning of life and their understanding of the QoL also change. Changes that occur result in adjustment to the new situation imposed by the disease (Allison, et al. 1997). With respect to their background, people use different kinds of psychological mechanisms to adapt themselves to a new stressful situation. Accordingly, their internal standards, values and definition of the concept of the QoL change, known as response shift phenomenon (Sprangers and Schwartz, 1999). Thus, response shift is accountable for inconsistency between objective and subjective evaluation of QoL. It means that as a result of shifting standards and values people evaluate their QoL unexpectedly, in spite of unchanged or even deteriorated health conditions. The standard approach to assessing change fails to address changes of standards, values and redefinition of the concept of QoL. The dynamic nature of QoL indicates that the meaning of QoL is less likely to remain stable for an individual over time (O'Boyle, et al. 1992). The change of the meaning of QoL over time reinforces the importance of examining response shift in

longitudinal studies. The QoL outcome measures, however, are based on the assumption that neither the concept of QoL nor the patients' perceptions of it changes over time.

The knowledge generated by QoL outcome measures has the characteristics of natural, predictive science. Making problematic the comparison between social sciences and natural sciences, Flyvbjerg (2001) examines the grounds beneath the social science failure in addressing the problems of humans and societies. He supports his arguments based on a modern analysis of the Aristotelian concepts of episteme (epistemology), techne (technology/technical) and phronesis. Scientific knowledge and technical knowledge create descriptive and predictive theory that contributes to the natural sciences, while phronesis is involved in knowledge that encompasses values, meanings and interests. "Phronesis is most important because it is that activity by which instrumental rationality is balanced by value rationality" (Flyvbjerg 2001, p.4).

One important feature of phronesis science is being context-dependent (Flyvbjerg 2001). The significant role of context was highlighted in Mishler's (1997) critique of dominant-text based model in the analysis of narrative accounts. Examining the nature of narrative, Mishler (1997) argues a narrative account as the outcome of interaction between an interviewer and a participant within a specific context. Phronesis science focuses on case studies, examples and exemplars (Flyvbjerg 2001), the similar approach is suggested by Mishler (1990) when he stresses the role of exemplars as an alternative to the experimental model. In evaluating the validity of qualitative studies, the researcher needs to provide "thick description" (Geertz 1993) of research procedure by relying on context not the standard rules (Mishler 1990). Attention to details and studying cases that are best illustrated in their contexts, are main methodological guidelines recommended for phronesis social science. Given the role of context in phronesis

science, dialogue remains at the centre of it because "the practical rationality of phronesis is based on a socially conditioned, intersubjective between-reason" (Flyvbjerg 2001, p.140).

In the present study, the patients' need to be understood by health care professionals was revealed by content and performance analysis of narrative accounts. For example, many participants were concerned about their multiple health problems and that their various health problems were not addressed by the outcome measures. This reductionist medical approach can only be tackled effectively through discourse and communication. They had a prospective scepticism about the operation that could be the source of their negative perception of the operation and their resistance to the intervention. These concerns could also be met within a contextually meaningful communication.

The issues discussed in medical communications group around the notion of "power". Comparing two medical decision making models, Quill and Brody (1996) examine the independent choice model versus the enhanced autonomy model. Opposing the dominant medical model the independent choice model as a patient-centred, control-based and discussion-based model shifts the responsibility towards the patient. As a relationship-centred and dialogue-based model, however, the autonomy model has focused on shared knowledge between patients and physicians and their collaborations. The physician is involved in medical care as a person who shares the responsibility of treatment outcome with the patient (Quill and Brody, 1996). Similar to the dominant medical model, the independent choice model views power as something that can be possessed. If one party loses the power the other party gains it. Power struggle, power shift and control are common rhetoric in this model. Nevertheless, the tendency to view power as "force relations" rather than as "entity" (Flyvbjerg 2001, p. 116) has given new

perspective to medical communications. According to this theory, the medical dialogue is a shared process (Stewart 1995) through which "the power is exercised rather than possessed" (Foucault 1979, p.26).

This study was initiated by grounding its research questions and objectives in Crotty's (1998) model of research elements. This project concerns the critical assessment of outcome from treatment. Specifically, it investigates the gap between patients' perspectives of outcome from THR surgery and data collected on self-reported standardised outcome measurement scales. To give meaning to research questions and to justify the rationale behind research methods, Crotty (1998) suggests that we should clarify our theoretical perspectives and the epistemology inbuilt in the theoretical perspective. In other words, the way the researcher views the world and the theory of knowledge embedded in the method of choice all are needed to create sensible and compelling research outcomes (Crotty 1998). My critique was concerned primarily with the type of knowledge generated in studies on validity and responsiveness of QoL outcome measures that represent a positivist paradigm. The generated knowledge emphasises a single reality that can be studied separately and the emerging evidence makes the reality (Lincoln and Guba, 1985, p.28). It is also based on the instrumentation theory in which a distinction is made between concepts at theoretical level and indicators at empirical level (Rose 1982, p.36). Through operationalisation, the concept of QoL is measured by a questionnaire as an indicator with certain items and domains. For example, measuring QoL by a generic questionnaire like the SF-36 is based on the concept-indicator distinction. The theoretical concept of QoL is reflected by eight sub-scales of the SF-36 as variables.

Choosing a qualitative research method design with narrative as the method of choice, my next attempt was to explain the epistemology embedded in the theoretical perspective and the method. The content analysis of participants' narrative accounts provided extensive data on participants' experience of hip condition including their perspectives of outcome from THR surgery. Furthermore, the performance analysis carried out on the narrative accounts of two cases produced in-depth perception necessary for developing the epistemology underpinning the research. As the data suggested, personal and social context played a significant role in understanding the participants' stories. Content and structure of the participants' stories were contextually formed. As a result, my interpretation was shaped by the way the participants constructed their stories and the themes they chose to include in their accounts with concentration on the contexts. Given the central role of context in the THR outcome study, my approach towards establishing grounds for the theoretical perspective and subsequently for the epistemology shifted. The case studies provided detailed information and reinforced the context-reliant nature of the study, a feature that has no place in scientific and technical knowledge (Flyvbjerg 2001). Investigating the practice of social science, Flyvbjerg (2001) examines a number of Michael Foucault's works to develop a perception of context-dependent and value-based social science. According to Flyvbjerg (2001), Foucault explores pragmatic technical knowledge (*techne*) without the dominant influence of scientific, context-independent knowledge (*epistemology*). Foucault relates technical knowledge to goals and advances the study of technical science from values, what is referred to as context-dependent and value-rationality practice of social science (Flyvbjerg, 2001, pp. 111, 57).

The participants shared a number of themes that were emerged from their narrative accounts. Each theme reflects a central concept related to the participants' expressions.

The shared concepts acknowledge the existence of some independent values that are considered important in patients' perceptions of outcome from THR surgery. The content analysis showed that certain features are viewed worthwhile in every participant's life that has experienced hip condition and THR surgery. The independent features were the basis for constructing a semi-structured interview schedule or a QoL instrument to assess patients' experience of hip condition. The subjectivity of participants' experience, however, was not overshadowed by the existence of shared values, as it was illustrated by the individualised, context-dependent approach of performance analysis. The case studies produced context-dependent knowledge that marks a departure from my earlier approach towards establishing an epistemology for the study. Therefore, instead of founding my research in an "ism" paradigm, which reflects epistemic knowledge, the small and detailed empirical knowledge grounded the study in "contextualism" (Flyvbjerg, 2001, p. 130).

Quality of life outcome measures are restrained by the ways of generating knowledge. The context-free nature of QoL outcome measures and the one-way process of producing data classify them as mere instruments to gain information. These instruments are not broad enough to take into account a range of issues seen in studies involving human subjects. For example, QoL outcome measures pose ethical questions regarding the patient-professional communications in which the current practice of outcome measure is established. Moreover, the value-free practice of outcome measures disregards the qualities of human-generated knowledge and treats it as technical and scientific knowledge (Flyvbjerg 2001).

On the other hand, the narrative approach is characterised by two main features:

1. The narrative generated data are context-dependent. It means that meanings are constructed in a specific context and in relation with particular individuals who are involved in the interaction.
2. Narrative is a conversation rather than a communication.

Given the features of narrative approach, it should be considered a suitable ground for studies of outcome measures, as it links an outcome measure study with issues of individuality, context, values and interaction and the ethical issues surrounding them.

Despite on going philosophical debates about the dynamic notion of QoL, QoL instruments are being developed ignoring these debates. Moreover, the ethical consequences of using these instruments to assess the QoL of patients are overlooked (Nordenfelt 1999). Focusing on three main dimensions of QoL as physical, psychological and social, QoL measures take evaluative and normative roles in health care. In other words, the instruments evaluate the QoL of people against external criteria as normal functioning, role performance and social accomplishment (Birnbacher 1999). Regardless of the type of research undertaken in terms of quantitative or qualitative methods in QoL outcome measures, the current appraisal calls attention to the researcher's philosophical perspective to minimise ambiguity in scientific merit. If scientific merit of human science such as QoL outcome studies is to be evaluated based on natural science criteria, our understanding of human experiences will be limited (Pilkington 2002).

The four waves of public health intervention from great public works, development of the germ theory of disease, the establishment of the National Health Service and welfare system towards focus on risk theory of disease are characterised by the rather triviality of the individual. This is important particularly in chronic and age-related conditions

(Lyon 2003). To address diversity and the significance of the individual which has been overshadowed by the influence of reductionistic paradigm and biomedical model, the International Futures Forum suggests a two-approach model of understanding the world (International Futures Forum, 2001). The core concept of the first world view is fear of the nature that consequently results in controlling it. Control leads to homogenising the world and creating abstract knowledge, as it can be seen with science and technology. This in turn divides people more from the nature and generates more control. The second world view is characterised by love and care in which, within a participatory world, all creatures belong to one unified world. A world that puts great value on diversity as its intrinsic value. "Instead of thinking of the world as a collection of objects, we think of it as a communion of subjects" (International Futures Forum, 2001, p.27). Therefore, rather than moving along the abstract, consumerist model of public health, the fifth wave of change as a balanced movement will be based on participation, care and compassion that empowers individuals (Lyon 2003). In other words, instead of applying an integrated model of care combining outcomes of standard medicine with psychosocial aspects of care, we could approach a more holistic view of patient's care by using an integrative model of care. An integrative model creates balance and harmony within an individual (Reilly 2001) as a whole unique person. In the search of a positive change, Reilly (2005) offers a balanced model, the Foundations of Healing, in which he combines art and science to reach a holistic approach of health care. Art as a qualitative approach consists of caring, compassion, honesty, passion, listening, time, etc., while science employs different tools, drugs and conventional medical intervention quantitatively. Therefore, a shift of paradigm not in terms of methods but in terms of the consciousness occurs (Lincoln 1997). "These paradigm shifts occur in response to awareness of anomalies-phenomena that do not fit or contradict or cannot be explained by the existing dominant paradigm" (Parry 1997, p.425). As response shift phenomenon

cannot be rationalised by the standard assessment of change and its underpinning medicine-based paradigm.

According to Kuhn's theory of the progression of science (2003) paradigms go through three historical stages: a pre-science period with no generally established paradigm, a normal science period where there is a shared accepted paradigm and a revolution period where paradigm shift occurs as a result of significant conflicts. Nonetheless, paradigms and paradigm shifts are closely related to natural science theory, which is not perceived constant anymore and its stability is interrupted by anomalies and research changes accordingly (Kuhn 2004). However, in accordance with Dreyfus's theory (1982, cited by Flyvbjerg 2001) Kuhnian interpretation of paradigm shifts cannot be applied to social sciences. Dreyfus's argument starts with the notion of theory and its six features including being explicit, universal, abstract, discrete, systematic and predictive. Thus, context should be excluded from theory in order to maintain its explanatory and predictive potentials. In human sciences, however, there is a relationship between context, methods and analysis and thus different construction of meanings. Therefore, "not paradigm shifts but rather style changes are what characterize social science, it is not a case of evolution [such as Kuhn evolutionary reasoning for the natural sciences] but more of fashion (Flyvbjerg 2001, p.30).

Chapter Five

Conclusion

This research endeavoured to understand the relationship between patients' perspectives of outcome from THR surgery and data collected on self-reported standardised outcome measurement scales by analysing participants' data individually rather than aggregated in groups.

Assessment of Quality of Life: The three QoL outcome measures used in the study provided complementary as well as overlapping information on pain, physical activity, and functional limitations of the participants. Both the SF-36 and the PGI also provided information on emotional functioning, social functioning, mental health, vitality and general health and the PGI provided some indications of other health problems and aspects of non-health areas of life. The measures were supplemented by narrative interviews, which revealed that the three instruments were not able to capture many dimensions of life, such as family/relationship, job and appearance, use of medications, hospital care and long term care. Although the revealed life dimensions could be used to construct an interview schedule for use in clinical settings, coping and change are less amenable to structured questioning.

Assessment of coping: An important critique of standardised measures was related to themes identified as coping strategies in subsequent narrative interviews, such as spiritual coping, self-oriented coping, problem-focused coping, emotion-focused coping, and comparative coping. In accordance with the principle underlying standardised measures, which aims to provide knowledge about groups of patients rather than individuals (Fitzpatrick 1999), they are restrained by their pre-defined items, which seek to encourage neutral responses. The coping-related themes that were identified through

indirect narrative questions led to examination of the notion of change. It found that individuals change their expectations and values and redefine their concept of QoL when they encounter a stressful health condition and inaugurate coping strategies. They used these coping strategies not to overcome the burdens of pain and physical limitations imposed by their hip condition but to accommodate to the harmful effects of pain and disability.

Assessment of change Changes in standards and values and re-definition of personal concepts of QoL over a disease trajectory are overlooked in the standardised measures because they employ the methods of standard assessment of change (Sprangers and Schwartz, 1999). For example, when changes in scores for different items of the Oxford Hip Score were examined in relation with one participant's narrative account, improvements in many dimensions of life were attributed to the use of different coping strategies. In the light of the elaborated coping strategies, the improvements were viewed as a change in the participant's standards and values and not attributable to the intervention. Although adaptation phenomenon or response shift and methodological approaches for assessing response shift are getting attention in longitudinal QoL research, the methods suffer from the same flaw as the methods used for evaluating QoL measures. They employ aggregated data, such as means, and inferential statistical tests to examine response shift, the very same positivistic approach used for assessing responsiveness.

Content of account v construction and context of narrative: Although, content and framework analyses revealed a much more comprehensive picture of participants' QoL compared with the standardised measures, I felt a need for a more in-depth look. I experimented with performance analysis as a narrative approach to understand how

individuals construct their stories of hip condition. It showed that their understanding of hip condition relies on how they construct their narratives rather than the content of their accounts. Understanding also depends on the context of the narrative in different situations and in interactions with different interviewees. The context-dependent nature of participants' accounts puts measurement of QoL outcomes in close association with communication in health care and highlights a major difference between standardised measures of QoL and narrative interviews. The information derived from the QoL outcome measures is obtained through a one-way process without considering participants' context. Narrative interviews, on the other hand, emphasise context and view interviews as interactions. To view the evaluation of health outcomes within a patient-centred communication model, we need methods to create meanings contextually and interactionally. In other words, the interviews should be regarded as conversations in which meanings are constructed as an interaction between two people and with regard to the context of the interview.

The importance of context: QoL is an individual and dynamic construct. People define it differently and its meaning changes for an individual over time. The dynamic and individual characteristics of QoL were well documented in the narrative data, where the meanings of QoL differed from taking life as it comes to comparing one's situation with others who were worse-off. For example, a widow who was living alone considered herself fortunate to have a beautiful house with a lovely garden to aid her recovery after surgery; and a man who was still dependent on his wife and mobility aides did not complain about his lack of independence but considered himself fortunate to be able to depend on them. Many participants used age as the target of social comparison to compare their situation temporarily over time or to compare their QoL with others at the same point in time and some contextualised their physical functioning with age to

maintain their level of QoL accordingly. This implies that definitions of physical and role functioning needed to be broad enough to allow for a range of practice and behaviour at different ages.

Perspective; Despite the complexity of measuring QoL, the use of case studies showed that this method can capture the perspective of individual participants. In support of Flyvbjerg's assertion (2001), case studies generated detailed, practical and context-dependent knowledge as opposed to abstract and theoretical knowledge produced by the QoL outcome measures. Performance analysis of narrative accounts of two cases illustrated how individuals' understanding of past events is shaped in view of their current situations. Studies of response shift involving shifts in peoples' values and standards over time also challenge QoL outcome measures. That is, while measurement of QoL outcomes is based on study designs that assume that pre-tests are always independent of post-tests, studies of response shift are designed to address the influence of post-tests on people's judgment of their initial assessments. According to my best knowledge, this study used a narrative model of time for the first time to examine response shift in an outcome study. Within the narrative model of time, two participants re-interpreted their past experiences while taking into account their current circumstances (Mishler 2005, Personal communication). In contrast, the measurement of QoL outcomes is currently performed within a clock model of time in which events are viewed in linear time and have no effects on each other (Labov and Waletzky, 1997).

Narrative model of time: The study itself was carried out within the narrative model of time. It means that the findings of the study had an effect on my initial understanding of the nature of knowledge. The individualised data questioned the assumed link between a theory of knowledge and the patients' perspective of hip condition. The context-reliant

nature of detailed narrative data made it difficult to develop a theory of knowledge, as it is in the case of natural science or even content analysis: there is no rule or theory that can explain patients' understanding of hip condition and THR surgery. The data obtained from each participant was created within their personal and social contexts. The search for a new theory or paradigm to explain the response shift in the field of assessment of change was challenged by in-depth and individualised data. The underlying criteria for a theory did not correspond with the context-dependent individualised data.

Self-Care: In the wake of increased long term conditions in developed countries, 17.5 million adults with a chronic condition in the UK, for example, initiatives such as Expert Patients Programmes aim to change the role of patients as a mere recipients of care to real partners in their health care (DoH 2001). Through such programmes, informed and thus empowered patients are expected to be able to manage their chronic conditions better and have more control and independency and thus improve their QoL. The new concept for self-management is called “self-care” (DoH 2005a). Self-care, as part of the model for supporting people with long term conditions, involves actions people take to maintain their physical, mental and social needs and, on a broader scale, the care of their family and community. According to the Department of Health (DoH 2005a), the impact of “self-care” on patients will be improved well-being and QoL and greater independence. An NHS and Social Care Model for improving care in long term conditions (DoH 2005b) also aims to encourage independency and to empower patients leading to enhanced QoL. The model supports self-care by providing information, skills and knowledge for the patients and their carers to manage their conditions, empowering patients by employing self-monitoring, and put patients in contact with the same reliable person.

Power: Thematically speaking, the issues discussed in self-care support gather around informed and empowered patients and improved QoL. Regarding the stressed themes in self-care models, three questions surfaced that have implications for the field of outcome measures:

1. How is power viewed and what it is meant by empowering patients?
2. Are patients empowered by information?
3. What is it meant by QoL?

The prime question concerns power and whether it is characterised as negative or positive power. While negative power as entity is concerned with control, autonomy and possession, constructive and positive power cannot be granted, taken or shared because it is exercised through a dynamic process (Flyvbjerg 2001). Narrative and conversation is one way to see how power is applied in health care. The detailed narrative shows the effect of communication in health outcomes. To move away from a traditional positivist stance towards a more humanistic approach, a good starting point is to put health outcomes in the context of patient-professional communication. In this way, we can observe how power is exercised rather than seeing patients to be empowered. Similarly, we need to rethink how power works in medically functional and informative care (Roter 2000) and whether it can empower patients, for example by informing and monitoring them.

Recommendations and further work

What is meant by QoL varies extensively among individuals. The meaning of QoL also changes for an individual over time. As a result, emphasis on improving patients' QoL is restricted to the assumptions that define the concept of QoL.

Although offering patients self-completion questionnaires appears to be time-efficient and narrative interviews appear to be time-expensive, a short interview conducted at a follow-up clinic or in the last treatment session beforehand can elicit more valuable information than is collected on standardised questionnaires. The prime requirement is enhancement of the communication skills of health care practitioners, to ensure that they are focused on what patients have to tell rather than what practitioners want to hear.

There are some aspects of this study that should be explored in future research. Regarding response shift, research is needed to examine change in self-reports before and after an intervention. For example, a change in the areas of life identified by the PGI would reflect re-conceptualisation, and a change in the weight given to different life domains and a change in the order of life domains would be interpreted as a change in values and reprioritisation, respectively. More research efforts could be directed into qualitative methods to examine response shift such as conducting narrative interviews before and after an intervention.

With regard to the relation between patient-professional communication and patient health outcomes, further research should identify health outcomes through models of communication to understand patients' concerns, feelings and thoughts. Additionally, research is needed to examine whether response shift can be induced as a self-therapeutic mechanism through an effective patient-professional communication by teaching people how to change their internal standards, values and redefine concepts of interests.

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**Outcome from total hip replacement:
From standardised measures to patient-focused
narrative-based assessment**

(Volume two: Appendices)

Nasrin Nasr

A thesis submitted in partial fulfilment of the requirements
of Sheffield Hallam University
for the degree of Doctor of Philosophy

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1. Appendix One

Total hip replacement surgery

"Total hip replacement (THR) is a biomechanical solution to severe arthritis of the hip joint, involving removal of the damaged hip joint and its replacement with an artificial prosthesis" (Fitzpatrick, et al. 1998). The operation is suggested to be successful in reducing pain and improving physical functioning. It is the most common orthopaedic surgical procedure and at least 50,000 hip replacements are done in the UK annually (NHS Direct website). The artificial joint referred to as prosthesis consist of three parts: a metal ball, a metal stem ad a plastic cup and it costs the NHS from £250-£2000 (Fitzpatrick, et al. 1998). The artificial hip lasts between 10-15 years after which it may need to be replaced (The Arthritis Research Campaign Website). THR surgery as a major operation can be associated with a number of complications that can happen during or soon after the operation (BestTreatments Website). Complications such as urine problems, blood clot in the legs, blood clot in lungs, damage to the nerves, broken hip, heart attack, stroke or chest infection, wound infection, new hip dislocation, hip infection, damage to major blood vessels, and dying from the surgery. There are some long term problems linked to the operation including limping, loose hip, hip infection, and wear and tear which lead to the second hip replacement (BestTreatments Website).

References

Fitzpatrick, R., Shortall, E., Sculpher, M., Murray, D., Morris, R., Lodge, M., Dawson, J., Carr, A., Britton, A., Briggs, A. (1998). Primary total hip replacement surgery: a systematic review of outcomes and modelling of cost-effectiveness associated with different prosthesis. Health Technology Assessment, Vol. 2, No. 2.

Surgery on bones and joints. www.BestTreatment.co.uk

Hip replacement, www.nhsdirect.nhs.uk

A new hip joint. Arthritis Research Campaign, www.arc.org.uk

Q I Message: Re: Permission si©

Monday, October 31, 2005 2:23 PM +0000

From: § "M.A. Sprangers" <m.a.sprangers@amc.uva.nl>

Subject: Re: Permission

To: S Nasrin Nasr <Nasrin.Nasr@student.shu.ac.uk>

Cc: § carolyn.schwartz@deltaquest.org

Bcc: 9 Nasrin Nasr

Attachments: i Attach0.html 2K

Dear Nasrin,

I am happy to give you permission for using the diagram on page 1509 in Social Science and Medicine.

However, I do believe that you need permission from the journal rather than from the author.

I would be very interested to receive a copy of your PhD thesis and thank you in advance.

Kind regards,

Mirjam Sprangers

At 02:06 PM 10/14/2005, you wrote:

Dear Dr. Sprangers,

I am a student involved in a study of evaluating the outcome of Total Hip Replacement surgery, under the supervision of professor Anne Parry. My reason for emailing you is to request your permission to reproduce your copyrighted work in my PhD thesis as follows:

A theoretical model of response shift and quality of life (The diagram), p.1509

IN: Sprangers, M.A.G., and Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. Social Science and Medicine, Vol.48, pp.1507-1515.

Thank you for the excellent work and I look forward to hearing back from you regarding providing permission to use your material.

Best regards

Nasrin Nasr
PhD research student (physiotherapy)
Health and Social Care Research

Collegiate Hall
Collegiate Crescent Campus
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Sheffield, S10 2BP
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Tel. (0114) 2255836

Prof. dr. M.A.G. Sprangers
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The Netherlands
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fax: +31-20-5669104

Message: RE: Obtain Permission =sf©

Tuesday, November 8, 2005 11:15 AM +0000

From: S "Moss, Marion (ELS-OXF)" <m.moss@elsevier.co.uk>
Subject: RE: Obtain Permission
To: § "'nasrin.nasr@student.shu.ac.uk,M <nasrin.nasr@student.sl
Bcc: * Nasrin Nasr

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Sent: 07 November 2005 18:54
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Collegiate Crescent, Sheffield Flallam University S10 2BP Sheffield United
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Telephone: (0114) 2255836
Fax:
Email Address: nasrin.nasr@student.shu.ac.uk

To use the following material:
ISSN/ISBN:
Title: Social Science and Medicine
Author(s): Sprangers, M.A.G. and Schwartz, C.E.
Volume: 48
Issue: 11
Year: 1999
Pages: 1507 - 1515
Article title: Integrating response shift into health-related

How much of the requested material is to be used:
Fig. 1. A theoretical model of response shift and quality of life (QOL) on
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Author at institute: No

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In my PhD thesis: Total hip replacement outcome study.

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01 June 2001 14:31:58

Message

From: danny@mwpavilion.com
Subject: RE: Copy Right Permission
To: Nasrin Nasr

Delighted for you to use the PGI

Good luck with your research

Regards

Danny

Original Message-----

From: Nasrin Nasr [mailto:Nasrin.Nasr@student.shu.ac.uk]
Sent: 01 June 2001 13:50
To: danny@mwpavilion.com
Subject: Copy Right Permission

Dear Dr. Ruta,

I am an overseas PhD student in School of Health and Social Care (Physiotherapy Group), Sheffield Hallam University, under Prof. Anne Parry 's supervision.

I would be grateful if you could kindly give me the permission to use the PGI in my project which is in association with the lower limb arthroplasty research group at Northern General Hospital Trust, Sheffield.

I am looking forward to hearing from you.

Thank you very much indeed.

Nasrin Nasr.

Igp Message: Re: Permission

Wednesday, November 30, 2005 4:59 PM +0000

From: ^ "Elliot Mishler" <emishler@comcast.net>

Subject: Re: Permission

To: § "Nasrin Nasr" <Nasrin.Nasr@student.shu.ac.uk>

Bcc: 9 Nasrin Nasr

Nasrin: I am pleased that you found my work useful and hereby grant you permission to cite and reproduce materials from the articles you refer to. I would appreciate your sending me a copy of the section of your thesis where you refer to and discuss these passages. Good luck on your thesis.
Elliot Mishler

Original Message-----

From: "Nasrin Nasr" <Nasrin.Nasr@student.shu.ac.uk>

To: <emishler@comcast.net>

Sent: Wednesday, November 30, 2005 7:18 AM

Subject: Permission

> Dear Professor Mishler,
> I'd like to thank you again for taking the time to provide me the
> prepublication draft of your excellent article: Narrative and Identity: The
> Double arrow of time.
>
> My reason for emailing you is to request your permission to cite and
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> In:
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> medical
> and life-history interviews. In: B-L. Gunnarsson, P. Linell, and B.
> Nordberg
> (eds). The Construction of Professional Discourse. Addison Wesley Longman.
>
> Many thanks for the excellent works and considering this request. I look
> forward to hearing back from you regarding providing permission to use
> your
> materials.
>
> Best regards
> Nasrin
>
>
> Nasrin Nasr
> PhD research student
> Health and Social Care Research
> Sheffield Hallam University
> Collegiate Hall
> Collegiate Crescent
> Sheffield
> S10 2BP
> UK
>
> Tel. (0114) 2255836
>

- 3.1. The SF-36 generic measure

SF-36™ Health Survey

Centre Number: _____

Patient Number: _____

Date: ____/____/____

Instructions: This Survey asks for your views about your health. This information will keep track of how you feel and how well you are able to do your usual activities. **Answer every question by ticking the appropriate box.** If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

- Excellent
 Very Good
 Good
 Fair
 Poor

2. Compared to **one year ago**, how would you rate your health in general now?

- Much better
 Somewhat better
 About the same
 Somewhat worse
 Much worse

3. The following items are about activities you might do during a typical day. Does your health now limit these activities? If so how much?

Activities	Yes - Limited a Lot	Yes - Limited a Little	No - Not Limited at all
a. Vigorous activities <i>such as running, lifting heavy objects, participating in strenuous sports</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
b. Moderate activities <i>such as moving a table, pushing a vacuum cleaner, bowling or playing golf</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
c. Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Climbing several flights of stairs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
e. Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Bending, kneeling or stooping	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
g. Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Walking several blocks (greater than 1/2 mile)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Walking one block (less than 1/2 mile)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of you physical health?

- a. Cut down the amount of time you spend on work or other activities L' No Yes
- b. Accomplished less than you would like No Yes
- c. Were limited in the kind of work or other activities C No Q Yes
- d. Had difficulty performing the work or other activities L". No Yes

5. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (*such as feeling depressed or anxious*)?

- a. Cut down the amount of time you spend on work or other activities No | [Yes
- b. Accomplished less than you would like | ;No | [Yes
- c. Did not do work or other activities as carefully as usual No | [Yes

6. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

- Not at all A little bit Moderately Quite a bit Extremely

7. How much bodily pain have you had **during the past 4 weeks**?

- None Very Mild Mild Moderate Severe Very Severe

8. **During the past 4 weeks**, how much did pain interfere with your normal work (*including outside the home and housework*)?

- Not at all A little bit Moderately Quite a bit Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

	All of the Time	Most of the Time	Some of the Time	All of the Time	A Little of the Time	None of the Time
a. Did you feel full of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you been a very nervous person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
c. Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
d. Have you felt calm and peaceful	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you have a lot of energy?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Have you felt downhearted and sad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
g. You feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
h. Have you been a happy person?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did you feel tired?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

- All of the Time
- Most of the Time
- Some of the Time
- A little of the Time
- None of the Time

11. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
b. I am as healthy as anybody I know	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My health is excellent	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Oxford Hip Questionnaire

Centre Number:

Patient Number:.

Instructions: This questionnaire asks about problems with your hip or hips if you are to have both hips replaced in the same operation.

Answer every question by ticking the appropriate box. If you are unsure about how to answer a question, please give the best answer you can.

. During the past 4 weeks- How would you describe the pain you usually have from your hip?

None

L:
Very Mild

Mild

Moderate

Severe

2. During the past 4 weeks - Have you had any trouble with washing and drying yourself (all over; because of your hip?

No trouble at
all

L
Very Little
trouble

Moderate
trouble

Extreme
difficulty

Impossible
to do

3. During the past 4 weeks - Have you had any trouble getting in and out of a car or using public transport because of your hip? (whichever you tend to use).

No trouble at
all

L
Very Little
trouble

Moderate
trouble

Extreme
difficulty

Impossible
to do

4. During the past 4 weeks - Have you been able to put on a pair of socks, stockings or tights?

Yes, easily

With little
difficulty

C
With moderate
difficulty

D
With extreme
difficulty

No, impossible

5. During the past 4 weeks - **Could you do the household shopping on your own?**

Yes, easily

C
With little
difficulty

With moderate
difficulty

With extreme
difficulty

No, impossible

6. During the past 4 weeks - For how long have you been able to walk before pain from your hip becomes severe? (with or without a stick)

No pain/ more
than 30 mins

16 to 30
minutes

5 to 15
minutes

Around the
house only

Not at all-
pain severe on
walking

7. **During the past 4 weeks-** Have you been able to climb a flight of stairs?

Yes, easily with little difficulty with moderate difficulty with extreme difficulty No, impossible

8. **During the past 4 weeks** - After a meal (sat at a table), how painful has it been for you to stand up from a chair because of you hip?

Not at all painful Slightly painful Moderately painful Very painful Unbearable

9. **During the past 4 weeks** - Have you been limping when walking, because of your hip?

Rarely/Never Sometimes/ or just at first Often, not just at first Most of the time All of the time

10. **During the past 4 weeks** - Have you had any sudden, severe pain - shooting, stabbing or spasms from the affected hip?

No days Only 1 or 2 days Some days Most days Every day

II. During the past 4 weeks - How much has pain from your hip interfered with your usual work (including housework)?

Not at all A little bit Moderately Greatly Totally

2. **During the past 4 weeks** - Have you been troubled by pain from your hip in bed at night?

No nights Only 1 or 2 nights Some nights Most nights Every night

4. Appendix Four

De-briefing: (Emerging ideas immediately after the interview session)

The first narrative interviews were conducted with twenty five participants in a hospital setting. Patients who had undergone THR surgery and attended the re-assessment clinic one year post operation. The study obtained ethical approval by the North Sheffield Ethics Committee. The participants had not given a notice in advance about the interview and only learnt about before the interview, after being examined by the arthroplasty nurse specialist. The first interview started with the initial question trying to induce narrative: "would you like to talk about your experience with your hip condition and the treatment you received for it? "The interviewees were not given any direction to the interview. However, verbal and non-verbal supports were given to encourage a narrative response. I realised that the participants in this study found it difficult to deal with the initial question. One reason could be that the interview was conducted in a clinical setting and participants expected a "medical like" interaction, which routinely seeks to evaluate patients' physical and functional performance.

Before conducting the narrative interview with the participants, I gave them the PGI. The PGI is similar to a semi-structured interview schedule and asks the participants in three steps to nominate five important areas of their life that are affected by their hip condition, to score each area out of 10 using a scale and to spend 14 imaginary points on these areas, more points on the areas that are most important and less on areas that are not so important. Areas affected by other health problems and non-health areas of life also are examined by the PGI. I used the PGI as a prompt to get the participants familiar with the idea of the interview. For the first couple of interviews I administered the PGI after the narrative interview. The participants' descriptions of their health on the PGI, however, mainly focused on the themes that they had raised in their interviews.

Having the perception of repeating themselves, I preferred to present the PGI before the interviews to encourage them to talk about their health problem. Although most of the participants did not show an interest in the PGI, they generally expressed an interest in the interviews or what they called as "our chat".

Participants were selected by the arthroplasty nurse specialist and I was contacted by the nurse and was informed of the participant's presence at the hospital either on the day or one day before the interview. On my arrival to the out-patient orthopaedic clinic, I reported to the desk and waited in the waiting room till I was called by the arthroplasty nurse. Then she introduced me to the participant and explained briefly the purpose of my study. The patient's consent form and the patient's information sheet were given to the participants. After the participant signed the consent form, the arthroplasty nurse left the room. To ensure that they had understood the purpose of the study and the contents of the information sheet, I reiterated the purpose of the study, the information they needed to know and the process of the up-coming interview. The interview process started with administrating the PGI. I helped them to complete the PGI which most of the participants found it difficult to complete. After completing the PGI, I turned on the tape recorder with the participants' agreement and asked them the initial question in order to induce a narrative.

Most of the interviews were interrupted on a single or several occasions such as knocking on door, telephone ring and construction noises. Some of the participants were brought to the hospital and collected by the ambulance. In that respect, I had to end the interview so the participant could catch up with the ambulance service.

Individual de-briefing (First interview): A few examples

Participant R: In this occasion, after the initial procedure of getting consent, the arthroplasty nurse took us to a small and untidy room, so I could conduct the interview in that room. The interview environment was very unsuitable and we were interrupted during the course of the interview. She did go straight to the point after my first question, and I think I got nervous and couldn't stick to the purpose of the interview. I felt empty handed after the interview, sort of waste of time. The interview did not go well as far as I'm concerned. The first interview at hospital was not easy to conduct, it was as a matter of fact an introductory session for me and the interviewee. Some of them had no idea what's going on and no matter how hard I tried to get back to the track of narration, the clinical environment won at the end. The hospital environment had a dominant effect on the whole interview procedure and the patients saw the interview as a clinical encounter. Even with a narrative induced question, their answers are more likely to be a biomedical one, including pain, physical limitations, functional performance and occasionally social activities. Participant R had difficulty filling in the PGI and felt that she was thick, but I reassured her that it is the nature of the questionnaire and not her. When I asked her about how her life had been before the hip, she talked about her life before she had developed the condition and didn't mention anything about her status before the operation. Her main focus was on pre-condition period rather than pre-operation period. Linking her condition to arthritis as something that runs in the family, she showed that she couldn't get much from the hip operation except for relieving pain.

Participant P: With a little bit of help she managed to complete the PGI. Although she wasn't very confident at the first that she could tell her story of hip condition, we created a story that followed a chronological order and looked more like a narrative story. In

response to my initial question, she divided her story into pre-condition, pre-operation and post-operation periods and was engaged in comparative and relative evaluation of her life. For de-briefing I was sitting in the waiting room and participant P was sitting beside me waiting for the transport. While she was looking at a patient in a wheelchair, she turned to me and said: "You always see somebody worse than yourself in places like this". She used down-ward social comparison to maintain her level of well-being. She expressed this statement with a feeling of satisfaction. I felt that she needed a worse-off referent in order to maintain or improve her quality of life (QoL). At that point, I realised that the scores on QoL outcome measures can change depending on whether they are administered to patients in hospital or they are used as postal questionnaires. In a hospital environment the patients evaluate their QoL while witnessing other patients who are either physically worse-off or better off. As a result, they appreciate their physical capabilities more and score on physical dimension of their life accordingly.

Participant O: He was polite, well-dressed and confident and I perceived that he could direct the interview. He was pleased with his operation, only concerned with his ankle. He didn't find the PGI useful and couldn't specify five areas of his life affected by hip condition. He used age comparison strongly to give his health problems a sense of normality (he's 70 years old). A technique used by many older people to adapt themselves to distressing situations. He thought he wasn't helpful, but I reassured him that he was a great help to me for understanding the issue, considering the limitations of a clinical setting. He raised his concern regarding standardised questionnaires. He believed that they were restricting him to a certain condition (hip), while his main problem at the moment was arthritis.

I had to spend a few minutes to get my tape recorder ready. He asked me repeatedly to prompt him, but I didn't want to direct him in a particular direction. I had the feeling that he didn't want to go back to his past, avoiding reminiscence. I felt that he liked to form a wall between his past and his present as though he is now another person, an old person who doesn't need to get involved in an active life. He mentioned he was a police officer in West Africa, a very active person who does not feel a need for more activity in his old days. Therefore, he seems happy with his present physical capabilities. His present physical capabilities don't let him down, because he's had a satisfactory active life in the past. I mean no regret. He was trying to provoke me to guide and to direct the interview and I was trying to return him to a narrative approach.

Participant S: She welcomed the idea of the interview warmly and was reluctant to fill in the PGI, so we went straight to the narrative interview. I felt that she wanted her voice to be heard by medical professionals. My perception was that she hoped that she could project her voice through the interview. I realised that I was able to implement "active listening" technique much better comparing with the very first interviews. I found the task of staying focused much easier in this interview and I managed to give my full attention to the interview as it was progressing. I think her main audience was medical professionals and I was a mediator through whom her voice could be heard. The operation itself formed a major part of her story and her experience with post-op care in hospital was important to her. She compared the two operations and the care she had received during the operations. The presence of an "outer force" was sensed during her story telling, particularly as she mentioned directly about her faith. She was trying to give the impression that she had been looked after, despite all her problems. On the other hand, the burden of physical and functional limitations made her to modify her expectations and give priority to goals that were not as important as in the past. I felt

that I was talking to different characters. She changed her position through the interview from a passive recipient of a medical intervention to an active agent who looked after many people in the past. Within a medical world she was passive and had no control over her life, but within a real world she was an active agent whom many people were dependent on her. As a carer in the past who looked after her ill husband, she re-evaluated her tough time in the past and made a positive outcome out of a negative experience which was her husband's illness and consequently his death. This positive reappraisal, however, can not be seen in the experience of her hip condition. Although she highlighted some advantages in her life that could ease the problem of her physical limitations, you could still feel some anger and frustrations in her voice when talking about her hip condition. Having multiple health problems, she beautifully portrayed how she was dealt with within a dualistic medical model. She is suffering from a degeneration disease which ultimately will affect her vision. The long for being able to walk and doing other physical activities while she has got her vision intact, is a cry for perceiving her as a whole person. Her physical problems are intensified partly because she is a widow and lives on her own. Her husband died many years ago. Yet, when she was talking about returning home from the old people's home she mentioned: "my husband got the house nice and warm" and quickly corrected to "my son got the house nice and warm".

Individual de-briefing (Follow-up interview):

Participant L: I arrived on time. She was, I guess cleaning the front door. She seemed happy to see me and so did I. I saw her with slippers on and I saw a shoe's rack with shoes on it in the corridor, so I asked her if she wanted me to take off my shoes and she said that it was ok. We went to the living room and she offered me a seat. The living room was cosy and clean and tidy and warm. The gas fire was on. I sat on a chair and

she sat on the sofa near to me. Before, I started the interview, we had a little chat and I asked how she was and she asked if I had found the address all right. As with the first interview, she again here insisted on being happy with the hip replacement and in general and nothing much she could really tell me. However, as the interview developed actually there was a lot she told me. She seemed a bit lonely and attached to home. She was worried if she was helping me at all. I reassured her that she was doing a great job for me to understand. I think the most important things to her were her two daughters who live in Canada. She had pictures of them and a wedding picture of her grand child around the room. She wasn't worried about things very much, because she believed in fate and things happen because they are meant to happen. She used a comparison technique to justify and rationalise many things. She didn't have a pet. She lived on her own. Her husband died 4 years ago. She talked about her neighbours and she knew them very well. I tried to have a normal conversation with her, I even shared some of my personal matters with her and realised that that helped in encouraging her to open up and talk. I was touched by her when she realised that I didn't have a car and came to her house by a taxi. She told me that she would've come to the hospital if she'd know that I hadn't had a car.

Participant H: She told me a story that I realised she hasn't changed many of her values. She had gone shopping and in a shop a man opened the door for her and waited until she could pass the stairs. She said: I felt so embarrassed and told myself: Am I so bad? Yet, I thanked the man for his kindness. She didn't like very much the idea of tape recording her words, while she was talking to me. She didn't say it to me while I was asking for her permission to switch on the tape recorder. But when I switched the recorder off, she was sort of relieved and started to talk a bit more. The reason she didn't like the recorder was that she felt a bit embarrassed in case she repeated herself or not

get to the point she's been asked to. The recorder put her off. However, she had no objection recording her voice, as she consented to it. She talked about a cousin of her who had the same operation and also had had cancer and that her cousin was in worse condition than her, but she actually didn't compare herself with her cousin and considered his cancer as the main reason for his problem. She also talked about another person that she had done her two hips and hernia operation in a short period of time and that she was doing well. Again she didn't compare herself with her. She rather appraised her for doing well. She found herself lucky and fortunate, because she said: My husband and I always used to save for days like this, so now I can get somebody to come once a fortnight doing the household and also somebody to do the gardening and this way I'll be able not to ask the neighbours, although they are nice and willing to help me.

She even mentioned that her husband was embarrassed to use a wheelchair around their house, because he didn't want the neighbours see him like that but whenever they went outside, in countryside he used the wheelchair and she was saying this with some kind of agreement to it.

5. Appendix Five

Interview summaries

Interviewee: Participant S (1), Sex: Female, Age: 71, Intervention: Total Hip Replacement surgery on both hip within two years, Occupation: Retired (used to run an after school club).

Key Points:

1. Seeking different coping strategies before and after the operation.
2. Engaging in social comparison.
3. Change over time as a result of both using natural coping mechanisms to withhold from the surgery and being in the waiting list for the operation.
4. Having multiple health problems and its effect on patient's perception of the treatment and her perceived quality of life in general.
5. Being a widow and living on her own and its effect on patient's perception of her health state and her quality of life.

Themes:

- putting up with hip problem for many years.
- putting trust in her doctor, resistance against the operation (*alternative intervention, conservative and more informal intervention*).
- self-motivated activities to help either avoid the operation or contribute with the result of the operation. (*Personal intervention*).
- hip weakness rather than pain (*Main problem before the operation*).
- being amazed by the fact that she had not hurt herself after having a bad fall (*Spiritual Coping Strategy*).
- difficulty in doing activities around the house (*Main Problem before the operation*).
- employing a gardener and a cleaner for a number of years (*Main problem before the operation*).
- being in the waiting list for 18 months.
- start difficulty going out (*Main problem before the operation*).
- giving the job up.

- receiving the appointment for the operation on Christmas Eve (*Spiritual Coping Strategy*).
- giving the job up at the age of 67 (*Age Comparison*).
- after the operation she realised how she had got used to the pain.
- post-operation physical limitations and her other health problems.
- adjusting to the new situation, compromising losing many activities for not having pain and being able to walk well. The effect of time on prioritising patient's life domains and compromising one domain for another (*Change Over Time*).
- having a worse experience with the second operation itself.
- the existence of an interrelationship between the rat story, going in an old people's home (run by church organisation) and being there for a fortnight which put her on her feet, a plot of faith (*Spiritual Coping Strategies*).
- fear of getting partially sighted.
- satisfied with moving into a new house with beautiful garden, cushioning the impact of the possibility of being house-bound, because of immobility and becoming partially sighted (*Cushion Theory*).
- being active in the past, looking after husband, parents and in-laws (*Temporal Upward Comparison*).
- having a nice life with her husband.
- having a tough time after his death.
- positive interpretation of her husband illness (*Positive reappraisal*).
- thinking of giving up, because of some physical limitations.

Data display:

1. Coping

- **Natural coping mechanisms**

"I coped for a number of years really and um then I started to have, I couldn't get in and out of chairs, it took me ages and I was having problems and I went to the doctor and um I had an x-ray and when I saw him, he he said: well, it needs a hip operation straight away and I've known the doctor for a long time and I said: well, **if you were me what would you do** and he said: well, try physiotherapy ((**Conservative informal intervention**)), but if the hip's gone too far, it means it

had to be done. **Before I had the operation I thought I would try and swim** and when I went to the swimming bath I realised how the movement had gone. Um, you know it is amazing that I hadn't been swimming for a while and I realised that the hip just wouldn't do it. Um, **but I did persevere** and I went every morning with a friend and tried to do the swimming, thinking that it would done me good **((Personal intervention))**".

- **Spiritual practice**

- **Indirect spiritual coping**

"The house I used to live the stairs um, you came down five steps and then on a little bit that you walked on and then another five. The number of times I fell down the second bit, I don't know why, fortunately I didn't fall far, **but it was amazing, I didn't really injure myself**".

"... I had to stay in the house and Christmas **and on Christmas Eve I got the letter to say that my hip ... appointment was 2nd Jan**". ((She said it with smile and relief. It seemed that receiving the letter on Christmas Eve was not a coincidence, but had had a message with it)).

" ... I came home, I got the home help. I didn't live at home two weeks after my op. the first hip. I found I thought somebody's trying to get into the house at night. Um, (short pause) and I was up all night and when the house help came she said: I think you've got mice, but to cut the story short I had rats. Don't ask me where they came from, I think while I've been absent, I found out after wards the detached house next door had had them for months and they hadn't had the people in it and so how they got in, I had no idea and the man who came said: he thought I would be as well moving out, or other wise I had to seal the doors and it wasn't hygienic in the kitchen and I think really they were all over which was horrifying. I can't I felt awful. Can you imagine how I felt?

Interviewer: Yeah.

Participant: And so um I thought well I have to find somewhere to go and um my daughter-in-law said: well, you have to ring the home help, they would to coming in, in the morning and would wonder where you are and think you had fallen in the house. So when I phoned up her and I said: I don't know where I'm going to go and what I'm going to do, she said: leave it with me and they phoned back in half an

hour and had got me into an old people's home um which did me the biggest favour in my life, because I went to O. which was um run by a church organisation, because I go to church and I have my faith and the atmosphere suited me down to the ground. I was spoiled. I thought if this is an old people's home, I have nothing but praise and I felt it was like a fortnight of convalescence and because it was on the flat outside, which my own home wasn't, I could practise walking with crutches and I used to go a little way, come back to the home. I didn't go long way **and that fortnight put me on my feet, isn't it strange**? ... I had an epidural for the operation. I have to say I couldn't understand **I thought I would be frightened**. I don't know why I think **I was just relieved** ... and the operation just seemed fine. **I know I sound strange**, but that is how I felt and I was just laughing and chatting and I thought well this is just wonderful".

□ **Direct spiritual coping**

"... I go to church and I have my faith ...".

• **Positive reappraisal**

" ... **I loved looking after them** in their own home ... but **David was lovely and cheerful and we didn't have a miserable life** ... but David wasn't miserable, my parents were nice, David's parents were nice, we just ...yeah we were all right. I mean, I mean I don't say ... **It sounds gloom and doom, but quite honest it wasn't, you know. We were ... David was cheerful and optimistic** and he worked quite up to the day he died. He died at his desk and that was a tough time after, a tough time after, because you know we were very close **and in a strange kind of way, when you've got someone who was in that state (short pause) um you get closer, you made the most of what you've got and I still think I have that in me, because if anyone asks me I go and if I can do anything I do, and I have many friends**" ((making a positive picture of the stressful situation)).

• **Goal rearranging (change over time)**

" ... I've lost movement for bending and getting down to things and I had to get in a car in a certain way and **there is loads of things in the house I just can't do anymore and I can't get down. That um it's not bothered me. I mean you just adjust and I think well, it's no big deal. I'm just relieved, that I am on no pain killers, I can walk about and I could walk very very well which was wonderful and I thought well if I could do that, I haven't been doing that for so long**".

- **Cushion theory (reframing expectations)**

"... I've moved between the two ops into a flat, because I realised I have to do which has been wonderful. I've got the most beautiful flat, um not very big, but to me. It's got a lovely garden and a view which makes it for me which you can make your own home nice. So all that has done which has been wonderful. I thought I was rushing between the two hips and it was it was a lot of it took some doing, but it is the best thing I have ever done. **Now I can't drive, you see and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden. I can sit in which I wouldn't ve settled without it**".

2. Social comparison (individual and aggregate)

- **Age comparison**

"... because I couldn't cope and I was waiting 18 months for the hip and decided I have to give my job up, because I realised I couldn't even go out anymore. ... **So I gave my job up and was nearly 67, so it was time that I did ... "**

- **Temporal upward comparison**

Interviewer: Do you remember how life was before you developed your hip condition?

Participant: "I have to say **I was extremely active** and you see I had a husband who had heart condition most of his life, so I did all the heavy work which didn't bother me at all, because I was I mean ... **I was physically very strong and I have done a lot work**, because David's parents, David's father had a hip operation done, it wasn't successful, so he was more or less in a wheelchair. His mum had heart trouble, we moved them near us, so I loved looking after them in their own home ... **I was doing all the garden, the work**, when there was David's parents, David's parents right up to the end ... home and then my parents weren't well, so when David's parents died, we moved them into the home again ... **I did all the heavy work, all the gardening** ... and moved David's mum and dad in, and it was rather sad, because my dad got two months off hundred and I looked after him and he died and I started with my own problems, didn't I? It's 8 and half years and and **so I mean really I did a man's work, but I can't... I liked decorating. I liked the garden ..."**

- **Temporal downward comparison (Main problems before the operation)**

" ... It wasn't the pain that made me, the hip gave way ... I really got problems for so long getting in and out of the chair and I couldn't do a lot of work in the house. I've

been I've been employing a gardener and a cleaner for floor for a number of years, um because I couldn't cope and I was waiting 18 months for the hip and decided I have to give my job up, because I realised I couldn't even go out anymore"

- **Changes in patient while waiting for the operation (getting used to the pain). .**

" ... I had been on anti-inflammatory drugs for about five years ... when I came out of the anaesthetic I felt I'm on a high, because the pain was so much better. I can't... you get used to pain and it wasn't there".

- **Being in the waiting list for 18 months and 15 months for the first and the second operation respectively.**
- **The presence of another health problem and its effect on patient's evaluation of the intervention under study.**

"... The second is so much better from the first. I hardly know I've had it done and you see how I've got a problem with the right hip the first one and to be perfectly honest I feel I'm back to where I was before (laughs) I had it done. So I don't know ...I know they don't want me to have it redone and trying to force me, keep it as long as possible, um but as far as I'm concerned I have to be mobile, because I've got macular degeneration and anytime, I don't know how long it will be I'll be registered partially sighted and that would more or less be it. **I think it's no good giving me another hip later, I want it now and I want to be mobile now, while I have my sight. I want my quality of life now** and I want to know the score and I am really going to be quite firm today, because I think I could understand. ... I really must ... I feel ... I'm disappointed that I'm not seeing Mr. S., because um there is something going on that is not right and if I've got to be on severe pain killers, I'll be very limited. Um, I don't know whether you can have three hips done and they're perhaps thinking of 70, 10 years there may be another op and I don't know whether they do three, but for me ... **I'm probably going to be house bound in any case with my eyes. I feel I'd rather be mobile now and that's I think that's it"**.

Reflections on interview:

- The interview started with the initial question trying to induce narrative and the interviewee was not given any other direction to the interview. However, I realised that the participant at first found it difficult to deal with the initial question. One reason could be that the interview was conducted in a clinical setting and the participant expected a "medical like" interaction which routinely seeks to evaluate patient's physical and functional performance. Also, the participant had not given a notice in advance about the interview and only learnt about it a few minutes before the interview, after being examined by the specialist nurse.
- I felt I could establish a rapport with the participant, because she used the referents in her account as means to express her experience, rather than simply giving a report of what had happened.
- During the process of member validation (going through the transcript and verifying it) the participant made explicit emphasis on her double disability (visual problem) and its effects on her overall quality of life. She had made it clear that how desperate she was to be mobile and get her quality of life back, before she got partially sighted. She had also added some lines wishing that she could still drive, an activity which has been affected by her visual problem and not the hip.

Implications:

- In follow-up interview I asked the participant two different kind of questions with two main purposes: 1) to encourage her to tell more about the themes that were raised in the first interview, 2) to explore the participant's values by asking questions to get at evaluation. By means of evaluation questions the interviewee's standards and values can be revealed and to what extent these standards and values have changed throughout her life, particularly over the disease trajectory.

- The importance of conducting the follow-up interviews at places other than a clinical environment, preferably at participants' homes. This is particularly important if the interviews are scheduled at the time when the participants turn up for the follow-up evaluation of the operation at the reassessment clinic.
- Having the participants informed of the study and its aims prior to the interview.
- The interviewer was introduced to the participant by the nurse specialist who was assessing the participant at the reassessment clinic. The advantage of this act is getting high response from the informants to participate in the interview. However, getting through the participants via a health professional who is engaging in care, treatment and evaluation of the outcome of the treatment puts the whole process of the interview in a traditional and reductionist medical frame.

Interviewee: Participant S (2). The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Multiple health problems and its effect on her overall quality of life.
3. Seeking different coping strategies, particularly spiritual practice.
4. Remaining Focused on uncontrollable disease-specific domains, having difficulty in changing the internal standards and beginning to experience some negative psychological feelings such as "boredom" as the consequence of this behaviour.

Themes:

- Not being as old as the rest of the ladies in the old people's home (*Age comparison*).
- Being cared and looked after in an old people's home.
- Being a widow and living on her own and having done everything for herself.
- Having strong faith in God and ask for help with her problems (*Direct statements about spiritual Coping*).
- Feeling sorry for those who do not have a faith in God (*Social comparison*).
- Getting benefit from having some kind of aim or faith (*Social comparison*).
- Not getting much help from the family, because of their own problems.
- The benefit of having a large family (*Social comparison*).
- Being looked after invisibly (*Spiritual coping*).
- The eye problem and its effect on her driving ability (*Having multiple health problems*).
- Having physical limitations such as getting in and out of the car, lifting the leg and going to the bath.
- Independency as the most important thing in her life (*No change of internal standards*).
- Visual problem as a barrier to change her internal standards (*Focusing on physical limitations as the hip-related domains outside her control*).
- Comparing self with others (*Social comparison*).
- Her look and people's opinion (*The importance of appearance*).
- Understanding the feeling of getting bored (*No change of internal standards*).
- Not feeling old at the age of 70 (*Age comparison*).

- Being lucky with her family and her friends (*Social comparison*).
- Being fortunate in a lot of ways (*Social comparison*).

Data display:

1. Social comparison (aggregate and individual)

- **Age comparison**

Interviewer: You said that you'd stayed in an old people's home for a fortnight and that fortnight put you on your feet. [That was for the first one.

All right! The first one, oh! That's interesting. I don't want this part go by without asking you to explain more about it.

Participant: "Well, um (short pause) I think it was (short pause) the environment (short pause) I mean even though it's an old people's home ... I think because **I wasn't as old as the other ladies**".

- **Downward comparison (indirect)**

" ... I think I have strong faith in God. ... Um **I feel sorry for people**, I think you do need (short pause) I think I think people would have an empty life (short pause) miss out ((low voice)) you know something. People think if you uh if you have a faith in God, perhaps you're stuffy, or you miss out on (short pause) pleasures. I don't think, I think they are the ones that miss out".

"I'd rather do my own work, never bothered me doing it, but I can't, I can't, so **I'm very very lucky with my family and friends**. I've got some very very good friends for years and um (short pause) you see these my friends their children are my friends and then they bring their children, do you know what I mean"?

"... but she's twenty years younger than me and she was a friend of my eldest son, a bit older than my M. and somehow we're very very close ... which is quite lovely. ... we just get on very very well and she's lovely really. **I'm very fortunate in a lot of ways, because I mix a lot with the younger people as well**, um (short pause) so yeah...".

- **Upward comparison**

"... you see both my daughters-in-law are not well. So uh they have very very severe problems and (short pause) so anyway, I can't rely on my family. It doesn't mean that they don't love me ... It isn't that they don't care, but he ((her son)) has a lot of problems and so does T. **And you see perhaps people who lived to have large families who can perhaps support and help them, I think having that kind of (short pause) uh that you're not alone** and you see I don't feel I am alone".

- **Advantaged-self**

"... **people with (long pause) some kind of aim or faith I think benefit it.** I think it gives someone (short pause) comfort and peace quite honestly, uh (short pause) and for me it helps me. It does. I do feel it helps me".

"... I mean some people love to spend hours around shops, it doesn't awfully appeal to me. **I can do something nicer** uh, I do like, I used to like to go out into the country, but I do get taken and I do go, but it this problem with the cars, which is it is ... you know being able to get out with all the buses ...".

"... I think you can give up if you're not careful and I don't want to do that. I ... you have to keep your brain going and I like my music ... **I do keep myself occupied, I I some people aren't bothered, are they?**, but um and I've got talking books um and um (short pause) I I don't think you've got ... you can't give up and I'm not prepared to do it, until I really really got to".

2. Coping

- **Spiritual practice**

- Direct spiritual coping**

Interviewer: How your faith, you mentioned before, helped you?

Participant: "I think my faith does help me. I think I have strong faith in God and I really feel when you pray, I DON'T MEAN I'M GOING OVER THE TOP AND SILLY OR ANYTHING LIKE THAT ((loud and quick)), but I do think if you feel that God loves you and he's in control and you can pray to him and ask for help and

strength to get well (short pause) I do THINK IT HELPS and you do feel alone you know, if you pray you can pour out. Um, I don't ask him for materials 'cause I think I'm very well blessed. I'll ask for help with my problems and for the strength to cope with them and somehow you get through and I think I think God helps me to cope".

□ **Indirect spiritual coping**

"I felt that the way things had worked out, it somehow been towards a plan, but it wasn't a plan. I think I was looked after there".

"Well, you see when I had the first hip done, I was driving and I really couldn't do a lot of work in the house. It always governed me. Um (short pause), um (short pause) I had to do what the hip would let me do, not what I wanted to do, but uh and I decided to move into a flat, when I realised you know I thought I got to move and I felt that I was rushing it, **but there again** (short pause) **um I felt I was looked after to get this flat. I really do**, because it's perfect for me".

3. No change of internal standards

• **The importance of independency**

"I feel I need to be able to get out, being independent uh and that is important to me. ... I mean 11 in the house ...I mean what I can't do, I just pay you know. I can flick a dust around and keep it tidy, but the actual heavy work I can't do, so I will have to pay for that um (short pause), but I don't... I like to be independent. I do like to be independent. I think it's quite important really. Um (short pause) I want to go to Church on Sundays, I I I do like the country, I do like to go out into the country ((low voice)) if I can. I like to walk...yes I will walk, going for a walk ((interruption)) and uh (short pause) it's perhaps and I will I will do it as long as I can ...".

- **The presence of other health problems, acting as a barrier for changing the internal standards (Focusing on physical limitations outside her control as the hip-related domains).**

" ... uh because of the double disability you see, **if I could be doing my painting and my reading and sewing, I don't mind not going out.** It isn't that I want to go and do anything uh (short pause) you know uh just normal things ...".

- **Experiencing some negative psychological feelings**

"... I've never had one (short pause) um (short pause) what you call the high life. It ... I much prefer going in the country and walking and seeing my friends and I'm happy. I like the theatre, something nice and things like that, but and the music, I like my music. I'm just sorry I can't do my painting. **I always used to say I can't never understand people being bored, but I think I need to understand now, because I've got my limitations, because I've got so many things I want to do that. You know I used to think I don't understand people being bored.** I'm still not bored really, you know (she laughs) yeah.

- **The importance of appearance**

"... I'm not really a person I don't allow myself to to to um grudge you know, I mean in the morning when I wake up I think oh how the hell I'm going to get going? and I feel rotten, but I know if I get up in about an hour an hour and a half, I feel a lot better for getting out of bed and getting going and I DO, I DO FEEL BETTER ((stresses)) and I think put something nice on and do my hair and I feel better. I can't ... I do feel better for for a **...I think when I look okay and people see me and they think I look okay I feel okay** (laughs) uh yeah it's just me ...".

Reflection on interview:

During the first interview with the participant S I felt that to some extent I had been able to conduct a narrative interview with the purpose of inducing a narrative response. Therefore, in the follow-up interview I focused on the themes that had been raised in the first interview. My aim was to get profound understanding of some apparently superficial notions which I had little knowledge about them. The participant clarified my perception of some concepts by talking directly about them. Moreover, to get at participant's values I followed a more structured approach in order to be more specific about them, though I realised that the participant had talked about her values throughout the interview in an implicit way.

Interviewee: Participant V (1), Sex: Male, Age: 69, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (Bus driver).

Key Points:

1. Engaging in social comparison.
2. Seeking problem-focused coping strategy.
3. Experiencing the feelings of anger, confusion and guilt.
4. The relation between past and the present selected coping strategy.
5. The relation between participant's sex and the selected coping strategy.

Themes:

- Being sceptical about having the operation.
- The advantage of having the operation.
- The post-operative trauma.
- Leading an active life in the past.
- Coming to terms with the post-operative trauma (**Seeking information, problem focused-coping**).
- Changing important things in the life.
- Being fortunate (**Social comparison**).
- Making life easier by using mobility aides (**Problem-focused coping**).
- Being reluctant to be pushed in a wheelchair.
- Being dependent on his wife and feeling selfish.
- Two important things in his life.
- The importance of his family.
- The inability of making plans for the future.
- The existence of worse-off people (**Social comparison**).
- Being wondered why this has happened to him (**Upward comparison, feelings of anger, guilt and frustration**).
- Being fortunate (**Social comparison**).

- **Data display:**

- 1. Problem-focused coping**

"... The sudden realisation that you've lost your independency, you know. You've got to rely on other people to help you and I am coming to terms with it now like my own doctor which I am fortunate I've got a brilliant GP, I owe him a lot uh and he helped me, he explained it all to me and he gave me a special leaflet for use to read on it".

" ... I have a mobility car. and I've also I got an electronic scooter. So uh I've also got a stair lift at home, so all these things makes life just a little bit better, just gives you a measure of independency. ... I can buzz around on it, so in that respect yes, I've sort of come to terms of being determined, I'm not going to become house bound and trapped and not going. I mean I've just been down to Cornwall. I've been to see my son in Somerset. Well, it's only because I've got that little electric scooter I can get about on, you see. So that made a big difference in my life and it is a big change in my life now yeah so uh (short pause).

- 2. Social comparison (aggregate)**

- **Downward comparison**

"... **I am fortunate.** I have a mobility car. and I've also I got an electronic scooter. So uh I've also got a stair lift at home, so all these things makes life just a little bit better, just gives you a measure of independency."

" ... My family is good, you know. My daughter and all out there always help me. my son lives in Somerset, I go down there, because it's so nice down there, I stay with them for two weeks, a time, but yeah (short pause) I just make the best of it and carry on. **I mean there are people worse-off than me, so I thought I should be thankful, I can at least keep going about, in that way,** you know using my scooter and things."

".... We have our own house. We live comfortably, so in that respect we've got our independency there, **so we're fortunate** (short pause)... "

- **Upward comparison and feelings of anger and frustration**

"... Sometimes you know, you get up in the morning, you think why me? Why has this happened? What have I done to deserve this? You know. I mean I'm an honest person, I worked hard all my life, I've never caused people trouble and then you know you see people've been absolute criminals, been in prison and they got a healthy life, why me? What I have done to deserve this? But that's life. It don't work as you think, does it? You know. Uh the people who you think well, you don't think anybody deserves this, but the people who you think might get punished for the way of life, don't seem to. Those who seem trying be as good as they can in the life seem to be punished for it. I don't know. Maybe one day I'll find out (laughs), yes. I don't know...".

3. Having difficulty in changing the internal standards.

" ... So yeah, I've come to terms with it now more or less. **It's just one of them things, isn't it? You don't know what's coming to you in life ... "**

" ... so I thought I should be thankful, I can at least keep going about, in that way, you know using my scooter and things, **but I would rather be able to walk about like anybody else does (laughs). That's life, isn't it?"**

"... We have our own house. We live comfortably, so in that respect we've got our independency there, so we're fortunate (short pause), **but still that's life"**.

" ... **but my biggest loss is my mobility, not being able to do what I want to ... "**

- **The advantage of having the operation.**

"... what they told me that the biggest advantage I got from it was to get rid of a lot of the pain from the arthritis condition, but I wouldn't get a lot from the mobility point of view, which is true. That's exactly what they told me ...".

- **The post-operative trauma.**

" ... mean I've led a very active life, I've been in control. I've worked without supervision for a greater part of my life and then suddenly came to a situation when

you can't get about, you dependent on other people to help you. In another words, you lost your independency. I couldn't live on my own now. I know that and I'm relying on my wife to help me with things like fastening buttons, you know generally getting dressed, sometimes at night arthritis getting that bad I've had difficulty turning over. Uh these are things and all that in your mind that's what affects you. The sudden realisation that you've lost your independency, you know. You've got to rely on other people to help you and I am coming to terms with it now

H

- **Two important things in his life.**

" ... Two most important things in your life are obviously: mobility, being able to get about you know and keeping your mental faculties and if you lose any of those your mobility or your mental faculties obviously then your life is affected , isn't it? I touch wood up to now I have not lost my mental faculties (laughs). I can't remember things as good as I used to do, but my biggest loss is my mobility, not being able to do what I want to ... ".

- **Depending on his wife.**

"... I owe a lot to my wife obviously. If it wasn't for her I don't know what I should do. I depend on her enormously right now, you know. I mean uh you feel selfish, don't you? Because you feel you're the one who should be doing things for her and I'm depend on her more than anything.

Interviewer: How do you feel about depending on your wife?

Participant: Uh well, I rather not. putting it that way, I'm comfortable with it now, first I found it awkward, but you know she says she understands it..."

Reflection on interview:

The interview started with a narrative induced question and the produced response was a narration. By the means of the following questions it seems difficult to return to the narrative. However, the questions have a dynamic nature which point to the participant's possible change over time. The interview was ended with a description of felt-emotions and production of a theory-text which reflects participant's opinion.

Given the very limited time I had for the first interview in an out-patient clinic, my attempt was to make the most of the opportunity I had with the participant. Therefore, while I was trying to hold on to the dynamic nature of my theoretical questions, exploring the participant's change over time by the adaptation of different coping mechanisms, to some extent I diverted from the "narrative only" questions and examined participant's emotions, beliefs and values while adhering to a chronological approach.

Interviewee: Participant V (2). The follow-up interview at participant's home.

Key points:

1. Seeking problem-focused coping strategy.
2. Having difficulty in changing internal standards.
3. Engaging in both down-ward and up-ward social comparisons.
4. Work-related health problem.

Themes:

- Being dependent on his wife and getting care from her.
- Not being house-bound and using mobility aids (**Problem-focused coping**).
- Adjusting to life and getting on with it.
- Being active in the past, including travelling a lot.
- The travel insurance disadvantage associated with arthritis (**Problem-focused coping**).
- Getting used to not working at present.
- Failing to do things which used to do such as fishing, swimming, travelling and not dwelling on them (**No change of internal standards**).
- The existence of worse-off people (**Social comparison**).
- Taking life as it comes (**No change of internal standards**).
- Experiencing anger and frustration by seeing some other people who are healthy (**Upward comparison**).
- The existence of a life beyond this life (**Cushion theory**).
- Belief in fate.
- The role of inheritance in his health problem.
- Looking at his health problem as a work-related condition (**Feeling of blame**).
- Comparison between present and past working conditions.
- His choices in life, easier options.
- Comparison with others in relation to using mobility aids.
- The feeling of freedom by being in vehicle.
- Being fortunate (**Social comparison**).
- Joining the pension scheme and getting full pension (**problem-focused coping**).
- Being comfortable (**Social comparison**).

- Using electric edge cutter for gardening (**Problem-focused coping**).
- People and their attitude (**Social comparison**).

Data display:

1. Coping

- **Problem-focused coping**

"Well, I can still, I mean I'm not I'm not house bound, because of the little electric scooter which is being carrying in the car, so I can still get out, but I need as you might say (clears throat) uh ... artificial help if you want to put it that way uh I couldn't walk without that and anything like that... "

"... but you see the other big disadvantage now is insurance for travelling abroad (clears throat) uh I don't know whether I'll be able to afford it really 'cause once really I caught somebody in a similar situation with arthritis and so 'cause (clears throat) and the insurance people wanted them to sign a paper to let themselves to cover the first £1000 of any illness, well (laughs) is no good saying yes I will do that if you can't afford to mess about like that, uh so these are other disadvantages that come with it, you see. ... The C. insurance accepted me and even they came by to me and they said they looked into it and considered all the pros and cons and their insure may be prepared to pay a premium of £22 a month for 10 years and then it to become a prepared policy like and I don't have to pay anymore for that... "

"... so in actual fact they gave me about 24 and a half years pension, well qualifying 25. So when I finished I got full my pension ... so we're fortunate in that respect ... same story again isn't it? You get out of life what you put into it. I'm not regret it joining in that pension scheme, I mean at the time the money you're paying could've been very useful, but in the long run it's paid the difference, yeah. That's guaranteed till the day I die and then if I go first wife will get 50% as you probably know these big self-pension you get 50% of what I get for the rest of the life. So it's been rewarded in that respect."

"... see in gardening now I mean I can't grab a spade and start digging and turning over and I have an electric edge cutter used to cut the edge ... "

- **Belief in fate (cushion theory?)**

"... and you think you know what's fair in life, why is that? ... That's as said that's why life is".

Interviewer: Have you found an answer to this question?

" No, not really (laughs). Maybe one day (laughs) you know. Uh (short pause), but some people say if there is a life beyond this life maybe then you'll understand what these all been about, won't you? ... I always think everybody's ends determined from the minute they born and no matter what you do and where you put yourself when your end comes, time and circumstances put you to this. You don't have to worry about it... Uh some people don't like going about a lot in a car, I mean I spent most of my life riding about... but if you start worrying about it and (clears throat), there is risk potential of being on the road, you will pack it up, you won't do it... , so you know as I say the fate take take what comes that's all you can do ... ".

2. Social comparison (individual and aggregate)

- **Downward comparison**

" ... just worse, **people are lot worse than me, at least that means something.** I can get out and about, go down to the coast, we went (clears throat) to Cornwall in June and then as I said we went down to our son's in Somerset, so you know still keep going out. I don't like myself get house bound. I always remember a relation of wife, he spent what would it be the last 10-15 years of his life [wife: yeah, in house, never moved, did he? Used to sit in a chair day in and day out, never moved, never moved, is a relation of wife, yeah, never moved and he stayed like that and he had been an [wife: accountant, an accountant yeah, very well educated man and he got sort of became disabled, didn't he? He gave way to it and just used to sit in and out day in, day out... and sat there until he died, so I thought I was thinking about that. I don't want to get like that, you know ... ".

" ... **I think in some ways we're fortunate.** Uh, (short pause)I mean we appreciate ... we live in our own house, so we don't have that problem ...".

" ... **so when I finished I got full pension ... , so we're fortunate in that respect and that we can live, we are not rich, but we are comfortable, we are not**

scratchy, not like some uh you know, so in that respect we are fortunate, yes. We're managing all right, we don't have great worries ((low voice)). I mean if wife wants to go out and buy anything she can do that. Not to start worrying wondering whether we can afford this or whether we have to go to Oxfam shop and anything like that, no we're all right in that respect. So in some ways we are more fortunate".

" ... so you've got to adapt, you've got to prepare to change (short pause) your ways of doing something different, but it doesn't mean you don't have to do it at all, **but I know there are people who take that attitude, don't they? I can't do it, I don't want to do it anymore.** So you've got to be prepared to adapt your life (short pause). It's it's a matter of attitude I suppose, isn't it? You can't determined what people will or will not do. You have to think about it (short pause). I mean there is an old lady up the street, she's already had one operation, bypass operation, she's 80, but she still go out, it won't stop her ... she catches bus and all that, well she could just as easy sit in the house and that's it. You know she does make efforts, she gets out (short pause). It's attitude that minds you know. Not counting for what some people will do and what another person won't do (short pause), that's the difference.

- **Upward comparison**

"... becoming frustrated sometimes you know, when you look around uh you see people and they don't deserve to have a good life, some of the things they get up to it, some of the things they don't [wife: Nothing ever seems to happen to them yeah, and then you see people really come to do the life, done the best and they are struggling and you think you know what's fair in life, why is that? As you get older you look back on lot of things and it makes you think why does that happen to them? Why does nothing happen to this other person? There is no accounting for it, is there? That's as said that's why life is".

3. Having difficulty in changing internal standards

" ... I used to like fishing, but I can't now, 'cause I can't support rod you know. Well, I wouldn't be safe on the river bank if I got there ... so you know that's about to forget about that (short pause) uh I once was in a shooting club, that's gone by the way, 'cause you can't you know, all these sort of things you always followed in the past, can't no longer follow ... ".

Interviewer: How do you feel about that?

"(sighs) well, you can't really afford to dwell on it, you know. You think about what you have done and may be what could be and can't be, it's no good dwelling on it, it isn't. What's the point, you know. It won't go away. It gradually get worse as years go on, so how many more years it's got to go, I don't know, but time tell, isn't it? Yeah (short pause). Just worse, people are lot worse than me, at least that means something ...".

Interviewer: You mentioned that you just take life as it comes, [Yeah, yeah I do. I take life as it comes. How do you do this?

"Uh (short pause) well, to take life as it as it comes, don't start planning a lot of things in future, because there is no guarantee that you'll be able to fulfil them plans ... as I say just got to take life as it comes, accept what comes and make the best of it, not not get withdrawn ... uh but at the same time don't build your expectations high ... you just got to accept what life brings you. Becoming frustrated sometimes you know when you look around, uh you see people and they don't deserve to have good life ...".

((There are participant's internal standards and his efforts to maintain a sense of control, as well as engaging in both downward and upward social comparisons. While downward comparison might induce a change in participant's self-evaluation of his overall life to maintain the level of quality of life, engaging in up-ward comparison might be stressful)).

- **Work-related health problem**

"... and working on public transport, driving buses and things like that wasn't a good idea you know. It's a wrong job to do ... you're wearing and tearing the joints you know, the actions you do and that's you don't wanna do if you're gonna develop something like that ..., so it wasn't a good idea, but I can't turn the clock back now. I've done it, haven't I? (laughs) (short pause) ..., but I can't do nothing about it now, it's too late, I'm done it yeah ... It's more common that I imagine it to be. It is, work-related things, yeah (short pause), ... and I think we are paying the price for um (short pause) possibly the end of the era of manual work if you want to put it that way, not to deny the present one, but if you look look at them today everything's automatic ... when I did it it was all manual ... I think a lot of the people you see today is (short pause) from the era of what I've just said, intense manual work and it's gone now, isn't it? manual and heavy works like that".

- **The role of inheritance**

"... when you look back at past life as well you see inheritance is some of these ... my grandfather side, my father's father obviously the grandfather side (clears throat) he was as I am now, he was exactly as I am now, you know. I DID KNOW me grandfather ... and I could picture him now, and limping in the antique garden until he got as he couldn't go anymore uh so in that respect (clears throat) uh yes it does come from me sides".

- **A big change in his life, sudden change in his work status**

" ... I've got used to not working now, that's a big change in mine suddenly finished work, especially what's I've done, transport, you live by the clock. I mean you work on public transport (short pause) uh you cannot make that job fitting to your life, your life is into the job. You literally live the job, it is your life, if you can't do that, you're wasting your time with the public transport, you see. You know you've got to be by the clock all the time. I've got used to be away from that now, you know. It takes a bit of time to the habit has gone for 40 years, yeah.

Interviewee: Participant E (1), Sex: Female, Age: 62, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (newsagent).

Key points:

1. Engaging in social comparison.
2. Using natural coping mechanisms before the operation.
3. The importance of appearance and its relation to walking aids.
4. Using natural coping as a means of self-benefit strategy in comparison with others.

Themes:

- The cosmetic aspect of the hip condition (**Appearance**).
- The physical limitations associated with the hip condition before the operation.
- The presence of physical limitations and discomfort as opposed to the pain before the operation and feeling fortunate for not having enormous pain (**Social comparison**).
- Walking unaided as the best achieved benefit from the operation.
- Seeking information and alternative treatments before the operation (**Natural coping mechanisms**).

Data display

1. The appearance

" ... You don't like to think that you've got to use a walking stick, um psychologically you don't like to think that you're aged by a walking stick and also the inability to do more things that you could easily do before".

2. The pre-op physical limitations

" ... so everything took much much longer, I was very scared about crossing the road from the time that I was on a stick, um because I felt so vulnerable, because I was so slow and so much a danger really to everybody else and yet couldn't help myself... um I think socially you had to think very much within the limitations of how far you could walk ... supermarkets wasn't too bad as long as I could hold on to the trolley (laughs), but certainly couldn't carry anything what so ever, um that was just out of

the question ... um I used to have times when if managed a small amount of gardening it was as though I'd climbed Everest, because against all the odds if I could do something, I felt that it was an achievement".

3. Social comparison (aggregate)

"Um, so yes I would say more than the pain it was a limitation of the condition that gave me most bother ... Um, **whilst I was waiting eventually for the hip replacement I felt it was much more the discomfort the limitation to my life as opposed to enormous pain which heard other people saying about having been,** um, I felt that the condition itself although apparently quite severe, because I couldn't walk unaided um, I felt that I wasn't in agony or any of those things that I'd heard people say. **So I felt fortunate from that point of view"**.

4. The advantage of having the operation

- **The use of walking aids**

"... I think that mentally I had allowed myself 12 weeks of being truly incapacitated, um and I was delighted by the fact that in the ninth week the the start of the ninth week, **I walked completely unaided, which to me was an enormous bonus** and from then on really I've gone from strength to strength and feel exactly normal and feel very happy, um able to tackle anything I want to do, don't feel I have any limitations and I'm extremely happy with life and especially with the operation".

5. Coping

- **Natural coping mechanisms**

" ... um I went to a physio and paid privately and he said in fact what had happened was that the sciatic nerve had become trapped ... um I did get quite a lot of benefit in reading the leaflets which are produced by the Arthritis Research Council ... Once I took on board the fact I did have to have the operation and and I tried with the idea of going privately, then turned it down ... ".

Interviewee: Participant E (2), The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Using natural coping mechanisms before the operation.
3. The importance of appearance.
4. Focusing on advantaged self.
5. The importance of pain severity on waiting time for the operation.

Themes:

- Cosmetic aspect of hip condition (**Appearance**).
- Family, health and security as the most important things in her life, respectively.
- The death of his late husband of cancer.
- Her home as her security, her home as a settled place and her life as a fairly routine one.
- The reinforcement of the importance of family by her health problem.
- Seeking alternative interventions (**Natural coping mechanisms**).
- **Social comparison (individual, aggregate, downward, upward, age and temporal).**
- Having more choices related to improved hip physical functioning.
- Being mentally active rather than physically.
- Having positive mental attitude (**Advantaged self**).
- feeling less pain and agony while waiting for the operation (**Advantaged self**).
- Going to physiotherapy, feeling less pain and being in more control (**Advantaged self**).

1. Appearance

" I think it's fairly common ((from a cosmetic point of view)) (laughs), because I met somebody at the weekend at a wedding who has shattered her knee in an accident... she has a knee brace, but also she has a walking stick. Now because she feels that it is so aging, um for the wedding she didn't bring the stick, even though it does help her a great deal ... because she felt that that was an aging thing, that people looked at somebody with a stick and thought that they were old and you know um (short pause) infirm. And so so it does seem to be a theme with women that they do feel you know it is a sign of aging. Um, so it's much better not to have to PROBABLY IT'S MUCH it's much better to limp (clears throat), excuse me, than to be seen on a stick".

"... The fact that I was moving about without a stick and people noticed that um I think that I I was very pleased with myself for getting rid of stick quite quickly ... I thought the stick is a hindering to me it's just getting on my nerves, because it's stopping me from doing things. It became a deterrence not an aid ... and also I was able to wear little heels ... of course to get back in to that little heel, was really something ((very happy voice)), so that was quite a major thing to get a little heel".

2. Coping

• Natural coping mechanisms

" ... I made sure that I did everything I could um I went to a physiotherapist who taught me the exercises that would keep me as mobile as I could within what I had wrong with me I used all the health remedies I could and did everything I could and also I tried to keep very positive about the whole thing. Once I'd come to terms with the fact that there was nothing I could do or anybody else could do to alter the situation, that I would possibly have to have this operation um I think I determinedly then tried to keep positive about it...".

"Actually I went to my doctor for the physiotherapy ... and that you know I needed help and could he suggest anything?"

"... Now I think if I had somebody like B. to go to I could've felt very differently about the situation. I'd been reading leaflets which you can pick up free in the N.Gand I did contact the A.R.C ...".

2. Social comparison

- **Downward (aggregate and individual, direct)**

Interviewer: What did you do to try to be positive and stay mentally positive?

" **II think that I looked at people who were very much worse off than I was.** I I knew somebody that I worked with and who wasn't very much difference in me age and she's now living down in Kent in a beautiful part of the country with the first time they own their own bungalow and everything should be going for her, but because of arthritis she is now in wheelchair ... **so I think I looked at people like that.... so I compared my situation which wasn't like that at least thank goodness I've got a lovely husband and I've got a nice family** and so if I wanted to go out somewhere I could go out somewhere, it it was just more difficult...".

Interviewer: Do you know somebody with hip problem and how do you see them coping with the situation?

" Yeah, I do know somebody and I know she's not coping very well, but then I tend to think that her life would involved in it all, because she was widowed ... and I saw her daughter and I was only just newly off the stick and that was probably the ninth or tenth week and M.((her friend's daughter)) said to me: What have you done with your stick? and I said: I don't have a stick now. She said: You don't have a stick! Her mother had her operation about (short pause) four or five months before and she was absolutely shocked that I didn't have my stick. **So yes when I compare myself with her I think that I have improved very much faster**".

"... you don't know exact details about the operation ((before the operation)), and you perhaps don't have anybody that you can particularly relate to or if you do it might be a bad () that you think well am I going to be like that ? Because in fact I did know somebody that had had hip replacement at a very young age, now obviously there must've been something drastically wrong with that guy (short pause), because in fact I think he'd had 3 or 4 hip replacements by the time I knew him and final one had been a total disaster ((low voice))... so I think I only knew somebody who had negatives about it...".

" I certainly found out being a widow that what I had gone through, um I used to relate to other people who may have been in the similar position and it's quite amazing how many common factors did come out of it ... I'm quite sure it's the same with the hip. You know I mean I'm still in touch with somebody that had the operation at the same time as me and we both think that it's wonderful that we've got our lives back ... ".

- **Upward**

" ... I didn't know at that stage anybody who had had the operation and said: well, I'm back to normal thanks. I didn't know anything like that, so it was very much unknown " ((desire for having an upward referent before the operation)).

" ... so I feel that is a big factor ((people's life and their life circumstances)), you know this lady that I know I wouldn't particularly say that, she went into the C. , so she did her own way of going in, because she went to in almost immediately she knew she got the problem ((not being in the waiting list)), she went in and had the hip done, but I feel that if her life in general were happier ... she just hasn't come to terms at all ... ".

- **Age comparison**

- Downward**

"... I for instance was a newsagent which is a very heavy difficult job ... **I mean I was at a age I could retire, I was over 60**, but at the same time I hadn't anticipated my retirement as being then. It was only that hip really didn't allow me to carry on and it is very daunting ... ".

- Upward**

"... and we both think that it's wonderful that we've got our lives back and **she was a lot younger than me**".

- **Temporal downward**

" ... I mean once somebody says to me: Oh, you know shall I get you a high chair instead of sitting on that seaties, it's very very low, we have trouble. And I say: Excuse me, but I have had the operation. I'm fine now, thank you. Because to me that was the

change, **I was like that before, now I've had the operation and I'm back to normal,** thank you ... ".

- **Advantaged self**

"... when I compare myself with her I think that I have improved very much faster".

Interviewer: Can I ask why?

"Why"?

Interviewer: Yes.

"I think it's mentally. I think because I'm happy um, my circumstances, my life, my everything, I think that I had it all right, whereas I think she feels that she's got it all wrong. So I do think a great deal is mental attitude ... ".

" ... when I attended the pre-admission clinic um (short pause) something was mentioned about pain and I openly admitted that in fact mine was more discomfort than actual pain at that stage. Yes, it was enormously uncomfortable, but I wouldn't class it as I was in absolute agony ... I didn't necessarily think that those people going with me were in more pain than I was, but I think it just depends you know how you are going to let ruin your life or not ruin your life ...".

" ... I used to do half an hour physiotherapy every single night in order to keep me reasonably mobile and free of pain ... and I'm sure it did have a big contribution to my well-being at that stage and you feel YOU FEEL YOU'RE DOING SOMETHING, it's something positive that you're doing, you are taking control by doing that physiotherapy

- **The pain severity and its impact on participant's waiting time for the operation**

" ... Yes, it was enormously uncomfortable, but I wouldn't class it as I was in absolute agony and the nurse more or less said to me if you could said that to the consultant then you you won't be an emergent case. Well, I mean I waited 18 months, you know, so how much more really I can't, but she was more or less saying you don't get the operation ..., but I think she ((the nurse)) felt that I should've been in absolute agony to have the operation ...".

- **The most important things in her life**

"Um I would say number one is my family, um probably number two is my health (long pause) and (long pause) probably number three is security".

- **Being mentally active rather than physically**

"I WOULD SAY I'M MORE ACTIVE MENTALLY THAN I AM PHYSICALLY. I read, um we play scrabbles ... I read an awful lot... I love reading, I love words ... I love um music, um you know the theatre, you know the arts tend to be be what I lean to more than as I say you know physical activities. You know I wouldn't go to the gym, but I would like to go to the theatre and things like that".

Interviewer: Have you been always like that?

"I've always been the same. I've always have been living towards the arts, even as a little girl... ".

- **Having more choices related to improved hip physical functioning**

" ... I certainly feel that now you know everything is open to me, whereas at that time I had to really think about what I am doing, because it certainly did have limitations".

- **The reinforcement of family as an important life dimension by hip problem**

" ... I think when you are in that sort of degree, I think the family again comes into play very much and you have to rely on them much more and so does really force the fact that they are the most important thing. So yes, I think it's always been there, but just reinforced it".

Interviewee: Participant C (1), Sex: Female, Age: 64, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired PE teacher and foster parent, now working as a volunteer at church.

Key points:

1. Seeking social comparison (age comparison).
2. Having multiple health problems.
3. No change of internal standards.

Themes:

- Physical limitations before the operation and its impact on her social life.
- The post-op benefits.
- Having multiple health problems.
- Age comparison.
- Being worried about her sister's disease in relation to her hip problem.

Data display:

1. The pre-op physical limitations

"Before I had it done, I could walk only about 200 yards before my hip was locked. So I couldn't really continue and I daren't go anywhere in case I couldn't get back. That was quite frightening really. I've been a driver all my life and I was unable to drive, it was quite difficult. I would probably stop about 20 miles to get out, stretch, wriggle around a bit and then get back into the car and try get back, so that cut down how far I could drive which meant that I couldn't go to visit family and generally my social life was cut back considerably".

2. The post-op benefits

"Since I've had it done within 8 weeks I was driving short distances, by twelve weeks I could do about 10 miles, and since then I've driven a 300 mile round trip without any effects. So I feel really good about that. I can walk for about a mile and a half before I think I need to rest...".

3. Having multiple health problems

"I can walk for about a mile and a half before I think I need to rest and I think it is to do with laziness, because I got out of habit of walking (laughs), but also my thyroid condition makes me very tired so I'm never sure what is the real cause of the tiredness, whether is the thyroid or is the hip condition. So I'm usually a little foggy with that. I'm never sure what is the real cause really".

4. Age comparison

"Since I've had it done my quality of life improved so much. It's well, I feel 10 years younger, that can only feel good".

5. Experiencing mild negative psychological states in relation to the hip operation and some other health conditions of the family.

"My next sister down has got multiplemyeloma. She is in remission at the moment but it's day to day, you know and I'm worried because I've had something put into my hip that would easily stir things up but nothing seems to happen so far. So I feel quite relieved about that".

Interviewee: Participant C (2). The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Having multiple health problems.
3. Seeking problem-focused coping strategy.
4. No change of internal standards.

Themes:

- Problems before the operation.
- Multiple health problems.
- Feeling older before the operation (**Age comparison**).
- Being a very active person in the past (**Temporal upward social comparison**).
- Comparing her past and present, no change of internal standards.
- Physical activities and being mobile as the most important things in her life (**No change of internal standards**).
- Changing her furniture and her car (**problem-focused coping**).
- Enjoying the process of adjusting and slowing down (**Positive reappraisal**).
- Not pushing herself as she used to do (**Age comparison**).
- The importance of relationships in her life.
- The presence of arthritis in the family.
- Having choices in her life.
- Being more careful and sensible after having the operation like anybody else (**Social comparison**).
- Age, pain, waiting list and the operation.
- The presence of metal inside the bone.

Data display:

1. Physical limitations before the operation.

"Well, when I when I started realizing that it needs to be doing, I found that I couldn't go walking, I couldn't go shopping, because I got tired and um (long pause) I got a lot of

PAIN and I was thinking what's wrong, ... It was pain and lots of discomfort, because it used to lock in a in a one position and I used to stand still and wait for it till it gets unlocked and I used to get a lot of sciatica which is really painful... I spent 3 or 4 days a mounth at home with really bad sciatica and it was awful and all I did was taking painkillers and sleep it off... ".

2. Social comparison

1. Age comparison (aggregate)

" ... I was thinking what's wrong, because I am a pretty healthy person, usually (short pause) and (short pause) uh actually I began to feel like an old woman and I WASN'T AN OLD WOMAN (laughs) and everything else in my mind was young, but but my body just wasn't letting me do the things that I thought I should be doing, so um (short pause) I don't know instead of feeling 60 I felt 70 (laughs) and uh I didn't want to feel like that...".

"I do pace myself, I don't push myself as I used to and I think I'm 64 now, why should I (laughs)"?

"... you know when you get over 60, you're going to to slow down, you're going to rest, so you have to adjust a bit really, which I think I'm doing quite well (laughs)".

"It's funny though a lot of people have said: You've got over it very well, you've done it very well, but they've all been older people who said that ... I was only 61 or 2 when I had it done ...".

2. Temporal (intra-personal) upward comparison.

Interviewer: Were you ((active)) in the past?

"IN THE PAST I WAS PE TEACHER (laughs). Yes, yes I was. I did all sort of things, camping, hiking, playing all sort of sports and and teaching of course. When I was really fit, I used to play lots of hockey, uh netball pretty active things to do. I WASN'T an athlete (laughs) but I was active. I was a very active person. I had three children, I worked full time, we were FOSTER PARENTS, so we had more than our own children in our hands and I still worked full time and I never felt never worried at all, so I WAS active, yes.

"... but the hip doesn't really interfere with my social life at all, OTHER THAN BEING CAREFUL AND SENSIBLE, which I suppose anybody who's have done it will do that".

3. Multiple health problems.

"... I can do most of the things that I used to enjoy doing. I don't go for long walks anymore, um (short pause) that is not necessary to do with hip, because my thyroid is disappearing and I get very tired, ... so you know I have these two things to be considered all the time, my hip really is my tremendous business. The thyroid won't get better until it disappears all together, which will do in about next year".

"If they could sort out my thyroid out as well as they sorted the hip, I'll be over the moon (laughs), because the thyroid is causing me a bit of a problem at the moment, MAINLY because it makes me tired um (short pause) and I can't say that hip is doing that. It isn't".

4. No change of internal standards ((comparing important things in her past and present)).

"Well, technically I'm not working, but I I work at church now voluntarily and sometimes help out with the lunch club for the elderly who are housebound, but that takes quite a lot of time, because I do the laundry, fetching them for church and shopping for church and I also look after SEVERAL NEIGHBOURS around here and friends who are in 70s and 80s and do their shoppings and things like that, so yeah I still do quite a lot (laughs), yes".

Interviewer: What things are really important to you in your life?

"I have got to drive. I absolutely love travelling and driving. It's just my life, you know (laughs) ... I JUST LIKE going out, seeing places. We are with the long term National Trust, so we visit quite a lot of lovely, various places. Um I visit my family quite a lot, because I tend to be more mobile as far as I've got a car and I can go and see people which is just what I like doing. I like going out for pub lunch and things like that, uh never been to a place twice. We go exploring you know (laughs)".

Interviewer: Do you think you've changed things that are important to you when you compare past and present?

"Not really, no. Because my most priority is to be mobile, to get out, see people and do things. Um (long pause) I don't know really (long pause) I suppose I do less overall. I do less than I used to do (short pause), but (long pause) no things haven't changed an awful lot.

"Well, they ((family))'ve always been important. Um we've been married nearly for 40 years now, so uh yeah it's important (laughs). I've got three daughters who all live away, um sort of 60-70 miles away, each one of them in different places and it's (short pause) been important for me to keep that sort of contact with them, so if they come to see me, I can go out and see them, because I can manage a journey like that and and I mean it was two weeks ago I helped my youngest daughter to move into a new house".

"I've got some very elderly (short pause) relatives in their 80s and 90s who rely on me to go and visit them which I do and it's lovely to go and see them, so I must keep this up

"

5. Coping

3. Problem-focused coping

"... I had a large seated car in those days and now I've changed my car, a high seat car, so I don't have to push it up all the time and the bed is a high bed and things like that made life easier ... Well, I've changed the furniture and the car, that's the major things and they've been absolutely wonderful".

" ... I've also resigned some of the things I do in church as well, because some of them physically are quite hard, a lot of things used to involve ladders, I don't do that anymore. I've got somebody else to do that (laughs). Although I'm carrying ladders round, there is no way I'm going to go up sort of 60 ft up the ladder anymore, which I would've done before, um I also don't decorate anymore ... ".

4. Positive reappraisal (as a result of the change).

"... when you get over 60 you're going to slow down, you're going to do rest, so you have to adjust a bit really, which I think I'm doing quite well (laughs). In fact, I'm enjoying it. I used to think (short pause) at first I shouldn't be paying this money out to somebody to do this job, but now I'm thinking well, WHY NOT? It's their job, they get

a job out of it and I get the pleasure of somebody else doing the hard work (laughs), so that's how I've changed (laughs)".

5. The presence of arthritis in her family.

"... 11 had lived all my life, when I was 10 my mother was in a wheelchair, so I've lived with that sort of joint problem all my life and and it didn't honestly worry me. I think because I've always known it being around and my oldest daughter had a dislocated hip as a child, so uh I I'm used to that...She's she's like me now. She said: I suppose I'll have that happens to me when I am your age (laughs) and she knows well, um, so as a family we are used to things like that and I think it makes sense to me, the understanding of it, the dealing with it makes much easier (laughs)".

6. Having choices in life.

"I choose (short pause) things like holidays and things like that yeah (short pause). I don't think it's got anything to do with the hip anymore and that is irrelevant now. Um I choose what I want to do and how hard I want to do things (laughs), so whether I am gonna to do them at all **and I am getting used to say no now, um which I was never before ... and if I don't want to do it just don't do it**" ((it can be part of the process of adaptation to the new situation as well as viewing the process of slowing down in a positive form which the participant sees it as a result of aging)) It's it's hard to remember back to the bad time, because for the last (short pause) year almost now it's got better and better and you've got you get to the stage when you don't think about choosing what to do, you just do it, because you know you can, whereas before it was haa! I am not allowed to do that (laughs) now I can say: yeah, fine. I can do it ...".

7. Age, waiting time and the operation.

"I was only 61 or 2 when I had it done and I think if needs doing better to have it done while you've got some energy and some youth and if it is to leave it to the, well my () at the end of this month to have her second operation. She's not walking and she is in a terrible state and she is very depressed, because she can't do anything and she's had to wait and wait and wait until she get seen and get to operated and I she's she's 74 and it's her fault. Um, I think if you need it doing get it done it early and I HAD quite backing of my own doctor about that. She thought I was too young to have it done, but I said my LIFE QUALITY is not good, so I need it doing (laughs) and she was she was suprised

that they agreed to do it" ((The data is also related to age comparison mechanism in which the participant is engaged in individual social comparison)).

8. The existence of an artificial device inside the body.

"now ((after the operation)) I HAVE I HAVE a couple of little twinges, that's when it's been cold and it's and it's funny, because I you know quite a big lump of steel in your bone that's what I was said. I do feel the cold in it. Um when it's been bitterly cold and icy, I've gone to church, I sat on the radiator to warm it. It sounds silly, but when it's actually warm, I can move around fine, but I can feel it cold.

Interviewer: Do you think it's because of this artificial thing?

"I think it's the steel, because it's not bone marrow, is it? Bone marrow sort of resets inside, whereas steel sort of torsion into the bone, if you like. Once I've got it warm I'm fine, um but just feeling of bitter cold is is really weird. I've never felt a cold like like that before. This is when it's quite frosty, when I get from a warm house like this to a warm car, go to a cold church, but the heat is coming up and I sit on a radiator".

Interviewee: Participant H (1), Sex: Female, Age: 75, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (Hairdresser, housewife).

Key points:

1. Temporal downward social comparison.
2. Having multiple health problems.
3. Rearranging goals as a result of change over time.

Themes:

- Physical limitations before the operation.
- Physical improvement after the operation.
- Having other health problems.
- Looking on the benefits from the operation.

Data display:

1. Temporal (intra-personal) downward comparison.

"Um, after my hip replacement, this last year has been much better than the year previous. The quality of life the year previous was nil. I was hardly getting about or doing anything, but since I've had my hip done with help and ... I can ... I've been on holiday twice with somebody. That's been very sort of considerate of my condition and health wise I've been better altogether. It's been ... I mean if I had to have my other hip done, I wouldn't be hesitated. I don't have detrimental feelings about it at all".

"... before I couldn't walk about. I mean sort of be taken to the car and my leg lifted into the car and that sort of things. But now I can do that by myself, ... If I go to the town I can do one shop I can't sort of start going over spinning out the shops. I have something in mind. I'm going in for somebody is with me. I go and get that one thing and look at that one particular area and that was something that I wasn't doing a year ago. Somebody was having to do everything for me, but I do feel I am benefited greatly with this.

"I also up to having my hip done was taken, oh (pause) anti-inflammatory pills which I don't think suited me. Since I've come off those I feel much better and I just take few paracetamole very often just to get me going first thing in the morning and then once I got going I feel much better".

2. Having multiple health problems.

"Health wise I'm better, but you see again I found out that I am anemic, so I got treatment for that... when I first get out of the bed, when I get those pills, I'm stiff. But again I think that is mostly from the back, and I don't think it's from the hip".

3. Goal rearranging.

"But I'm not a morbid sort of person actually, you know. I'm trying to look on the benefits that I've had from it and how much better I am".

Interviewee: Participant H (2). The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Having multiple health problems.
3. Work-related health problem.

Themes:

- Physical limitations before the operation.
- Physical improvement after the operation.
- Comparing her health condition before and after the operation (**Temporal downward comparison**).
- Having multiple health problems.
- The importance of independency all through her life.
- Being an independent and caring person in the past (**Temporal upward comparison**).
- Heavy works done in the past as part of the problem with her current health condition.
- Not expecting help from others.
- Expecting more help from the health services.
- The importance of relationships with family and friends.
- Being fortunate with friends and family (**Social comparison**).
- The change of important life domains comparing past and present (**Goal rearranging**).
- **Age comparison.**

Data display:

1. **Social comparison.**
- **Temporal downward comparison.**

"Um, I'm much better in my health, because I'm not on medication, um anti-inflammatory that I told you before, um and I'm getting about much better, um yeah".

Interviewer: Do you remember the time before you had your hip replacement done, can you remember how life was before [

"I was really struggling, um I I couldn't go out unless anybody took me. I was dependent on neighbours for shopping and even sometimes to get me to the doctors, I couldn't go unless somebody took me. Um, I was taking anti-inflammatory which I think maybe I was sleepy. I was sort of sitting down after a meal and sleeping afternoons and anything I did even sort of changing the bed unless somebody helped me, I couldn't I couldn't do it. Um, I can now with difficulty, but um I've got myself a bit more organised in that respect, but um NO I just had no no quality of life at all, no independency".

" ... now I can I can do some little walks and um (short pause) certainly I'm more mobile. I can't carry things now, but the it is due to my back, but I think it is um but with me it is a case of finding a medium between my hip and my back. As far as with just the hip problem I think I would be (short pause) um really back to my old self now".

- **Temporal upward comparison.**

" ... I think I've always been the person who looked after other people. I had my mother living with me from 82-85 who needed looking after. I had my husband I believe 10 years who died 9 years ago and he had emphysema and asthma, we had to stair lift him to get him downstairs and upstairs, so I had always been so capable of doing things and be able to do things for other people, where it is hard when you can't do it.

" ... I used to drive as well, because my husband used to be in hospital quite a lot and I used to get him to the hospital, then my eyes started deteriorate and I thought I was not sort of particularly safe on the road, so I gave up".

"I'm not active as I used to be. I mean I used to do a lot of um baking, cooking and um made my own curtains and you know sort of all household that are central points really, but now again because of my eyes, I can't do it. But I would never wanted it to not the

last 20-30 years, I would never wanted to watching T.V. I used to do a lot of walking and swimming occasionally".

"... and I used to spend a lot of time a lot of time in the garden, then when I started with my hip and my back I couldn't do that, that I miss".

Interviewer: Has your life changed since your husband died?

"Oh yes, yes ((low voice)). It's changed changed quite a lot really, because he he had a big family and we used to be going to them or they coming to us, but like the rest of us they're getting older and um I do see them and keep touch with them, but I don't see them every now and then, well in fact three of them died since (inaudible). I think this is what you find sad when get my age. Um and not having somebody there to discuss things with them".

- **Downward comparison.**

"I JUST I JUST ACTUALLY FEEL I AM VERY LUCKY TO HAD my hip done and to be out of that pain and to be, this last 12 months I've been able to do things that I thought you know get about and thought I wouldn't do again you know. Just go for a little walk there and again you see meet people, you talk to people, it's I FEEL I AM LUCKY to live where I live with nice neighbours and the people round about are nice, but we just I just feel fortunate in that respect... very fortunate, neighbours either side is a caring community ... yeah, yeah, I'm very fortunate really (short pause). I'VE GOT NOTHING TO COMPLAIN ABOUT REALLY, nothing and (long pause). I'm probably the wrong person to ask about".

- **Advantaged self.**

Interviewer: When we talked before you said: I'm not a morbid sort of person [No
Could you explain this a bit more?

"I don't I don't suffer from depression, you know. I think some people when they're on their own can get depressed and as you're saying expect a lot of things from other people. Um, I'm not it's not my nature to be like that. I've always been one been able to do for for other people, you know like that. No, I'm not. I DON'T SIT HERE sorry for myself at all".

"I have an exceptionally good neighbours who I couldn't manage without, but I try not to (short pause) put on them without reason. I manage to get somebody to come once fortnight just do me a couple of hours things that I can't do, rather than be asking a neighbour. It's same with my garden. My husband quite enjoyed and I don't want to let that go and ruin, so I get somebody come again once a fortnight just to do an hour work to things get tidied, loads of things that are so important to me. No, I don't expect. In fact, I'm trying doing the other way round to say that I'm all right ... you know and I think certainly don't ask them to do things that are not willing to do for me".

"I'd rather go, I'd rather die on the operating theatre than be um relying on somebody to look after me, if things go more wrong with my back you know and I couldn't move my back at all, that would be worrying me than than (short pause) and I did say if anything goes wrong while I'm under anaesthetic, don't try to bring me back. Let me go, you know. I mean , I WASN'T AFRAID, that didn't that didn't worry me at all and I know and I didn't any problem neither with the operation".

- **Age comparison.**

" ... I always used to be definite and get on with things, now I don't think a lot of things you think in the past mattered I think it's just the phase of getting older. I don't think it's so much with my health you know. I think when you get older you realise that what you think is important when you younger is not important anymore".

Interviewer: Did you feel any fear after the operation?

"NO, NO. I um I can't believe I would've it done when I was younger or had somebody relying on me or my husband would be alive and I'm thinking oh dear I can't you know they need me, these sort of things, but once you're on your own I think that don't count".

Interviewer: Are you expecting yourself to look after other people[Not now.

"I've done that, didn't I (laughs)?

Interviewer: How do you feel about that?

"All right. Um I think it's part of growing old".

"Um I don't think position is very important. I think when your're younger you want to do something and have something sort of keep up with the as it were, but when you get older you think that's the hell life and this is mine and I'm comfortable, I'm warm, I'm not I'm not sort of um trying to be best as it was ((**Goal rearranging**))".

2. Multiple health problems.

"Well, I'm very satisfied with what I have done, I mean I'm still have problems, because of my spine you know, trouble with walking with stick now is not related to hip at all.... I can't carry things now, but the it is due to my back, but I think it is um but with me it is a case of finding a medium between my hip and my back ... I still have problems with my backs that I can't carry things".

"As far as my hip is concerned, it's been 100% successful and (long pause) and it's given me more mobility back than I didn't think ever would have back again, even though I'm not 100% mobile. It's not due to my hip, it's due to other problems. I also have a bad hernia um which causes me problems, but that's nothing to do with my hip".

" ... I used to drive as well, ... then my eyes started deteriorate and I thought I was not particularly sort of safe on the road, so I gave that up ... I mean I used to do a lot of um baking, cooking and um made my own curtains and you know sort of all household that are central points really, but now again because of my eyes, I can't do it".

- **Expecting more from the health services.**

"... the only thing as far as care would concern, I did feel when I came out of hospital that should've could've been a better follow-up from the community care, you know. I mean I couldn't get in the bath or anything like that, because I hadn't have a shower. They said: nobody could come and help me, so I just used to um first week my neighbour used to come and fill the wash bowl and put it on the bath room floor and I washed myself down the bath ... I was on my own you know. I mean it's probably all right I haven't children on my own, so it is um um it would've been help from to just have somebody to follow, give me a hand with things".

- **Work-related problem**

"I mean I think probably that part of the problem with my back now is I used to get my mother in and out of bath, I used to get my husband in and out of the bath and I used to get them hang around my neck, you know to sort of lift them up and I think that's what's happening to me now".

Interviewee: Participant L (1), Sex: Female, Age: 79, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (housewife).

Key points:

1. Engaging in social comparison, especially in downward comparison.
2. Focusing on advantaged self.

Themes:

- Comparing her present situation with pre-operation period (**Temporal downward comparison**).
- Having multiple health problems.
- Having good friends and neighbours (**Reflecting on selective self-advantages**).
- Not complaining a lot (**Downward social comparison**).
- The meaning of quality of life from her point of view.

Data display:

1. Social comparison.

- **Temporal downward comparison**

"Five years before I had it done, I went to the doctors and I did have pain and quite a bit you know as it got worse ... then I came in and had it done ... and oh I had frames while I was in and then I went on crutches, came out with crutches but after a couple of days, I didn't need them. I just had a stick, then three weeks after having had the operation, I didn't need anything. It was marvellous since, yeah. So there's nothing much to say. Only that I'm very pleased. ... I had lot of pain and when I came out of the theatre it all gone. That's all I have to think, so I'm really pleased. So I haven't much more to say".

- **Downward comparison (aggregate)**

"I haven't much to grumble about, because you can see a lot worse so

Interviewer: I mean has surgery got anything to do with your quality of life?

Probably, I guess. It's been better much. Yeah, but I am really pleased and happy about it. I wish everybody was the same (they laugh). I don't know what else to say really, because I'm quite happy about it".

- **Advantaged-self**

"I've got some good neighbours, good friends, you know. I'm all right then, yes. So I'm a happy person (they laugh)".

Misfit data

1. Having multiple health problems.

"... and then the year before I should've had it done, I went uh ... I had skin cancer, so I couldn't come, then I got a terrible cold so I couldn't come and then I pulled a ligament in my heel, that was that year then I came in and had it done ...".

2. The meaning of quality of life.

Interviewer: How do you perceive your quality of life at the moment?

"All right, but I haven't got any family here. My two girls are in Canada and I lost my husband, so I get on OK. I've got some good neighbours, good friends, you know. I'm all right then, yes. So I'm a happy person (they laugh). I haven't much to grumble about, because you can see a lot worse so ..."

Interviewee: Participant L (2). The follow-up interview at participant's home.

Key points:

1. Engaging actively in social comparison, particularly in downward comparison.
2. Focusing on advantaged self.
3. Changing the standards, but having difficulty to change the values.

Themes:

- Having multiple health problems.
- Waiting time for the operation.
- Comparing her current situation with pre-operation time (**Temporal downward comparison**).
- Important things in her life.
- **Age comparison.**
- **Upward comparison (individual).**
- **Downward comparison (individual and aggregate).**
- **Temporal upward comparison.**
- The importance of family all through her life, but relating her quality of life to other life dimensions such as gardening and having good friends (**Changing her standards, but not the values**).
- Having a particular belief (**Advantaged self**).
- The importance of independency.
- Having good friends (**Advantaged self**).

Data display:

1. **Social comparison.**
 - **Temporal downward comparison.**

"I mean when I think about it, uh I did have a lot of pain, but I had to use these sticks, but after three weeks I was really fine you know I've done everything. I've been in the garden, DIGGING, so to me now I'm just normal".

"Actually when I came out I had no pain from waking up (sniffs) in hospital I had no pain since. I just normally can walk up and down stairs just do anything, bend, first time I told you, didn't I? First time I could bend I washed the kitchen floor three times (they laugh), I was pleased to be to get down".

Interviewer:do you think this hip replacement helped you to be more independent?

"Oh yeah, yes. I mean I couldn't carry a lot. Mind you I don't carry a lot now, because there is only me, but I couldn't if I wanted to, but I could now, you know. I'm just really normal, yeah".

Interviewer: What do you mean you are lucky?

"That mine was all right [Yeah. When I came out I had crutches, then that was for a week, then I had a stick, that was for a fortnight. I didn't need anything after that. I was fine, so I am lucky, aren't I (laughs)"]?"

- **Downward comparison (individual and aggregate).**

"I am really really please with my hip, because I know people who had it done before me and still on sticks, so I'm very lucky, aren't I? When look back (laughs) I am".

Interviewer: Do you know somebody with hip replacement who didn't improve as much as you did?

"Oh yes, two sisters. Yeah I know one or two and I had a friend over around and she still had a lot of pain when she came out, but she's got better you know (short pause), so I'm lucky (laughs)".

Interviewer: Do you think your life has changed since your husband died?

"Oh yes, because I think you're lonely, you know what I mean"?

Interviewer: Yeah.

"I know I have friends, but you know in the winter that's the worst time. See I can't go out there, I can't and when you draw your curtains that's it, yeah (short pause). Oh yes altered a lot, but there are thousands like it, aren't they? So you have to put up with it".

" ... but hers ((her friend)) it took her 6-7 weeks to get over it which isn't bad, is it? It is not bad".

Interviewer: And you were quicker?

"Yeah, yeah".

"It's a pity everybody's not like me".

- **Age comparison.**

" ... I mean I lived here all my life in Sheffield, so I'm not bothered now. If I'd been younger, yes I would, but I've got a cousin, she's 85, but she's marvellous for her age".

"I'm 79 and I seem to have got on and battled it, but you never know later on dear, you know (short pause). I mean as you get older, you get more **fable?**, don't we"?

Interviewer: How long haven't you been swimming?

"About from my hip started, I did mean asking them ((the hospital)), then I...you know my age (laughs)".

- **Temporal upward comparison.**

Interviewer: You talked about swimming. Did you use to swim when [yeah

"Right from going to school and I put weight on (sniffs). I used to be as thin as a lath. I put weight on, doing a bit and having sit a lot you know and I can't get rid of it, the weight".

- **Upward comparison.**

"She is 79 and she's all right, you know. She can get about you know (short pause). She's on her own, but she's got a son lives there and his wife and grand children, so (short pause), but when they come we always got a full house (laughs)".

- **Advantaged self.**

"... so I'm lucky (laughs). I mean when I came out of hospital one daughter came for a month and the other came for a month, so I was all right. They kept coming and she ((the neighbour)) kept coming, so I was all right".

Interviewer: Did you feel any fear of cancer [No, no. ,because of your sisters and brothers?

"Somebody was asking me that the other day. No, I've never thought all they had it so I'll have it. Uh, no. I don't think I've ever had. I'm a big believer of what has to be will

be and if I did have it, I would and that's it, so I won't worrying myself thinking oh I might have that. A lot of people do, don't they"?

- **Changing her standards, but not the values.**

Interviewer: What things are really important to you [in my life in your life?

"Not a lot now (they laugh), not a great lot now, because (sniffs) when you're on your own I mean I DO GO OUT A LOT, I go with my cousin, and I do go with friends, but I don't have any activities. That's my activity".

Interviewer: The garden?

"I can't see more challenge you know about it... I'm quite happy out there".

Interviewer: Are relationships important to you?

"Well, I haven't any. See mine are in Canada. I have two daughters both live over there. They did want me to go and live there, but I said: no. I think they should be on their own and I mean I lived here all my life in Sheffield, so I'm not bothered now".

Interviewer: Which part of your life seems to you much more important? What is really important to you?

"You mean all through my life"?

Interviewer: Yeah, all through your life.

"All through my life? Uh, let me think (short pause). I don't know. I suppose it is being married you know, having your children, but then it is just that's that. When they've gone, because house seems empty, you know (sniffs), but I'm happy having the children".

Interviewer: So still having children are most important to you?

"I think so, yeah, yeah (long pause). I've been happy, you know. What I mean, I've been happy, yeah, but it is just sad when they are gone and leave you here, if it WAS ANOTHER TOWN, all right, but when it is another country (laughs) you know".

- **Waiting time for the operation.**

"Uh, (short pause), but actually it would've been five years and four months that I waited".

- **Having multiple health problems.**

"but lots of things, my skin cancer, then I had a very very bad cold, so I couldn't go in, so it was my fault not the hospital, yeah".

- **The importance of independency.**

" ... I will try and if I can't then I'll ask somebody, but I do like to have a go myself first (laughs) yeah ... If I stopped being independent, that's it. I'll give up, you know, so I'd rather try".

Interviewer: What do you mean by independent?

"I'll do things for myself and if I can't then I'll ask someone, but I prefer to have a go myself first and if I can't, I can't".

Interviewee: Participant X (1), Sex: Female, Age: 77, Intervention: Total Hip Replacement surgery on both hip joints, Occupation: Retired (Shopkeeper).

Key points:

1. Engaging in social comparison.
2. Seeking spiritual coping strategy.

Themes:

- Comparing her current situation with pre-operation period (**Temporal downward comparison**).
- Having faith and its role in helping her going through the disease process (**Spiritual coping**).

Data display:

1. Social comparison

- **Temporal downward comparison.**

"The first one, the left one (short pause) um rather long time I was only 53 when I started with it, but then gradually got worse and worse and the thing was that the left one was gradually longer than than the right one and I had a lot of pain with that and um (short pause) few years before I had the operation I had to walk with a stick and then I had the operation 5 years ago and then the other one went the same way, so um three years later I had the right one done".

Interviewer: The second one?

"Yes, and It is two years now and it's been like living again. It's been fantastic, yeah marvellous. Um, after the first operation um that I was able to (short pause) what should I say? that both legs were the same, so therefore I wasn't limping with you know they were both the same length and that was lovely yes (short pause)".

Interviewer: How these operations did affect your life?

"Well, um if you go to a room with a lot of people before I used to have sit and wait for people come to me, because I couldn't get up, I used to stand up and wait, um before I could sort of (short pause) go, but now I can mix in with people, therefore um getting more social life and um friendliness you know, it's lovely. It's a lot better you see,

because just imagine you just sat on a chair, you expect people to come to you. You know it's not always the thing".

"I'm more flexible and that pain and when you've got pain like that you sort of mentally hit you mentally as well, because you see your mind's constantly on this pain, so therefore you've got more interest in life and that's right it's like living again, because you've got different life up together, yes".

2. Coping

- **Spiritual coping.**

Interviewer: Can I ask you about the things that are really important to you in your life? What things are really important to you in your life?

"Um, well I go to Church and things like that you know and thank God for bringing me through and you know making my life again really you know, it's been lovely yes and (short pause) yes and I don't know it's made a difference, yes".

Interviewee: Participant X (2). The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Seeking spiritual coping strategies.
3. Seeking alternative informal and personal interventions.

Themes:

- Comparing her situation with pre-condition period (**Temporal upward comparison**).
- Seeking alternative interventions before the operation (**Natural coping strategies**).
- Having faith and its role in helping her going through the disease process (**Spiritual coping**).
- Comparing her situation with pre-operation period (**Temporal downward comparison**).
- Feeling lucky going through the whole process of two operations and disease process (**Social comparison**).

Data display:

1. Social comparison

- **Temporal upward comparison.**

Interviewer: Before the age of 53, um when you started with the hip, before that, do you remember how your life was?

"Well, I've had a heavy job really, during the war. I was in a fruit shop, where you had to lift bags of potatoes and hundreds weighs bags. There was no men there, because they were gone to war for quite long time and so we did I did have to um some heavy lifting to do".

Interviewer: So you were an active sort of person [Active life, very active, yes.

Could you please explain more?

"I could walk. I could walk quite a bit you know, what I mean. This job I had um it was mentally and physically (short pause) mixing sort of thing, how it worked (short pause)

for about 10 years I was in that job, because I was close to te home and with bombing and things like that I wasn't um home, my dad said: he'd rather me working close to home (short pause), so I had this job you know close, yes".

- **Temporal downward comparison.**

"Well, yesterday I was able to go on buses. I have gone church by myself, but I was able to go on buses. Life is more (short pause) you know (short pause) how can I say it? I can do lot more things now than I ever do before, yes. It's been all the trouble, the inconvenience. It's been worth it".

- **Downward comparison.**

Interviewer: Anything else you'd like to tell me about the whole experience with the operation and anything else you remember?

"No, I wouldn't wouldn't say to anybody that they should have it, because we are different you see. we are, I am very lucky that I've come through two operations and they've been success, but I can't you know, it's to everybody individual. It's whatever operation it's it's you got to (short pause), it's a (short pause) risk sort of thing, isn't it? [Yeah, it's a risk, so um but taking that risk and I'm really truly glad that I did do".

2. Coping

- **Natural coping strategies.**

Interviewer: The problems you had with your hip after you developed your hip problem, you said that you had pain and limping, a bit of limping, and couldn't mix in with people, couldn't walk far, how did you manage not to let these things get in the way?

"(long pause) I just had to live with it you should think (laughs), (short pause) Um, it started to pain gradually it got worse and worse until I had to do something. I had acupuncture to try to relieve it and physiotherapy which didn't do it any good really, so I had to go to C. to see a doctor".

Interviewer: At first you seemed a bit reluctant to have the hip done, and then you said: it got so bad that dragged me to have the hip done [Yes, yes. It did. could you please explain about it a bit more?

"Oh, well, over the years I was (short pause) I couldn't get on with my life. I was restricted in terms of what I can do and so it does, if you got pain and you've got to do something about it which I tried to do before, but that was no good, it needed this

operation. (long pause) So eventually because I wasn't getting any help much and (short pause) I thought that BEING ON MY OWN SPECIALLY, I had to help myself and do something about it".

- **Spiritual coping**

Interviewer: You said: Thank God for bringing me through and making my life again [Yes, and I really mean that. That's really interesting. Is this all right if you explain a bit more?

"I really mean that [Yes. yes, I feel that I really truly there is a God ((getting emotional)) and um he has got me through anything you know. Through operations and through my husband dying and anything that way and I've got new friends. I've lost a good friend and that I've lost her now, I've got lot of friends you know. They can't come to see me, but I go and see them in Church. The service I go to yes".

Interviewee: Participant T (1), Sex: Male, Age: 51, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (Soldier and miner).

Key points:

1. Engaging in social comparison.
2. Changing standards and values over the course of the disease.
3. A long waiting period for the operation.

Themes:

- Comparing his present situation with pre-operation period (**Temporal downward comparison**).
- Comparing his present situation with pre-condition period (**Temporal upward comparison**).
- Concentrating on more important dimensions of life after the disease (**Change of standards and values**).

Data display:

1. **Social comparison**

- **Temporal downward comparison**

"Um, before I got me hip done I was in constant pain, virtually 24 hours a day ... A bit of pain when I had it done after that pain's gone till there was nothing. Uh, uh as I say I feel I'm 50 and I feel I'm 25 years old. I just feel great, and as I said it I would recommend anyone to have it done, if they need it".

" as I say I got it back really because I couldn't walk now I can walk uh I could even get a () uh and I'm doing things, what I couldn't do through me hip so I think I have got my life back, better life than one I had when I had a bad hip, so...".

"I do what anybody do, the washing () do anything that anyone else can do really, but as I said while I was suffering me hip I couldn't but now I can and I haven't got that constant pain 24 hours a day which I had before. Since I had it done I've hadn't had the pain etc. So I hadn't uh I've got my life back. I think I've been given it back and given a bit extra. I do so".

- **Temporal upward comparison.**

Interviewer: Do you remember your life before you developed your hip problem? How was your life?

"I was soldier and a miner, so my life was active. So it was active and good. And it just came on like a twinge then it went on getting worse until I had to see somebody and they just told me, yeah you need a new hip ... but before then I had a good active life. Starting to get it back".

Interviewer: How do you feel about that? Uh, you were an active sort of person and uh how do you...

"Well, uh I liked to play I used to play rugby, I liked to play rugby but (short pause) as I found out with it" poppin" I can't do things like that. I love to do it, but I can't".

2. Change of standards and values.

" I used to play rugby, I liked to play rugby but (short pause) as I found out with it" poppin" I can't do things like that. I love to do it, but I can't but I found other things to do. I like walking and er even um motorbikes, I like motorbikes, so I found something else that I know I can do, without hurting myself really so ... "

" I I just take things as they come if I think there something well I can do that I've helped some old ladies to do the gardening you know, cut the grass and things like that, but I know it's not going to affect me. I've done that. I didn't think I'd be able to but, I've done it, so there's things like that I just get on with 'em and try it but if I think it's going to be a bit doggy I won't do it so ... "

Interviewer: Is it really important for you being not active as you used to be?

"Well, I went home by myself with two with two grandchildren. One's eight and one's ten, and I've had them since they were two or one, so yeah I really need to be a bit active to look after them, which I do. I do a lot of since I've had it done then when I had before so there's that".

- **Long waiting period for the operation.**

"And it just came on like a twinge then it went on getting worse until I had to see somebody and they just told me, yeah you need a new hip but where I was said I couldn't tackle to 65. So I had to wait and wait and I had to wait from 1980 up to (short

pause) 1999 and then things started moving when I saw Mr. S. and then from then on it was ok, but before then I had a good active life".

Interviewee: Participant: T (2). The follow-up interview at participant's home.

Key points:

1. Engaging in social comparison.
2. Change of standards and values.
3. The impact of long waiting pre-operation period, involving pain and limitations, on patient to engage in down-ward social comparison after the operation.
4. Age as a criterion for the operation.

Themes:

- Comparing his present situation with pre-operation period on frequent occasions and insisting on it (**Temporal downward comparison, present situation and pre-operation period, while waiting for the operation**).
- The relation between long waiting period for the operation, having pain and limitations and using down-ward social comparison post-operatively.
- Change of important dimensions of life over the disease process (**Change of standards and values**).

Data display:

1. Social comparison

- **Temporal downward comparison.**

Interviewer: So during this period, this 19 years you were waiting, how was your life?

"Poor, [Ah. constant pain, real constant pain where as (short pause) I could've chopped me finger off and that would've relieved the pain in me hip. I had a thought about that then. Pain in me hip was constant. It got you really, you felt low with it all the time and (short pause) it was just really bad, so I couldn't get about much and I couldn't do, I could do very little with it, because it just the pain, you try to do different things, it got worse".

Interviewer: Was it only the pain?

"Well, pain I couldn't (short pause) I couldn't I couldn't bend me leg to put my socks and shoes on properly. I couldn't (short pause) stand in a shower and life my leg up and

wash it. I (smiles) worked something out you know with a bath brush to wash that leg, because I couldn't manage with it".

"Since since I've got the joint put in, it's improved, not as much as it was before I even had bad hip, but it's improved a lot, do a lot more things uh since I had me hip up to this period, when it's popped out, so that's more or less ... The last two years I've been perfect, doing different more things that I used to do and trying to do little ball games with little lads in the garden and things like that, walking a lot more (excuse me) uh and I even wanted to run, just want to go and run, but I saw Mr. S. and he advised me not to which I took his advice".

- **Temporal upward comparison.**

Interviewer: Can you compare your life during this period with your life before that?

"Um, active. I was in the army. Uh, as you know we ought to a lot of running. I used to play rugby and things like that when I was in the army, uh (short pause) out when I came out of army, I still played rugby and I worked as a miner. It didn't affect me, I could do anything, anything. You name it and I would've done it and as soon as it started, this twinge me and it got worse and worse and I couldn't even out there I couldn't even lift my foot uh when I was working 6 inches to get my foot off an obstacle, so before you could say it was really ATHLETIC, I WAS ATHLETIC [Yeah. I did ah running, actually boxing as well, everything, so um when I got me hip done, I couldn't do any of them ((very low voice))".

2. Change of standards and values.

Interviewer: Can I just ask you about things that are really important to you in your life at the moment?

"Ah ... well only thing I can say at the moment live with my grandsons. I've got two grandchildren, both 10 and 9 years, so at the moment that's the only important thing going on in my life at the moment, looking after them two".

Interviewer: Do you think you've changed the important things in your life?

"Well, I can say is that I've gone back to more responsibility looking after two little ones, before I had my bad hip I was a lad, just enjoying myself and then I got married, I had children, I had to look after them, they went and I've got two grandsons to look after and so all my priorities are them, (short pause) Everything I do is around them".

3. Pain, limitations and a long waiting pre-operation period (Mixing Temporal upward and downward social comparisons).

Interviewer: You said: I feel 25 [Yes, I did. can you explain it a bit more?

"Well, uh let's see. When I was 25 I was in army, doing more or less what I like different sports, uh go where I wanted, when I wanted. Uh, when I had me bad hip, I was not be able to go places, because uh of the pain, uh people asking me: What do you look? You look as if you're in pain. I explain to them. When I had me hip, I lost all that pain and as I've just said, I just wanted to get up and go home and actually I just wanted to get up and run, not in pain and I felt a lot younger that I could do these things, but I couldn't do when I got my bad hip and I just wanted to get up and I just felt (short pause) 25 years old, wanted to get up and get on with things".

Interviewee: Participant O, Age: 73, Sex: Male, Intervention: Total Hip Replacement surgery on both hip joints, Occupation: Retired (Police officer).

Key points:

1. Engaging in social comparison.
2. Having multiple health problems.
3. Returning back to work as an indicator of improvement.
4. Seeking no coping mechanisms before the second operation, because of getting familiar with the disease process during the first operation.

Themes:

- Comparing his present situation with pre-operation period (**Temporal downward comparison**).
- Being familiar with the signs and symptoms of the disease due to a previous hip replacement (**No natural coping mechanisms**).
- Having more problem with the first hip replacement at a younger age (**The relation between patient's routine function, here returning to work, and his functional limitations**).
- No change of standards and values.
- Being a lucky person (**Downward comparison**).
- Having arthritis in both ankles (**Having multiple health problems**).
- Being an active person in the past (**Temporal upward comparison**).
- Age comparison.

Data display:

1. Social comparison

- **Temporal downward comparison.**

" ... in the morning when I got out of bed or when I was in bed at night um, it was painful, every time I turned over ... Um, my restriction on obviously before the operation restriction on my what I where I can go and what I can do. I I couldn't go round the shops for very long, it was very difficult, um but now that's perfectly all right again and I haven't got that problem. Um, that problem increased up to just before the

operation, um where I really didn't get out very much and I was walking on a walking stick and um, I could drive the car ... Um, having had the operation after a few weeks my wife drove me again and again I had very very little restriction to my normal life style".

- **Temporal upward comparison.**

"Um, I used to, when I was a young man I was very much more active, because I was a police officer in in East Africa and I was 25 years in East Africa and I I quite was very mobile then, and I was walking a lot then, and that when I was very young man. I'm 73 years old now and I could never do that sort of things again".

- **Age comparison.**

"I'm 73 years old now and I could never do that sort of things again ((doing activities))".

- **Downward comparison.**

"Um, after 12 weeks my ordinary lifestyle everything I was doing before, I could do again. Um, I think I've been fortunate um, I'm trying to do everything the way I was told to do it and it appears that it worked very well".

2. No change of standards.

Interviewer: How was your life before you had the operation, do you remember?

"My life style hasn't really changed very much. Um, I know that I didn't any active sport. Um, my hobbies are not are not active hobbies, so it hasn't had really I haven't really much difference to my life style".

Interviewer: How do you see your quality of life at the moment in general?

Participant: My quality of life is good, back to my normal standards. I enjoy my pint of beer and I don't smoke, I am not a smoker, I never have been, but I do all the normal things that I would do them any way. I enjoy going out, in the summer we go to prepare air show, find this place, I'm able to walk around fairly well, without these () do a bit of photography and um really there is no change in my life style at all, is very good.

Interviewer: Are you a photographer?

Participant: Pardon?

Interviewer: Are you a photographer?

Participant: No. It's only a hobby. I just photograph for Aeroplanes and occasionally make models. I've been to Aeroplanes. Again this is a passive type hobby as opposed to an active one.

Interviewer: Right, so before you had this problem with your hip you did the same hobby, photography.

"Same thing, exactly yes, yeah. There are these shows most weekends in different parts of the country. I only go to about 6 in the year, but um I I was restricted immediately before the operation for the last hip replacement. I didn't go to a couple of weekends. It was too difficult, but as soon as I was mobile again afterwards that same summer about June, May, June that year, I think operation was in April, I think I was at that show in June and I had no problem. So but as I say again, it is not very active, it is only walking gently round the large field and it is not an active hobby".

3. Multiple health problems (Blaming on other factors rather than the hip problem).

"My only problem now as I mentioned to the sister just now is that um, I developed arthritis in in both my ankles and my ankles are restricting my movement. My mobility is restricted with with my ankles. For instance, getting from the car park here up to the consulting rooms, um I found that, trying on the hill I stopped half way up, because my ankles were at the angle, an unusual angle, and the ankle is is not quite on the same position, it gets me a bit...Um, I don't think there is a connection, I am not an expert, I don't think there is a connection between the arthritis and hip any way".

- **No natural coping mechanisms before the second operation.**

"I knew what was happening, because I'd had a previous hip replacement on the opposite side, so I did know what was happening and I did know what to expect. Um, the progress of it, so I went to my GP and explained what was happening. My GP got me an appointment for the first consultation and then after the consultation I was put on the waiting list for the operation".

- **The relation between patient's routine function (returning to work) and his functional limitations.**

"The previous hip replacement was a little more of a problem in the () of work and I had to get up and go to work every morning, whereas on this one I was retired when it was done".

Interviewee: Participant R, Sex: Female, Age: 60, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Housewife.

Key points:

1. Engaging in social comparison.
2. No change of internal standards.
3. Seeking alternative reasons for the limitations.

Themes:

- Comparing her present situation with pre-operation period (**Temporal downward comparison**).
- Comparing her present situation with pre-condition period (**Temporal upward comparison**).
- Focusing on disease-related problems and getting depressed (**No change of internal standards**).
- Hip problem as a genetic-related condition.
- Laziness as a reason for functional limitation (**Alternative reasons for the limitations**).
- **Age comparison.**

Data display:

1. Social comparison.

- **Temporal downward comparison.**

Interviewer: Please tell me about your experience.

"Oh, before I had it done the pain was terrible. I used to cry all night through with the pain in my groin down my leg, you know. It was such a relief to get it done and I couldn't walk at all, just a few yards, well a few feet then I had to sit hip stopped me and it was like a miracle when it's been done".

- **Temporal upward comparison.**

Interviewer: Do you remember how was life before ...

"Oh, before I had my hip, oh marvellous, working, cleaning, decorating (she laughs) everything, but that put stop to everything.

Interviewer: Your hip?

Participant: Yeah, well it still has, because I mean I used to paint my own house, decorate but I can't now. You know it's just ... It's arthritis in general, that wearing my fingers, my feet and everywhere".

"Um, (long pause) well, I mean I've been active. I could clean all through my house and go to my mother's and same day do hers, just look at me now (she laughs) seems () it. Things like that, you know (she laughs)".

- **Age comparison.**

Anything else you like to say?

"No, I can't think of anything. No, oh dear (she laughs)".

Interviewer: Ok, thank you very much.

"One of the things of getting old".

2. No change of internal standards.

" ... I used to paint my own house, decorate but I can't now. You know it's just ... It's arthritis in general, that wearing my fingers, my feet and everywhere.

Interviewer: How do you feel about that you can't...

"Oh, I don't like it, I get depressed, because I've always been so active. You know and some days I don't even feel like doing house work, but have to do yeah. Well, I used to clean bedrooms every week (she laughs)".

Interviewer: So how do you try to compensate for (short pause) not being active?

"Well, I don't like it at all. I've always been so active ... "

Interviewer: So it's how you feel about it?

"Yeah, it's not nice really when you are not really active, yeah. Mind you some days I feel a bit more active than other, but I used to get up early in the morning and get all my work done, but now I don't feel if I've got any energy in the morning. I have to do it in the afternoon".

- **Alternative reasons for the limitations.**

"Yeah, it's not nice really when you are not really active, yeah. Mind you some days I feel a bit more active than other, but I used to get up early in the morning and get all my work done, but now I don't feel if I've got any energy in the morning. I have to do it in the afternoon, when I could you know gather my (), yeah. So (she laughs) it's laziness I think.

- **Genetic-related problem.**

"I've got a husband and a son yeah, and a mum and brothers and sisters yeah, but my mother she's crippled with arthritis. She's in a wheelchair with it. I think it must run in the family. My brother's got it in his knee and I think it just runs in the family.

Interviewer: Yeah, except for hip what other joints are involved ..."?

Interviewee: Participant Q, Sex: Female, Age: 83, Intervention: Total Hip Replacement surgery on both hip joints within a year, Occupation: Housewife.

Key points:

1. Engaging in social comparison.
2. Seeking alternative reasons for the limitations (having multiple health problems).
3. Change of internal standards, no change of values.

Themes:

- Comparing her present situation with pre-operation period (**Temporal downward comparison**).
- Comparing her present situation with pre-condition period (**Temporal upward comparison**).
- Not blaming on hip condition, but arthritis (**alternative reasons for the limitation**).
- **No change of values.**
- **Change of standards.**
- Having multiple health problems.

Data display:

1. Social comparison.

- **Temporal downward comparison.**

Interviewer: Would you like to talk about your experience with your hip condition and the treatment you received for it?

"Well, um I used to be in general pain with both hips ... I have quite a number of aches and pains in my (), but of course it's arthritis and I accept that, but the actual hip replacement has been fantastic. I have no complaint what so ever, you know, so ...".

- **Temporal upward comparison.**

Interviewer: Do you remember your life before you developed your hip problem?

"Yes".

Interviewer: How was it?

"Oh, fine. I've always been active. I had a big family, seven children and I've been always active and sometimes it's this, because I can't do things, I get frustrated. And I have a cleaner coming, I watch the cleaner, oh you know, I want to be um doing. I do (short pause) um look after myself, I can wash, bathe. It's the trouble getting in and out of the bath. Um, but I'm on the waiting list to have the bath take in-out and a walking shower, you know, so I don't have to get in ... that is one big problem at the moment, is bathing ...".

- **Age comparison.**

"It wasn't done the both ((hips)), because of my age, you know ...".

2. No change of values.

"I cook my food to eat. 11 (short pause) can manage all my own dressing and feeding. I can do my own washing, well I put it in the washing machine and take it out, you know (she laughs) easy way. So I manage quite well. I have a daughter that comes in every day and she does me what I call it daily shopping, my bread and my milk and if I want anything quick she fetches me and then my youngest daughter she does me my heavy shopping at the weekend and I have a cleaner coming ... she comes in once a week and cleans through. I live in a ground floor flat, so it's like a clean sweep through every week. So I get all that done, she does me windows. My heavy washings like curtains and like that, my daughter does them. So I quite well looked after. Yes, but it's just that, I get frustrated, because I can't do things for myself. Um, it's my own feelings. I think when you've been so active, you've got to re-learn your life, kinda things, so I'm trying".

Interviewer: And are you ok with that, with that re-learning?

"Yes, yes, yes. (short pause) um, I just get frustrated, because I can't get up and walk and I have a tripod, like a zemmo frame, I bought it myself, but it's got wheels and I walk about with that. Um, if I go if the family takes me out anywhere, I have a wheel chair. So you know, but it's this that hurts that I can't... I can't walk myself".

3. Change of standards.

Interviewer: Yeah, do you try to compensate for that frustration, some how?

"Um, (short pause) yes, um ... I'm getting better, you know. I read a lot and I do puzzles. You know puzzle books and I read a lot and I don't watch telly that much. I I'm at the moment, because I like snookers, so that's at the moment., but usually through the day I

I like the quiet, but yet on Monday my daughter comes and she brings her great grand child, her great aged grand child, which is my great grand child and I loved to see her play and she comes and I lift her up, you know and we have a cuddle and I love to see them and I've got all the toys and they make a mess you know, but they clean up before they go, but I love to see them, I love all children, you know. I love all the children and um I love to see them, but it's nice when they're gone, because it's quiet again".

- **Alternative reasons for the limitation.**

"... I have quite a number of aches and pains in my (), but of course it's arthritis and I accept that, but the actual hip replacement has been fantastic. I have no complaint what so ever, you know, so ...".

- **Multiple health problems.**

"so they did the other hip and um it happened to be Easter time and I think it was the Friday when they did this hip and because of all the holidays, I didn't see Dr. H. again and don't think it was until on Monday and of course when he came and visited me yes, fine except that there is something wrong with my foot, so um he examined me and then he explained that oops! I have cut a nerve or a tendon and it caused a drop foot. Now this is my only problem that you know is is this. I have to wear a splint and I've no use in my foot, about here it's like dead, just one of those thing, um you know, but apart from that and of course I have arthritis which caused hips and if it spread it you know sometime no feelings ...".

Interviewee: Participant P, Sex: Female, Age: 74, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Housewife.

Key points:

1. Engaging in social comparison.
2. Seeking problem-focused coping strategy.
3. Having difficulty changing the internal standards.

Themes:

- Comparing her present situation with pre-operation period (**Temporal downward comparison**).
- Comparing her present situation with pre-condition period (**Temporal upward comparison**).
- Using a high chair and a bath lift (**Problem-focused coping**).
- Taking things as they come (**Having difficulty changing the standards**).
- **Social comparison.**
- Having multiple health problems.

Data display:

1. Social comparison.

- **Temporal downward comparison.**

"I couldn't get my leg in and out of car, sort of slide it... I know the problem all started with trouble in the groin and this was the worst".

- **Temporal upward comparison.**

Do you remember how was your life before you had the operation?

"In what way"

Interviewer: Um,

"I was am a farmer's wife. I live in a farm, um I didn't actually do anything to do with the farming. I only helped out with carving cows, but nothing to do with it, but on the others I just was a family housewife. There was no problems there and I had no problem at all, until I fell down and everything just went on from there. I was just a farmer's wife, a house wife, looking after the children. Um, that's about it (she laughs). I can't

climb and I can't kneel down, that's it. I'm very boring like I do now, (she laughs). I can't really say anything? Is there a question you can ask me that I can answer that?

Interviewer: Did this operation make a difference to your life?

"Well, I can't go on long walks, um I can't go where ... If I'm walking on the flats no problems. I can't climb and I can't kneel down. Um, that is it (she laughs) I do everything else. Um (short pause) that made a big difference. I don't go on buses now, because the steps are a bit too much sometimes. This one some days it doesn't want to bend as easily as it should to go up steps, but I have two daughters and a son and the daughters if I have to go anywhere they usually take me or if they are going out say: Do you want to come and I go, but when I think I walked enough I sat down on a seat while they carry on doing the shopping. That's about it just normal life going on (she laughs). I can't do gardening which I do miss, sit and bending over, I miss that but knitting was my hobby. I can't do it now, because of the arthritis in the hand. I can't do that, so I do cross words puzzles instead (she laughs). Um, just a boring life. I don't mean boring particularly just an everyday normal things you know. Do anything, not out of the ordinary (she laughs)".

Interviewer: Do you think you have to change things that are important to you after the replacement?

"Such as"?

Interviewer: Just normal things or things that are important to you?

"No, I don't (sighs). I don't think so. We do have kids that are small, the youngest is only three. There are objects when I can't get on the floor, you know to do jigsaws and things like that, but I don't really do that any more. Well, I do it, but I have to do it on the table. As far as I think no, I can't think of anything that's changed drastically. I don't walk ... since 92. I walked down the hill to the village and carried shopping. If I do go down, it takes () and I can't. I think that's about the only thing that has altered, that I can't go in the village myself, you know. Because it's rather steep hill and if I go down it takes me half an hour instead of 5 minutes and and coming up I think I should have problems. I think that's the only thing that has changed. We don't go on holidays, because I can't sit for a long time. I got to get up and walk around and I have to have a high seat on the toilet, that's another thing, but but we never did go what we call ... (inaudible). Anything else you would like to ask. I am not very good at it, I'm very boring person (she laughs)".

- **Downward social comparison.**

"I suppose I'm lucky really, because I don't have a lot of problems ... So I suppose like a lot of people make life for myself easy, I made things easy for myself and carrying on like normal".

2. Coping

- **Problem-focused coping.**

" ... I've got a bath lift, we've got a chair, because I find getting off a normal chair a problem. I did have trouble getting in and out of bath eventually, so I've got a bath lift".

3. No change of standards.

"I just take things as they come. I found I can cope better by doing that not worried about it. That's it go gently and you know sort it out".

Interviewee: Participant Y, Sex: Female, Age: 69, Intervention: Total Hip Replacement surgery on one hip joint, Occupation: Retired (Hospital worker).

Key points:

1. Engaging in social comparison.
2. No change of internal standards.
3. Genetic factor as the cause of hip problem.

Themes:

- Comparing her current situation with pre-operation period (**Temporal downward comparison**).
- Comparing her current situation with pre-condition period (**Temporal upward comparison**).
- No change of internal standards and experiencing some negative feelings.

Data display:

1. Social comparison.

- **Temporal downward comparison.**

"From the start when I was ill with it, when I couldn't walk, uh well, it was very very painful, I could neither stand, sit, bend. I couldn't get out of the chair. My husband pulled me out of the chair. In bed he used to have lifted me up, practically lift me to my feet, it was so sore, um (short pause) I had got no life at all really, the quality of life was practically nil. Uh (short pause) walking on stick which AFFECTED ARMS which I had to have injections in the arms, because I couldn't move the arms, (short pause) uh it was very very bad really, uh (short pause) till I had the operation. ... and after 6 weeks I took the crutches off and I never had to use them again, so I'd been able to walk better than I could, NOT FAR, but I could walk um (short pause) painful at times, I think bottom and back were more painful than hip, isn't it ((looking at her husband))? Bottom wasn't fine, so I couldn't walk too far (short pause) uh when I'm walking, it gets me irritated (short pause) and I know it because I can't walk very far (short pause) uh but I think really on the whole it's not been bad at all (short pause), so I haven't got the pain that I had and that's the main thing (short pause) and I have got a better life".

- **Temporal upward comparison.**

Interviewer: Do you remember your life before you developed hip condition?

"OH YES, OH YES. I had a healthy life, a full life. I worked to the hospital. Um (short pause) I could do things, I could dance, all these things, it was very good. I worked very hard, looked after the family, looked after my mum, looked after my grand children (laughs), so I had a full life, but when this happened I just couldn't do anything, it was bad (Interruption). It's not more than I can add to that really. It's (short pause) better life and that's the main thing".

Interviewer: How do you compare your life before your hip condition with now, at the moment?

"Well, it was good before, was good before, yes (short pause). Very hard working, life was better, 100% really, till hip started".

2. No change of internal standards.

Interviewer: Do you think you're living by the same standards as before you had the hip problem?

"Am I living by the same standards now as the same as before"?

Interviewer: Yes.

"No, no. I'm not. It's slow down, slow down a lot. Uh I get (short pause)"

Interviewer: How do you feel about that?

"A bit upset sometimes, because I can't do things I would like to do (long pause), but I say otherwise the pain's gone and that's THAT IS ONE BONUS REALLY. I can't bend down as good as I used to do, can't kneel down".

Interviewer: How do you feel about that?

"Frustrated (laughs) very frustrated, yeah (long pause)".

• Reasons for the condition.

"Very hard working, life was better, 100% really, till hip started, um I think IT IT'S GENETIC when these things happen, because my sister (Inaudible) had () at 61 as well and it ended about that actually, hips begin to deteriorate".

Interviewee: Participant D, Sex: Female, Age: 50 Y/O, Intervention: Total Hip Replacement surgery, Occupation: teacher.

Key points:

1. Engaging in social comparison.
2. Living in pain for a long period of time.
3. Absence of pre-condition period in the patient's account, because of the nature of the hip condition (congenital dislocation).Co

Themes

- Comparing her present situation with the long pre-operation period in details (**Temporal downward comparison**).
- Living in pain for a long time during pre-operation period.
- Comparing herself with non-specific others (**Upward comparison**).

Data display

1. Social comparison

• **Temporal downward comparison**

"... I've had a faulty hip since I was born. It was congenital dislocation. I was put in plaster for 18 months to form the hip joint and somehow my hip joint got twisted and so for all my walking life I've been wearing my hip joint out, and I ended up with a flat side on my hip bone. So basically I've had pain. I've lived with pain, always um, and gradually got worse, but because you're used to living with pain, you don't know how much you're expected to put up with. So you just get, I'm not a moaner. So you just get on with life. Um, and probably I left my hip too long before I had it done".

"... I waited as long as I could until I was desperate. By the time I had the hip replaced I was desperate. I couldn't get upstairs. I couldn't get on buses, couldn't lift my leg on to the bus platform. I couldn't get in and out of the car".

"... So having had the operation, um, from the day I had the operation I had no pain at all even from the operation. Um, so I just can't believe what it's like to live without pain. It's wonderful".

"... I've got an ache in my right hip which I wouldn't ve noticed because of the pain in the other side, um, but nothing really compared to what I'm used to. It's only a twinge now and then, so that's not a problem".

"... and I'm back at work and I have more energy than I've had in years. I've done three residential visits with the children this year and apart from being careful with things like sailing and canoeing, I can't get out of canoe (laughs), um, you know there's nothing I need to refuse to do, because of my health I was starting to have to refuse to do things because of my health and when you're a teacher that's difficult because it's like admitting defeat, you know. Things are a challenge. So you're not going to turn anything down, but I was having to and I felt my hip was letting me down. But it's lovely to be pain free so it's been well worth it".

- **Upward social comparison**

"So little everyday things that people take for granted, I had trouble with".

- **A long pre-operation period**

"... So basically I've had pain. I've lived with pain, always um, and gradually got worse, but because you're used to living with pain, you don't know how much you're expected to put up with. So you just get, I'm not a moaner. So you just get on with life. Um, and probably I left my hip too long before I had it done. Everyone was saying I should have it done now and I'd say, but you don't know, you don't know what's going to be happening in the future. You don't know how good it's going to be. So instead of having it done at 14, I waited until I was 49. Because I'd had been told when I was 16 to wait as long as possible, because of course the life of the hip joint. I waited as long as I could until I was desperate".

Interviewee: Participant I, Sex: Female, Age: 44, Intervention: Total Hip Replacement surgery, Occupation: Housewife

Key points:

1. Engaging in social comparison.
2. Physical and cosmetic related-problems following the hip replacement.

Themes

- Comparing her present situation with pre-operation period (**Temporal downward comparison**).

Data display

1. Social comparison

- **Temporal downward comparison**

"First I couldn't walk very far, constant pain all the time and I came and had my replacement. First 12 weeks was torture, but now I'm getting on fine really".

Interviewer: How do you see your quality of life at the moment?

"At the moment all right, because I can get about, walk about, things I couldn't do, I can now do. Before operation, since I've had it done I can do lots of things, I can put socks on, shoes on, wash and dry myself. It made a big difference".

"I do shop on my own, get on and off the bus. I don't use car as much I used to, tend to walk a bit more than I used to before I did it. That's it really. Just made everything a lot better".

2. Physical and cosmetic related problems

" But only one problem, I've got one leg a bit longer than the other one, so I've attached wedges to my shoes, apart form that I don't admit having it done".

Interviewee: participant K, Sex: Male, Age: 49 Y/o, Intervention: Total Hip Replacement surgery, Occupation: Mechanic

Key points

1. Engaging in social comparison.

Themes

- Comparing her present situation with the pre-operation period.
- Upward and downward comparisons, using extreme situations.
- The effect of long existing pain on the patient's quality of life and his perception of life quality after getting rid of that pain.

Data display

1. Social comparison

1. Temporal downward comparison

"Before I had the operation, I'm forty years old, before I had the operation I walked with two sticks, like somebody in 80 or 90 years old. The operation and the treatment I received was good and successful and it just transformed my life and I'm very grateful for that. Nothing else to say really".

Interviewer: How do you see your quality of your life after the operation?

"It's totally different. It's brilliant to what it was. A pain like that that you've got all the time, it wears you down. It tires you out, even you don't realise it, you know. Just grinds you down, but now it's totally different. It feels marvellous now. It's just changed my life, from being ... I think I would've been in wheelchair, but I was in for a really short time. But now I can do well. I can't run a marathon, I never could, but I can do everything I want to do now, just about and that's great".

Interviewee: Participant M, Sex: Male, Age: 50, Intervention: Total Hip Replacement surgery on both hip joints, Occupation: Business

Key points

1. Engaging in social comparison.

Themes

- Comparing her present situation with the pre-operation period.
- Focusing on immediate post-operation period.
- Having done both hip operations at the same time.
- Having no pain before and after the operation, only a bit of discomfort.
- Lack of pre-operation narrative.

Data display

1. Social comparison

- **Temporal upward comparison**

"I've got to change anything a little bit more careful than what I used to be, you know. Uh, do things, uh, got to be careful to sit down or try to get up quick or make sure I don't twist anything, other than that, it's I'm getting used to that. It's not a problem".

Interviewee: Participant U, Sex: Male, Age: 61 Y/O, Intervention: Total Hip Replacement surgery, Occupation: Factory worker

Key points:

1. Engaging in social comparison.
2. Having multiple health problems.
3. Being on the waiting list and having pain for a long period of time and getting used to pain as a consequence of it.
4. Being on the waiting list for a long period of time and developing other health problems as a consequence of taking pain killers.
5. Hip not as a major cause for his current pain and limitations.

Themes

- Comparing her present situation with the pre-operation period and the pre-condition period.
- Age comparison.
- Long period of being on the waiting list and developing some complications as a result of it.

Data display

1. Social comparison

• Temporal downward comparison

"Well, yes uh I was, I was waiting about 3 years for the operation and uh I was working on nights 12 hrs nights and uh I used to get uh terrible pain you know after the day, because uh with me job uh and on the 1st February uh 2001 I my hip went so I absolutely couldn't walk well the pain was so much and uh I was taken home from work".

"I was in pain and uh it took I used to do it you know I didn't complain about it but it was painful... the pain I used to have I already said I used to get home from work, sit on the flat and cry my eyes out, but you know but of course when I'd rest a bit it wasn't too bad"

- **Temporal upward comparison**

Interviewer: Before the hip problem uh started how was your life?

"Well, I was very active uh I used to go walking uh I played football ... I was very active I used to work lots of hours you know as I say before I came off with me hip, I was working 12 hrs 13 hrsnights. I worked for 3 years like that you know".

- **Age comparison**

"Well, I'm 61 now uh but I think that contributes to me problems you know arthritis".

2. Negative consequences of being on a long waiting list

"I had to wait quite a long time before I got the operation but uh I had lots of pain. I used to uh I had tablets actually that's what caused my problem which made my stomach bleed and that's what caused my platelets".

Interviewee: Participant F (1), Age: 67, Sex: Male, Intervention: Total Hip Replacement surgery and a surgery on foot (ankle), occupation: Retired.

Key points:

1. Having multiple health problems.
2. Hip problem as a consequence of other health problems.
3. Engaging in social comparison.

Themes

- Comparing her present situation with pre-operation period.
- Having physical and functional limitations as a consequence of foot and heel problems.
- No functional limitations as a result of hip problem.

Data display

1. Social comparison

• Temporal downward comparison

"The hip apart from the dull ache when I walk is alright, all the sharp pain is finished. Used to hurt just sat and watching television or in bed at night. Used to get shooting pain like toothache and that's gone, but it just hurts now when I walk, so I know that's muscular and it may get better I don't know, hopefully".

2. Multiple health problems

"Um, well, it is not very good now because I can't play sport and can't go walking far and can't play golf, also got...I had to have my heel fused, so that's quite painful. It's got to be improved to normal. That's about it really".

3. The cause of hip problem

"The first thing is I broke my heel bones, shattered the bones 25 years ago. That was an accident, fell about 30 ft floor and that's always been bad, but I've just you know I've just to put up with it. I used crutches for a long time and I think with limping so much on that it's caused my right hip to wear out 'cause left one was O.K. I've had

I've had in the past trouble with my back. That's I was in the hospital years ago and they said it was arthritis, so I could only presume that's caused by the fall from 30 ft floor and actually broke both my heel bones".

Interviewee: Participant F (2). The follow-up interview at participant's home.

Key points

1. Having pain and functional limitations as a result of foot and heel problems.
2. No major problems with the hip.
3. Need for using walking aids (sticks and crutches).
4. Having a poor and even worse quality of life after the foot surgery.
5. Being uncertain about the future.

Themes

- Having pain and functional limitations, walking with aides and not being able to play sports.
- Comparing hip with the foot and having no major problems with the hip.

Data display

1. Pain and functional limitations

"I can't go for a nice walk and I can't play sport and I mean pain just for walking. I have to use crutches all the time. I can't put any weight on. I have to use crutches".

2. Not having major problems with the hip

"But the hip is nowhere near it as bad. It's my heel bones. ... I can manage with the hip. For the moment it might get worse as the time goes on, but at the moment I can manage with a stick but the heels I've got to keep all the weight off and use the crutches just lightly touch the floor and I don't know when it's ever going to get better. So not very happy (laughs)".

3. Regret and uncertainty about having the foot operation done

"I thought perhaps a week or so after removing the plaster it would I thought it would be become free and not painful, but it's just as painful and sometimes I think it's worse. It's definitely worse now than before I had it fused. I could walk a little short distance without pain, when I had it fused, but I can't now, without taking all

the weight from the crutches, unless it improves. I could've made a mistake having it done. I don't know. We'll wait and see (laughs). Time will tell".

Interviewee: Participant W, Sex: Female, Age: 79, Intervention: Total Hip Replacement on one hip joint, Occupation: Housewife.

Key points:

1. Engaging in social comparison.
2. Experiencing physical limitations and pain.
3. The importance of family
4. Having multiple health problems.

Themes:

- Comparing her situation with others in general.
- Post-operative physical limitations and pain.
- Having a negative experience of hip operation.
- The adverse effect of operation on her job.
- Satisfaction with care.

Data display:

1. Social comparison

• **Downward social comparison**

"We've had our ups and downs like every body else, you know. ... but we've been a happy lucky family, more or less, you know.

• **Advantaged-self**

"... I do like my own time to myself, you know. I can make frocks or knit or saw or embroiders, so I always for one of kids, great grand kids. We've got two, two great grand kids, so I do for them, you know so all good really".

• **Upward social comparison**

"I was in terrible pain for two and a half years (after the operation). I am looking after my 82 Y/O husband which is hard work and because he's had his displaced five times and he's had his brace on. I was in terrible pain, I don't know, I carried on. ... I had to do

it for him (her husband), you can't have still women coming in and cook a bit of something and going out, leaving out. You've got to so much, haven't you? Well, you know, you're probably married [yeah, and yeah you have to do and this is what's happening now. ... Doing things dancing, going away, walking. We did everything you know, swimming. I can't swim now, because of my hip, but I love it, love swimming. If I do that, I'll hurt my leg".

2. Experience of operation

"... Dr. X came to see me. Anyway, he said: We're going to operate on you and then I got a nasty surprise. They took me down, they didn't tell me whether I'm going to have an anaesthetic or anything else. And two big women got me on a bag of beans or whatever it is, bean bags and tried to push a needle in my back and I said: Don't do that ... he (the surgeon) means well, I mean they all do. This is just these things that come and to try it on, aren't they"?

6. Appendix Six

Different transcription methods

Participant S (1):

Interviewer: **(interaction)** Please tell me about your experience of hip condition and how things happened up to now? Start wherever you like and take all your time you need.

Participant: Do you mean with the way it started or since I had the operations?

Interviewer: Um, wherever you like to start, since it started or [

Participant: **(narrative)** Yes, well, um with my right hip, um I I thought I'd strained some muscles in the groins and I went to the doctor and he said he thought it was a hip problem and um but, I coped for a number of years really and um then I started to have, I I couldn't get in and out of chairs, it took me ages and I I was having problems and I went to the doctor and um I had an x-ray and when I saw him, he he said: well, it needs a hip operation straight away and I've known the doctor for a long time and I said: well, if you were me what would you do and he said: well, try physiotherapy, but if the hip's gone too far, it means it had to be done. Before I had the operation I thought I would try and swim and when I went to the swimming bath I realised how the movement'd gone. Um, you know it is amazing that I hadn't been swimming for a while and I realised that the hip just wouldn't do it. Um, but I did persevere and I went every morning with a friend and tried to do the swimming, thinking that it would done me good. Um then I had the the operation. I was working, um running an after school club, and um my biggest problem was that the hip used to give away without any warning. Um, it wasn't the pain that made me, the hip give way. Um, it was if I was on an uneven surface or on a step and suddenly I was down and I had a nasty fall down on a friend's stairs, very very lucky really and I had a nasty hemotoma in my arm. The house I used to live the stairs um, you came down five steps and then on a little bit that you walked on and then another five. The number of times I fell down the second bit, I don't know why,

fortunately I didn't fall far, but it was amazing, I didn't really injure myself. When I came in in the car and I stopped at the top of the drive and I got out of the car, I couldn't move, it was a pain from top to bottom like severe cramp and I had to wait a minute and it kind of cleared and I went to open the garage door, drove in then when I got out of the car, the same thing and I really got problems for so long getting in and out of the chair and I couldn't do a lot of work in the house. I've been I've been employing a gardener and a cleaner for floor for a number of years, um because I couldn't cope and I was waiting 18 months for the hip and decided I have to give my job up, because I realised I couldn't even go out anymore. I had to stay in the house and Christmas and on Christmas Eve I got the letter to say that my hip...appointment was 2nd Jan. So I gave my job up and was nearly 67, so it was time that I did and then when I was waiting for outside the theatre, Mr. S. came and said the other hip was as bad. Well, I wasn't really aware of that. It may sound strange um ,but I said to him: well, I'm fine. I'm not aware of any problems, but I had been on anti-inflammatory drugs for about five years and (short pause) when I had I had an epidural for the operation. I have to say I couldn't understand I thought I would be frightened I don't know why I think I was just relieved and um I had an epidural which went well, the operation went well and when I came out of the anaesthetic I felt I'm on a high, because the pain was so much better. I can't... you get used to pain and it wasn't there and the operation just seemed fine. I know I sound strange, but that is how I felt and I was just laughing and chatting and I thought well this is just wonderful. Um when I came I asked Mr. S. then if I could do with the other hip while I was in, because he said it was bad and he said no, because he hadn't put I think it was cement as much in, because with my age he thought, there was only perhaps 10 years it would be last and therefore it may have to be redone, so he couldn't do the other hip. Um, the thing I wasn't prepared for was how little I could do. That was the shock to me after the operation.

(1) You know, you can sit in a chair, you've got to keep the 90 degrees, you can't go forward.

(2) living 'cause I am a widow. I've been a widow now it's fourteen years.

(narrative) Um, if I lost a crutch I wasn't allowed to get down, living on my own it was difficult, um and getting um I couldn't stretch to one side. I thought I was prepared, but it was an awful shock how little I could actually do, because I realised if I wasn't careful, it could dislocate, and um that took a lot of adjusting for me and living on my own you know the home help's came in a little bit, but they don't get a lot of time and once or twice I got in a mess um and I felt a bit frightened if I couldn't do this, often I wouldn't, what I am going to do, but um then I've done very well with the first hip. I've lost, Mr. S. said: I've lost movement for bending and getting down to things, and I had to get in a car in a certain way and there are loads of things in the house I just can't do anymore and I can't get down.

(3) That um it's not bothered me. I mean you just adjust and I think well, it's no big deal. I'm just relieved, that I am on no painkillers,

(4) I can walk about and I could walk very very well which was wonderful and I thought well if I could do that, I haven't been doing that for so long.

(narrative) Then the other hip was playing up, well I did realise that then I did have a lot of pain and had to keep on with the tablets and when I saw Mr. S. I went on the waiting list and um (short pause), but there again I didn't have pain and I wasn't in the mess with the second hip as with the first as much, but um the hip was bad and when I actually did come in after about 15 months to have it done, Mr. E. did it and he said it

had deteriorated a lot and that um when I had the operation done, it was a longer op. than the other. I have to say as far as the op. was concerned and the epidural, it seemed totally different. It did bother me the epidural and I wasn't worried about it. I was expecting the same as the last time and it wasn't the the lady who went in to my back, I don't know whether she hit a nerve twice, but I nearly hit the roof. It was strange, because I felt I was in a dispensary and everyone was round me, I wasn't aware of that with the first time at all and um I was aware of the feeling in my legs going which was odd. They packed me for the op with like bean bags or something, all very strange to me, because I don't know why I wasn't aware of that with the first, but I did feel very ill after the op in the recovery room. I couldn't... felt dreadful. I couldn't stop shivering and I think I was in there for a long time. I really felt quite ill. Um, when I came out I still didn't feel myself at all and then I don't know what it was in the end, I couldn't spend a penny and um (short pause) um I felt shivering again as I was going to ... just shiver and they sent for a doctor and I think he increased the drip and the flow was very quick , because I could feel it coming in me cold and he saidand also I did have a problem which I've always had all my life with a very low blood pressure which I have to be careful about standing up after an op and I think that had dropped very low, but when he came back he said he was very pleased, because he said the numbers and figures were a lot better. After that I did very well, I did very well,

(5) and is that.

(interaction) Is there anything you want me to...

Interviewer: No, go on.

Participant: I'm not chatting too much, am I?

Interviewer: No, you're not.

Participant: I'm just trying to say how things were um in between the operations when I had the first operation I realised ...well I had had strange problems which do you want to know of it?

Interviewer: Yeah, yeah sure.

Participant: Nothing to do really with the op. **(narrative)** Um, I came home, I got the home help. I didn't live at home two weeks after my op. the first hip. I found I thought somebody's trying to get into the house

at night. Um, (short pause) and I was up all night and when the house help came she said: I think you've got mice, but to cut the story short I had rats. Don't ask me where they came from, I think while I've been absent, I found out after wards the detached house next door had had them for months and they hadn't had the people in it and so how they got in, I had no idea and the man who came said: he thought I would be as well moving out, or other wise I had to seal the doors and it wasn't hygienic in the kitchen and I think really they were all over which was horrifying. I can't I felt awful,

(interaction) Can you imagine how I felt?

Interviewer: Yeah.

(narrative) And so um I thought well I have to find somewhere to go and um my daughter-in-law said: well, you have to ring the home help, they would to coming in, in the morning and would wonder where you are and think you had fallen in the house. So when I phoned up her and I said: I don't know where I'm going to go and what I'm going to do, she said: leave it with me and they phoned back in half an hour and had got me into an old people's home um which did me the biggest favour in my life, because I went to O. which was um run by church organisation,

(6) because I go to church and I have my faith

(narrative) and the atmosphere suited me down to the ground. I was spoiled. I thought if this is an old people's home, I have nothing but praise, and I felt it was like a fortnight

of CONVALESCENCE and because it was on the flat outside, which my own home wasn't, I could practise walking with crutches and I used to go a little way, come back to the home. I didn't go long way,

(7) and that fortnight put me on my feet, isn't it strange?

(narrative) and when the house was clear I paid someone a lot of money to clean and they cleared the cupboards, they did everything, because I didn't know where they had been and I had to be clean and it cost me a lot of money that, a lot of money, because the kitchen carpet was in shreds, um they chew wires, I couldn't believe it, would you? So with the home and I did get a 100 pounds for each week from the social service which I didn't expect, but I had to buy new carpets and all sorts...My son came to help (interruption). When I came home, my son had got the house nice and warm and when I got in I thought oh I'm going chilly. I'm going to bed. The boiler was gone, the central heating, boiler.

(8) So there many problems that were very big problems to me, that was sorted out.

(narrative) The second hip was a dream for recovery. That was cemented. This first one was a TPs. I know I'm on Mr. S.'s study for TP's. I know I've not have it, because I've been seen both x-rays and it's a different shape. The second hip, the recovery was cemented in and all I can say is you would probably know what hiphashad. The second is so much better from the first. I hardly know I've had it done and,

(9) So I don't know,

(10) I know they don't want me to have it redone and trying to force me, keep it as long as possible,

(11) um but as far as I'm concerned I have to be mobile, because I've got macular degeneration and anytime, I don't know how long it will be I'll be registered partially sighted and that would more or less be it. I think it's no good giving me another hip

later, I want it now and I want to be mobile now, while I have my sight. I want my quality of life now.

(12) and I want to know the score and I am really going to be quite firm today, because I think I could understand...I really must... I feel ... I'm disappointed that I'm not seeing Mr. S.,

(1 3) because um there is something going on that is not right and if I've got to be on severe pain killers, I'll be very limited.

(14) Um, I don't know whether you can have three hips done and they're perhaps thinking of 70, 10 years there may be another op and I don't know whether they do three,

(15) but for me ...I'm probably going to be house bound in any case with my eyes. I feel I'd rather be mobile now,

(16) and that's I think that's it.

(17)1 don't want it you know, yeah

(18) I think Mr. S.'s marvellous, I think he must get satisfaction from seeing the difference he makes, because he certainly made a difference and I'm certainly not complaining, because this hasn't lasted and I'm not complaining at all. I'm very very grateful and they are very clever men,

(19) and (short pause) if I have to say anything and I really don't like saying this, but the difference in the nursing care between the first hip and the second. It was bad for the second, and it's that that frightens me, if I had to have another op.

(narrative) I've moved between the two ops into a flat, because I realised I have to do which has been wonderful.

(20) I've got the most beautiful flat, um not very big, but to me. It's got a lovely garden and a view which makes it for me which you can make your own home nice.

(21) So all that has done which has been hard.

(narrative) I thought I was rushing between the two hips and it was it was a lot of it took some doing, but it is the best thing I have ever done.

(22) Now I can't drive you see,

(23) and I've got a beautiful view and if I'm going to be house bound, at least I can I've got a lovely garden. I can sit in which I wouldn't ve settled without it.

(24) because ...um so yeah all I know um (short pause). I've done that which was needed to be done.

(narrative) because where I lived before I realised it was steps, steep hills, couldn't get to shops, um just wasn't suitable anymore.

(interaction) Interviewer: Do you remember how life was before you developed your hip condition?

Participant: I have to say I was extremely active and you see I had a husband who had heart condition most of his life, and um really it was high blood pressure which he was born with it, he didn't develop it and he had his first severe heart attack at 38, um at 31 he was in hospital with heart failure, just the high blood pressure hadn't been controlled, so I did all the heavy work which didn't bother me at all, because I was I mean ... I was physically very strong and I have done a lot work, because D.'s parents, D.'s father had a hip operation done, it wasn't successful, so he was more or less in a wheelchair. His mum had heart trouble, we moved them near us, so I loved looking after them in their own home, looked after ...D. worked he managed to work, you know. He gave up his business. He had his own business, plumping and heating. He gave that up, but he had a job estimating. Um and they were wonderful to him, thought the world of him really, but his health was doggy and if he couldn't go to work in the Winter, they brought the work to him and he did the estimates at home, not many companies wouldn't done that, and he got about 50 and he had three heat attack in 18 months and they just couldn't stop them and they said they wanted to do a by pass not for the normal reasons, they

didn't know whether there would be any benefit actually. Um when they operate, they said to me the heart was badly damaged and they never thought he'd pull through the op, but he did and with 4-5 good years after, um but they told me that the heart really was so badly damaged they wouldn't even actually done the op if they had known him and because he died and but I was doing all the garden, the work, when there was D.'s parents, I looked after D.'s parents right up to the end, you know they were just down the road. When D.'s mum, her heart was quite bad and she was in a bit of mess, we brought them to my home for a while and they lived with me, then they went back home and then my parents weren't well, so when D.' parents died, we moved them into the home again. You just ... If you walk it's five minutes and in the end I had to keep my father. My mother died and I had to. It was all tough really, hard work, um because my mum was in hospital with the cancer op, on the same day, the day as D. was in NG for his by pass,

(interaction) see you can imagine how I felt.

Interviewer: Yeah.

(narrative) Um, but my brothers took over and they gave me a room at the NG, and I stayed there until he was out of intensive care, but D. was lovely and cheerful and we didn't have a miserable life and I did all the heavy work, all the gardening and looked after D.'s mum and dad, and it was rather sad, because my dad got two months off hundred and I looked after him and he died and I started with my own problems, didn't I? It's 8 and half years,

(25) and and so I mean really I did a man's work, but I can't...

(narrative)... I liked decorating. I liked the garden, but D. wasn't miserable, my parents were nice, D.'s parents were nice, we just ...yeah we were all right. I mean, I mean I don't say...It sounds gloom and doom, but quite honest it wasn't, you know. We were ...D. was cheerful and optimistic and he worked quite up to the day he died. He died at

his desk and that was a tough time after, a tough time after, because you know we were very close

(26) and in a strange kind of way, when you've got someone who was in that state (short pause) um you get closer, you made the most of what you've got and I still think I have that in me, because if anyone asks me I go and if I can do anything I do, and I have many friends.

(interaction) So is that any good? (she laughs).

Interviewer: Yeah, yeah. Thank you. I really appreciate your willingness to express your feelings.

(27) Participant: I do think you can give up. Um, I got down a fortnight ago, because I really really thought I'm going to stuck in this house and but um I can't... I can't get a plastic bag on the back seat, get my legs up, even get in a car. Um, I just ...I can't, I don't know, I just can't do it, any way.

Interviewer: Thank you very much.

Interview with Participant L (Follow-up interview)

Interviewer: Would you like to add anything else [about what I told you before? [Yeah, about what you told me before.

002	memo 1	I don't know really, because I know I've been very ok. I know that.	reduces the importance of what she's saying (6)
003		Uh, (short pause) but actually it would've been five years and four months that I waited,	waiting
004		but lots of things my skin cancer, I had a tumble leg, then I had a very very bad cold, so I couldn't go in	other health problems
005		so it was my fault not the hospital, yeah,	her fault
006		I don't know really (short pause)	(6)
007	memo 2	I mean when I think about it, uh I did have a lot of pain, but I had to use these sticks, but after three weeks I was really fine, you know	Intra-personal comparison (4)
008	memo 3	so I don't know I don't know what I can add to what I've told you.	(6)
009	memo 4	<i>Interviewer: What kind of activities do you have?</i>	activities
010		Participant: Anything, that is what I was going to ask you. I like swimming. Well, my daughters are living in Canada and one of them she's actually been in the games for Canada and (she's trained a lot) and she loves swimming, when she's come over, I've got with her but I haven't been able to now could I? Could I go swimming now?	medical interaction a) seeking advice
Oil		<i>Interviewer: I think you'd better ask X ((the nurse)). Have you got her [her card, yeah? [card</i>	referring to medical staff
012		Participant: I ought to have asked when I went in.	
013		Interviewer: Because she's specialist [in arthroplasty lip replacement [yes I should've asked when I went to hospital.	
014		<i>Interviewer: You can call her.</i>	
015		Participant: Can I?	

016	<i>Interviewer: Yeah, yeah. You can call her [and if she's not</i>	
		<i>[oh</i>
	<i>there you can leave her a message [there is a voice mail. I'm</i>	
		<i>[oh</i>
	<i>not sure if I say that it is [right or wrong</i>	
		<i>[no</i>
	<i>I'm sorry about that.</i>	
017	Participant: I've done everything. I've been in the garden DIGGING, so to me I'm just normal.	garden activities
018	<i>Interviewer: Can you tell me, for instance, three different things that are really important to you? um, in your life.</i>	being normal evaluation
019	Participant: I don't get what you mean.	
020	<i>Interviewer: What things are really important to you [yeah, in your life? [in my</i>	
	<i>life?</i>	
021	Not a lot now (they laugh), not a great lot now, because (sniffs) when you're on your own	loneliness (2)
022	I mean I DO GO OUT a lot, I go with my cousin and I do go with friends, but I don't have any activities	going out no activities
023	<i>Interviewer: Yeah</i>	
024	(short pause), That's my activity ((laughs and points towards the garden)). Yeah, I can't see more challenge, you know, about it, because as I say I should've (). I'm quite happy out there.	garden happiness (3)
025	memo 5 <i>Interviewer: Are relationships important to you?</i>	relationships
026	Participant: Well, I haven't any.	no relationship
027	See mine are in Canada. I have two daughters both live over there.	ler daughters
028	They did want me to go and live there	
029	➤ I said: No. I think they should be on their own and	
030	mean I lived here all my life in Sheffield, so I'm not mothered now.	
031	f I'd been younger, yes I would, but	intra-3ersonal comparison 4) (intra-pc)

032	I've got a cousin, she's 85 and she's marvellous for her age.	inter-personal comparison (5) (inter-pc)
033	<i>Interviewer: she lives here?</i>	
034	Participant: No, she lives over X Road near Y Hospital. She lives up there, yeah and I do see her yeah, but ()	
035	<i>Interviewer: What about friends?</i>	friends
036	Oh yes, I've got friends and I've got good neighbours,	good friend & neighbours
037	but the next door is going, she, they have been good and they're going to live higher up and (sniffs)	
038	and I've got one you know when you get Did you come this way? Did you come down?	
039	<i>Interviewer: Yes, I think so, down. I don't have a good sense of direction (she laughs).</i>	
040	About five houses among them, they are very good, they are very good to me.	being good to her
041	and so is she. They took me out mother's day, you know. That's nice.	mothers' day
042	Then her birthday. She's about 38. Her birthday is the day before mine, so they took me out	birthday
043	then so you know I get along. I haven't got a lot to grumble about.	not grumble
044	I've been enjoying my life.	enjoying life (3) '
045	so that's it.	
046	memo 6 <i>Interviewer: Are you ok with the skin cancer?</i>	skin cancer
047	Oh yes, yes. I had I think I had about 14 stitches	(1)
048	but I had lost two brothers and two sisters with cancer, 'm the only one left now.	osing relatives with cancer
049	Well I should think is nearly two years and I've been all right, so that's good (she laughs).	
050	<i>Interviewer: How did you cope with the skin cancer?</i>	coping
051	Participant: I had no problem at all.	

052 I had this little spot and I kept catching it when it came, it went came back, went came back and I thought this is funny, you know (1)

053 so I went to the doctors and he said to me I'm sending you straight away to X Hospital and I had to make an appointment to go up

054 and I had no problems since, which is good, isn't it? minimizes the importance of her claim (7)

055 *Interviewer: Yes, it is. It's two years now?*

056 Participant: Must be

057 *Interviewer: Anything else you like to talk about?*

058 Participant: No, I don't think so. I think that's it. You know.

059 memo 7 I am really really pleased with my hip, because I know people who had it done before me and still on sticks, so I'm very lucky, aren't I? When I look back ((laughs)) I am. (5)

060 *Interviewer: What do you mean you are lucky?*

061 Participant: That mine was all right. When I came out I had crutches, then that was for a week then I had a stick, that was for a fortnight. I didn't need anything after that. I was fine. **So I am lucky, aren't I? (she laughs).** (7)

062 memo 8 *Interviewer: Yes, you are.*

063 I don't know. I can't think ((long pause)) (6)

064 memo 9 *Interviewer: Do you know some body with hip replacement who didn't improve as much as you did?*

065 Participant: Oh, yes. Two sisters. Yeah, I know one or two and I had a friend over around X Road and she still had a lot of pain when she came out, but she's got 3etter you know (short pause) (4) (5)

066 so I'm lucky (she laughs).

067 mean when I came out of hospital one daughter came for a month and the other came for a month daughters

068 so I was all right. So I don't know much else I can..

069 Participant:

070 memo 10 *Interviewer: You talked about swimming. Did you use
to swim when [Yeah*

071 Right from going to school and

072 I put weight on (sniffs). I used to be as thin as a lath. I
put weight on, doing a bit and having sit a lot, you (4)
know and I can't get rid of it, the weight.

073 *Interviewer: How long have you been swimming in the
past?*

074 Participant: From school

075 *Interviewer: and after school?*

076 Yeah, still kept it.

077 Apart from I had children you know and then took
them and yeah and they can all swim, they can all
swim.

078 My husband he was 62 or 3 before he learnt to swim,
but I always loved it. (5)

079 *Interviewer: How long haven't you been swimming?*

080 Participant: About from my hip started.

081 I did mean asking them ((asking the nurse about blaming
swimming)) then I you know my age ((she laughs)).

082 *Interviewer: It is the only sport you are interested?*

083 Participant: Yes, yeah, was. (long pause). Yeah, it is
really. When I look back, yeah. I enjoyed it.

084 Youngest daughter, she was in Common Wealth
games for Canada.

085 *Interviewer: Oh, is she a swimmer?*

086 Triathlon: the swim, cycle and run, yeah (short pause).
Dople said: how come you're doing it for Canada (she
augh) and not for England? She said: because
Canada has been really good to me

087 so they got on they got on marvellous

088 They got a lot more there than here.

089 *Interviewer: Yeah*

090 so, I'm never blaming them,

091 but I didn't want them to go. (2)

092 *Interviewer: Do you want them here?*

093 Participant: Pardon?

094 *Interviewer: Do you want them here?*

095 Participant: Oh, I would love that, (2)

096 but they've got such a good life. reasoning (8)

097 The oldest, she works for X Financial in British Columbia.

098 and I don't know how many holidays she has some () in Texas and she went there for 12 days, she came back on Sunday, yesterday she went to Mexico for five days. (8)

099 *Interviewer: Do they visit you here?*

100 Participant: Pardon?

101 *Interviewer: Do they visit you here?*

102 Participant: Yes, every year, yeah.

103 They want me to go up there, but

104 I'm all right going but it is coming back.

105 Oh, I'm terrible. I can't sit still and I'm awful, I'm really, so

106 I said : no.

107 I have a grand son and a grand daughter there. They both married Canadians now, so you know.

108 memo 11 That's the grand daughter up there top ((pointing to a wedding picture of her grand daughter with her husband hanging on the wall)).

109 (short pause) I went to their weddings.

110 *Interviewer: I just wanted to ask you which part of your life seems to you much more important? What is really important to you?*

111 Participant: You mean all through my life?

112 *Interviewer: Yeah, all through your life.*

113 Participant: all through my life, uh, let me think, (short (6) 3ause). I don't know. I suppose it is being married, you know, having your children,

114 3ut then it is just that's that. When they've gone, (2) because house seems empty, you know (sniffs)

115 3ut I'm happy having the children. (3)

116 *Interviewer: So still having children are most important to you?*

117 Participant: I think so, yeah, yeah, (long pause). I've (3)
been happy, yeah.

118 But it is just sad when they are gone and leave you (2)
here,

119 memo 12 if it WAS ANOTHER TOWN all right, but when it is (2)
memo 13 another country (she laughs) I know you know.

120 memo 14 *Interviewer: but as much as they are happy you are
happy?*

121 Participant: Oh, they are, they are.

122 Yes, they are married. One's been married about
twenty (short pause) no it's more. One's been married
about 30 years

123 and the other's been married about 32 or 3 years, so
yeah

124 and the eldest when she got married she went to live
in Derby and then

125 the youngest she went to live in Jersey and then went
to Canada. She went first and then

126 Hazel and Jim went after ((short pause))

127 Yeah, I'm happy about life, you know when I look (3)
back (short pause)

128 My mother lived until she was 90, so I must take after
her.

129 *Interviewer: Do you enjoy looking back and [yeah
?*

[

reminiscing

130 Participant: Oh, yeah, (she laughs). I've got time now, (7)
haven't I? (long pause).

131 My husband died. He had two strokes (
) nothing general.

132 *Interviewer: How many years ago?*

133 Four in May. (short pause) Time flies, oh it does.

134 *Interviewer: Yeah, yeah, (short pause). Do you think
your life had changed since your husband died?*

135 Participant: Oh, yes, because I think you're lonely, you (2)
enow what I mean.

136 *Interviewer: Yeah.*

137 memo 15 Participant: I know I have friends, but you know (2)

138 in the Winter that's the worse time. (2)

139 memo 16 see I can't go out there, I can't (laughs) and when you (2)
draw your curtains that's it.

140 Yeah (short pause). Oh, yes altered a lot, but

141 memo 17 there are thousands like it, aren't they? So you have to (5)
put up with it. (7)

142 I mean if I did go and live in Canada, I would be more (8)
lonely

143 the work, I don't know the people, do I? (7)

144 I can't catch a bus to go to town, whereas I can here, (8)

145 so I would be more lonely over there (8)

146 memo 18 so I'm better where I am. (long pause).

147 I've had a good life, I've had a good life. (3)

148 *Interviewer: Do you think you've changed things that
are important to you now compared with the past?*

149 Participant: No, I don't think so, no.

150 *Interviewer: Things that were important to you in the
past but are not now or visa versa?*

151 Participant: Well, you lose a lot, don't you? You (7)
know, when you get older like I have quite a few
friends that they died. You just lose your friends as (2)
you get older (short pause)

152 and a good friend who lived down here, I went to
school with her

153 she died of cancer. (7)

154 It's a nasty thing, isn't it? (short pause)

155 know my oldest sister when she got it.

156 der husband been killed two years before in his car
and

157 left work for two years to look after her

158 because, she couldn't have it done and she was
because her stitches became undone three times

159 *Interviewer: Skin cancer?*

160 Participant: No, breast cancer.

161 My oldest brother died of lung cancer, then my oldest
sister died of breast cancer then the next one sister,
she died of blood and the youngest brother, he was
younger than me of throat. They all had different,
(short pause)

162 There are sad times, aren't they? There are very sad (7)
times, (short pause)

163 *Interviewer: Did you feel any fear of cancer [because
of your sisters and brothers? [*
No, no.

164 Participant: Somebody was asking me that the other
day.

165 No, I've never thought all they had it so I'll have it. (9)
Uh, I don't think I've ever had.

166 memo 19 I'm a big believer of what has to be will be, and if I (9) beliefs
did have it, I would and that's it.

167 So I won't worrying myself thinking, oh I might have (9)
that.

168 A lot of people do, don't they? They worry about that, (5)
but
(7)

169 no I've never have been, no. (short pause)

170 and I've never had any illness really. I think I went in (4)
hospital when I was young and I had my tonsils out
that is about that all

171 so I've done well (short pause). (3)

172 so that's all about.

173 You know I look back I've been really happy, very (3)
lappy, but

174 my parents didn't die of cancer.

175 *Interviewer: They didn't?*

176 Participant: No, no. Heart and as I said my mother was
90, hers just gave up, you know (short pause)

177 Terrible things are cancer, terrible, (long pause)

178 *Interviewer: What kind of coping strategies do you theoretical
use? For instance when you've got a problem do you question
try to seek help from professionals or you've got your
coping approaches?*

179 Participant: No, I've never (sorted?) from
professionals.

180 I don't really have big problems.

181 I've have small problems like anybody, but no I don't (5)
have () and that's all you know, yeah.

182 I don't have really big problems.

183 When my husband died there was a big problem then,

184 because he used to pay bills and everything, so I had
to do all that. That was a problem, but

185 you learn, you learn yeah.

186 Now I have got an assistant.

187 *Interviewer: sorry?*

188 Participant: An assistant.

189 (long pause) I've never had problems where about to
seek help, you know.

190 *Interviewer: Maybe you are able to solve your
problems [maybe spiritually or emotionally?
[Yeah, yes*

191 Participant: I'm 79 and I seem to have got on and (4)
battled it, but

192 you never know later on dear, you know ((short
pause))

193 I mean as you get older, you get more () don't
we?

194 (very long pause) I'm wondering if the other one needs
to be dealt with.

195 *Interviewer: Is there any problem with it?*

196 No, no, but I just wondered, because some people do (5)
have both done, don't they?

197 If there is any pain [or
[Yeah, I would have to ring the
nurse.

198 mean I have a friend on, she is very good to me (5)
actually, on X Road.

199 They fetch me most Sundays for my lunch, very good (5)
to me.

200 and she had a hip operation 5 years ago and then she (5)
lad to go in again for the other one last year, but

201 she had hers done private (5)

202 3ut she's good now, but (5)

203 hers it took her 6-7 weeks to get over it, which isn't (5)
 bad, is it? It is not bad.

204 memo 20 *Interviewer: And you were quicker.* (5)

205 Yeah, 3. (5)

206 Actually when I came out I had no pain. From waking (4)
 up (sniffs) in the hospital I had no pain since.

207 I just normally can walk up and down stairs, just do (4)
 anything, bend

208 first time I told you, didn't I? First time I could bend I (4)
 washed the kitchen floor three times (they laugh)

209 I was pleased to be to get down. (4)

210 memo 21 *Interviewer: And the only problem you had was the*
 lady snoring! (she laughs)

211 Yes, yes. She did snore. I couldn't sleep, no. She
 couldn't help it.

212 *Interviewer: Well, thank you very much for your time.*

213 Participant: Well, I am sorry I can't say anymore.

214 *Interviewer: Oh, no. You were great. You really*
 helped me to understand more about the issue, thank
 you. (participant laughs)

215 memo 22 Participant: It's a pity everybody's not like me. (5)

216 That one, the other I would never be frightened to go
 in again, I know I wouldn't

217 and funny part about it was when I went down to have
 the operation, one of (sniffs) the men said to me: how
 long have you lived down X Crescent? So I said:
 Forty years. So he said: Do you know Mr. X? and I
 said: Yes and he said: He was my uncle (she laughs)
 who lived there.

218 Only a small world.

219 memo 23 *Interviewer: They must mean a lot to you, the*
 neighbours?

220 Participant: Well, they've they have been good.

221 mean when Albert ((her husband)) was dying in
 hospital, they rang me up and it was half past one in
 the morning

222 and they've got to go to work

223 memo 24 and they wanted to stay with me, but

224 ' said: No, because they had to go to work, you know
 and

225 ' thought that was really nice that, but

226 I said to her the other day I don't know what to do
when you're gone and she said: we're only over hill
(she laughs) and

227 they've got my keys as well in case anything happen,
they've got my keys to get in (short pause)

228 but they both work.

229 I don't see them a lot, no. (short pause)

230 I mean they work full time,

231 so I think it's three weeks since I saw them, (short
pause)

232 but they are if I want anything (long pause)

233 I can be independent (she laughs). I will try and if I
can't then I'll ask somebody, but I do like to have a go
myself.

234 She said, Lyne said: You are too independent.

235 When if I stopped being independent, that's it. I'll give
up, you know, so I'd rather try.

236 *Interviewer: What do you mean by independent? [*
physically /"I'll

do things for myself.

237 Participant: I'll do things for myself and

238 if I can't then I'll ask someone,

239 but I prefer to have a go myself first and if I can't, I
can't.

240 *Interviewer: Yeah, and do you think this hip
replacement helped you to be more independent?*

241 Participant: Oh, yes, yes. I mean I couldn't carry a lot. (4)

242 Mind you I don't carry a lot now, because there is only (2)
me,

243 but I couldn't if I wanted to. (4)

244 But I could now. You know I'm just really normal, (4)
yeah (short pause) i

245 *Interviewer: Your hobby is the garden, isn't it?*

246 Oh, yes. I've got everything ready to plant (she
laughs). I've got my canes up for my kidney beans and

247 t's helping me passes time, something to do.

248 *Interviewer: It's really lovely.*

249 Participant: I suppose I could have a flat, but I would
be lost.

250 I like walking to a garden.

251 We bought this (long pause) and

252 I do need bedroom when the girls come over. One's
coming over in July

253 They stay here and then

254 her mother-in-law in Derby, but she comes as well. (2)
She stays so it is nice to have a bit of company, you
know.

255 (short pause) I do go to Derby sometimes and stay
with her.

256 We get on well.

257 *Interviewer: You are the same age, maybe?*

258 Yes, we are. She is 79, and she's all right, you know.
She can get about, you know.(short pause)

259 She's on her own, but (5)

260 she's got a son lives there and his wife and grand (5)
children, so (short pause)

261 but when they come we always got a full house (she (2)
laughs)

262 People coming, you know to see them (short pause) (2)

263 I don't know whether they'd come back here when (6)
they get to retiring age, I don't know.

264 I think the youngest would, but

265 I don't know about the oldest.

266 I think they would like to come back when they get to (6)
retiring age, whether they want or not, I don't
know It's nearly 11.

267 *Interviewer: Thankyou again, thank you very much.*

Memos: (Emerging ideas during the transcription)

Participant L:

Memo 1: Although she said: "I don't know really" she didn't say it firmly. Her tone was like she wanted to start a journey with me and seemed she needed a bit of help from me.

Memo 2: She said the sentence: "I did have a lot of pain" in a very firm tone and emphasized on it. She said in a way that showed she really had felt the pain with all her cells and used this expression to back up and support the treatment which she received for the pain. In other words, she gave an indirect insight about the treatment which gave value to it.

Memo 3: She said "I don't know" in a way that was really different from the "I don't know" at the start of the interview. I think she might've been disappointed by my question which didn't give her any support or clue and left the discussion totally to her. I noticed the disappointment in her face as well, so I decided to break the silence and start my questions which aimed to explore her values and standards.

Memo 4: By asking this question about activities I was trying to get at her dimensions of her life that are important to her, apparently the question looked medical and I seemed like a medical professional who is doing her job within a biomedical model, returning to square one with the same old questions seeking to evaluate patients' physical ability. Yet, looking at positive side and the answer I gave her, cleared my position for the participant. I think she maybe put me in a different category apart from doctors and nurses who she's dealing with during the course of her hip disease (more than five years).

Memo 5: When I asked her about relationships, she said that she hadn't got any and immediately referred to her daughters, who are living abroad. Later on she talks about her good neighbours and apparently her good relationships with them, but according to her these are not the ones she means by a relationship.

Memo 6: The question about the skin cancer might seem again like a very typical medical question. However, firstly skin cancer was a topic raised by the participant in the first interview, which **I** wanted to focus on more in the following interview and secondly **I** wanted to know how she had coped with the pressure of the disease.

Memo 7: She uses a comparison technique to evaluate her quality of life, either by comparing herself with other people who had the same problem or using age comparison. She uses a downward comparison.

Memo 8: When **I** said: " Yes, you are " **I** probably shouldn't have confirmed her statement about being lucky in order to give any direction to the interview, but under circumstances **I** couldn't not to do so, because morally **I** felt it wasn't right not to agree with her.

Memo 9 : **I** realise now that the last part of the question wasn't appropriate as leads the informant maybe towards a downward comparison without giving a chance to compare herself with those better off.

Memo 10: She interrupted me and talked about swimming with proud. **I** could see the pride on her face. Talking about swimming in the past and not doing activities at the present and putting weight didn't seem like negative expressions. She talked about them easily.

Memo 11: **I** showed particular interest, looking at the picture.

Memo 12: She said: " another town " in a loud voice which seemed she was sort of angry and not happy with them leaving her here and going to another country.

Memo 13: Before **I** started the interview, she asked me where **I** came from and how long **I** had been in the UK. So she found an immediate example to maybe verify her expressions and feelings.

Memo 14: Here I tried wrongly to fix her concern and sadness by making a very leading comment, which I should not have done, instead I should've stayed with the account.

Memo 15: She said : " I know I have friends " loudly, implying that no one can replace her husband what so ever.

Memo 16: This sentence was said in a very down and low voice, expressing a feeling of sadness and loneliness.

Memo 17: Comparison with other people who are the same as she is.

Memo 18: Making a comparison between home and Canada and justifying her decision about not going to Canada.

Memo 19: Belief comparison.

Memo 20: I knew she recovered from the operation after 3 weeks, I just wanted to understand why she mentioned 6-7 weeks recovery period of her friend. She answered me proudly and compared herself and the period she needed to get over the surgery with others.

Memo 21: I had one hour to do the interview and my time was nearly over, so I tried to end the interview in a way which was pleasant for the interviewee. So I reminded her of something she already told me in the first interview which actually was funny and a good way to end the session.

Memo 22: Comparison.

Memo 23: She didn't agree with my comment.

Memo 24: She said: "They wanted to stay with me as if she couldn't believe their kindness.

Interview with Participant H (Follow-up interview)

- 001 *Interviewer: Would you like to tell me more about your experience with your hip condition? Where ever you like to start is ok.*
- 002 Well, I'm very satisfied with what I have done,
- 003 I mean I'm still have problems, because of my spine you know
- 004 trouble with walking with stick now is not related to hip at all.
- 005 Um, I'm much better in my health, because I'm not on medication, um anti-inflammatory that I told you before
- 006 I mean I'm still have problems, because of my spine you know
- 007 *Interviewer: Do you remember the time before you had your hip replacement done, can you remember how life was before [*
- 008 Participant: [I was really struggling.
- 009 Um, I couldn't go out unless anybody took me.
- 010 I was dependent on neighbours for shopping and even sometimes to get me to the doctors, I couldn't go unless somebody took me.
- Oil Um, I was taking anti-inflammatory which I think maybe I was sleepy.
- 012 I was sort of sitting down after a meal and sleeping afternoons and
- 013 anything I did even sort of changing the bed unless somebody helped me, I couldn't I couldn't do it
- 014 Um, I can now with difficulty, but
- 015 um I've got myself a bit more organised in that respect, but
- 016 um NO, I just had no no quality of life at all, no independency.
- 017 Um, my brother did take me on holiday,
- 018 but I finished I was sitting in hotel most of the time, because I thought I was holding them back all the time, but

019 now I can () I can do some little
walks and um (short pause) certainly I'm more
mobile.

020 I can't carry things now but the it is due to my
back, but I think it is um but with me

021 it is a case of finding a medium between my hip
and my back.

022 As far as with just the hip problem I think I would
be ((short pause)) um really back to my old self,
now.

023 I still have problems with my back that I can't
carry things.

024 *Interviewer: What do you mean by "old self"?*

025 memo 1 Participant: Be able to do things, when my
original sorry you don't use those terms, my old
self is when I'm back on my feet, oh dear um. I
don't think Is there anything specifically you
want to ask me?

026 *Interviewer: What things are really important to
you?*

027 Oh, independency. Independency is the main
thing.

028 To be able um, to be able to do little jobs for
yourself without um (

029)
but um I think I've come to terms with that and
realise I'm sort of much better in myself really

030 I'm so much more um aware of what's going on
around me than I was about 12 months ago before
I had my hip done.

031 um being in a room full of people talking

032 I do honestly think it got a lot with anti-
inflammatory that made me sleepy

033 whereas now I'm taking a few Paracetamole and
I'm trying not to take too many of them.

034 and I'm pleased with myself what I can do.

035 I can't do great pile of ironing, I probably say three
days which I would've ironed one afternoon before
you know.

036 *Interviewer: Has independency been always so
important to you?*

037 Participant: Yes, because I think I've always been
the person who looked after other people.

038 I had my mother living with me from 82-85 who needed looking after.

039 I had my husband I believe 10 years who died 9 years ago and he had emphysema and asthma and we had to stair life him to get him down and up stairs, so

040 I had always been so capable of doing things and

041 because to do things for other people where it is hard when you can't do it.

042 I think probably that part of the problem with my back now is I used to get my mother in and out of bath, I used to get my husband in and out of bath and I used to get them hang around my neck, you know to sort of lift them up and

043 I think that's what's happening to me now.

044 but um, um (short pause) is there anything else I can any other line?

045 *Interviewer: You mentioned you're a very caring person for relatives, do you expect people [to care for you? [*
No, no. Not at all. I don't.

046 Um I have, I have a I lost my other brother who was very good for me, died about 18 months ago.

047 I have a younger brother, but he lives in X which is very away, but still very caring and he gets in touch keeps in touch with me regularly and comes to visit once fortnight or once

048 or have me there you know for weekend.

049 I have an exceptionally good neighbour who I sort of couldn't manage without, but

050 I try not to (short pause) put on them without reason.

051 I manage to get somebody to come once fortnight just do me a couple of hours things that I can't do,

052 rather than be asking a neighbour.

053 It's same with my garden.

054 My husband quite enjoyed and I don't want to let
that go and ruin, so

055 I get somebody come again once a fortnight just to
do an hour work to things get tidied, loads of
things that are so important to me.

056 No, I don't expect. In fact, I'm trying doing the
other way round to say that I'm all right

057 I'm very fortunate, neighbours either side is a
caring community, you know

058 and I think certainly don't ask them to do things
that are not willing to do for me. (short pause).

059 So the only thing as far as care would cancer, I did
feel when I came out of hospital that should've
could've been a better follow-up from the
community care, you know.

060 Somebody could've um come and sort of give me
a ()to what to do.

061 I mean I couldn't get in the bath or anything like
that, because I hadn't have a shower.

062 They said: nobody could come and help me, so I
just used to um first week my neighbour used to
come and fill the wash bowl and put it on the bath
room floor and I washed myself down the bath.

063 but I did feel then that could've been just a little bit
of help for the first couple of weeks so,

064 but I was told that if I lived round the comer
which is Derbyshire, I would've got that, but
because it is Sheffield they didn't provide it.

065 (short pause) So I don't mean to carry on all the
time, but do things when you first come out, I was
on my own, you know.

066 I mean it's probably all right I haven't children on
my own, so

067 it is um um it would've been help for me to just
have somebody to follow give me a hand with
things.

068 *Interviewer: How is your relationship with the relatives and friends? Are relationships important to you?*

069 Participant: Oh, yes. Very important, very important.

070 I've been very close to my brothers and believe me now my brother died, his wife comes to see me at least I mean she's 70-80 something like that, but still she drives and she comes to see me once a week mainly if she didn't have problems with health herself and

071 I have nephews, but unfortunately um they're they're um living in X which is in Edinburgh, too far away really speaking to pop in too much but um yeah,

072 the family is very important to me (very low voice).

073 As it my relationship with that next door, I've been for forty-fifty years and so has she, so her children as we brought up them used to come in and now her grand children, still come in and and which I think is unusual these days.

074 People are on their own times, (capsulated)

075 Yeah, yeah. I'm very fortunate really (short pause).

076 memo 2 I'VE GOT NOTHING TO COMPLAIN ABOUT, REALLY nothing and (short pause).

078 I'm probably the wrong person to ask.

079 *Interviewer: Everyone has got some important things for them, um there were some important things for you in the past and there are some for you in the present. Do you think you've changed things that are important to you when you compare past and present?*

080 Participant: Yes, I think (short pause). Yeah, yeah. What do you mean by important?

081 As far as change is concerned yes, because I always used to be (very short pause) definite and get on with things

082 now I don't a lot of things you think in the past mattered

083 I think it's just the phase of getting older.

084 I don't think it's so much with my health, you
know.

085 I think when you get older you realise that what
you think is important when you younger is not
important any more.

086 *Interviewer: For instance, can you give me an
example?*

087 Participant: Um, I don't think position is very
important, s

088 I think when you younger you want to do
something and have something sort of keep up
with the () but

089 when you get older you think that's the hell life
and this is mine and I'm comfortable, I'm warm,
I'M NOT I'M NOT SORT OF UM TRYING TO
BE BEST AS IT WAS.

090 I don't know if it was a good example or not, but I
think people matter more than (short pause) than
positions.

091 (long pause) I can't think of anything else.

092 *Interviewer: Did you use to work?*

093 Participant: Yes, yes. Um 11 you mean after I was
married or anything, yes, I was working . Actually
I was a hairdresser and then

094 I had my own business and

095 after I married I gave it up, um after 3 or 4 years I
gave it up and I went back to do clerical work, sort
of receptionist, clerical work for a while and

096 I gave that up when my mother started to be ill
and I had my mother come and live with me

097 um, she died in 85, I think she died in 1985.

098 My husband, um he died 9 years in September, 9
years rather ((very low voice)) and from 85, well
before that from 1980 actually my mother was 80
when she came to live with me, IWAS MORE OR
LESS FULL TIME CARER BETWEEN THE
TOW OF THEM.

099 *Interviewer: Your husband and your mother?*

100 Participant: Yes, yes. and um (short pause) then I ,
I used to drive as well, because

101 my husband used to be in hospital quite a lot and I
used to get him to the hospital

102 then my eyes started deteriorate and I thought I
was not sort of particularly safe on the road, so I
gave that up.

103 That was a blur really, because I think that um it is
far from dependency that you lose, but it's the risk
that's is worth it and it's other people you might
take with it.

104 and I used to spent a lot of time in the garden, then
when I started with my hip and my back, I couldn't
do that, that I missed.

105 NOW I'LL BE ABLE TO potter a little bit. I've
got a () thing in the back yard. I can stand
and do that and

106 that's actually an achievement and I get lots of
pleasure doing that.

107 I think because my husband spent such a lot of
time in the garden ((low voice) he used to grow
seed and plant (), while he could do it, but

108 that's why I feel I can't let it go and keep it at least
tidy ((short pause)) and but I'M SLOW DOING
THINGS

109 I think that now this is the thing I'm sort of very
slow at doing things and (short pause) again
you've got plenty of time, so maybe that makes
you slow, I don't know.

110 *Interviewer: Has your life changed since your
husband died?*

111 Participant: Oh, yes, yes.(low voice). It's changed
changed quite a lot really,

112 because he had a big family, and we used to be
going to them or they coming to us,

113 but like the rest of us, they're getting older and

114 um I do see them and I keep touch with them, but
I don't see them every now and then

115 Well, in fact three of them died since (
) um and

116 I think this is what you find sad when get older (
) (long pause),

117 not having somebody there to discuss things with
them.

118 SILLY THINGS, ABSOLUTLEY SILLY
THINGS.

119 *Interviewer: What are your main activities at the
moment?*

120 Participant: Activities (she laughs) that's hardly
the word.

121 I'm not really that active. It's just the case of
keeping, keeping things tidy and

122 when I can going out

123 the garden and

124 my neighbour takes me out shopping once a week
and that's quite an activity

125 like going to Safe Way (she laughs) and last week
I did go to town on the bus, on my own and into
Marks and Spencer and I got two things and came
home (she laughs) and that was an achievement.

126 Um, again I told you my neighbours are very
good.

127 When their grand kids come around, playing cards
with them and that keeps my mind active and

128 I read a bit um not a lot, because of my eyes, you
know

129 um I'll listen to the news once a day, but don't like
the rest of the programmes.

130 and and that's that's it. That makes my life very
good, isn't it? (she laughs) (low voice)

131 *Interviewer: Were you sort of an active person?*

132 Participant: I'm not active as I used to be.

133 I mean I used to a lot of um, baking, cooking and
um made my own curtains and you know sort of
all household

134 but me now again, because of my eyes, I can't do
it.

135 But I would never wanted it to not the last 20-30
years, I would never wanted to watching T.V ()
) I used to do a lot of walking and swimming
occasionally () (long pause)

136 *Interviewer: When we talked before you said: I'm
not a morbid sort of person [could you explain
this a little bit more? [No*

137 Participant: I don't I don't suffer from depression.
You know

138 I think some people when they're on their own can
get depressed and as you're saying expect a lot of
things from other people

139 um, I'm not it's not my nature to be like that.

140 I've always been been one able to do for for other
people, you know like that.

141 No, I'm not. I DON'T SIT HERE SORRY FOR
MYSELF at all.

142 I JUST I JUST ACTUALLY FEEL VERY
LUCKY TO HAVE my hip done and to be out of
that pain and to be

143 This last 12 months I've been able to do things that
I thought, you know get about and I thought I
wouldn't do again, you know.

144 I just go for a little walk there and

145 again you see meet people, you talk to people it's

146 I FEEL I AM LUCKY to live where I live with
nice neighbours and the people round about are
nice, but we just I just feel fortunate.

147 *Interviewer: Do you think you've got choices in
you life?*

148 Participant: What kind of choices do you mean?

149 *Interviewer: Um, any (short pause) in your life.*

150 Participant: Not typical. You're restricted in what
you can do physically, so it restricts your choices.

151 I mean I (short pause) I can't sort of do um what
really (long pause) restricted by how I can walk.
So I haven't be

152 If I go out with my brother, I we go I walk so far
I'll find a seat and sit down and I say well I'll catch
you on the way back that sort of things, you know.

153 Because you don't feel you want to you're
restricted on that point of view.

154 I can't um but (short pauses) I don't know actual
choices.

155 Your main priorities becomes keeps yourself
going, you know.

156 I mean even I had this rotten cold, I thought well
I'm not stopping in bed, because if I'm stopping in
bed then then that's it.

157 I thought get myself up and get going and then
maybe in the afternoon sit down for an hour and
(short pause),

158 but now I can sit down and read or maybe watch a
programme on T.V or something like that

159 whereas, before I was sitting down and I was
falling asleep, I was sitting after my lunch and I
had my tray here and I fell asleep after my lunch
and then I wake up and I've been asleep for an
hour, you know that sort of things but

160 I'm not doing that now, so um um (short pause)
choices I can't think of (low voice) (long pause),
no.

170 *Interviewer: Do you feel any sort of
disappointment or fear in your life?*

171 Participant: No, I don't think so. I mean yes minor
disappointments, but nothing you know (long
pause) no. I can't really say, but nothing that stays
with me you know, but um (long pause).

172 *Interviewer: Did you feel any fear after the
surgery?*

173 Participant: NO, NO. I um I can't believe I
would've it done when I was younger,

174 or had somebody relying on me or my husband
would be alive and I'm thinking oh dear I can't you
know they need me, these sort of things,

175 but once you're on your own I think that don't
count,

176 because you think I know I had a general
anaesthesia () I'd rather go, I'd rather die
on the operating theatre than be um relying on
somebody to look after me.

177 If things go more wrong with my back you know
and I couldn't move my back at all that would be
worrying me than (short pause) and

178 memo 3 I did say if anything goes wrong while I'm under
anaesthetic don't try to bring me back, let me go,
you know.

179 I mean I WASN'T AFRAID, that didn't, that didn't
worry me at all.

180 *Interviewer: Did you feel any fear after the
operation when you got home?*

181 Participant: No, no. Not at all. (low voice). No, I
didn't. Um even when I got the thrombosis,

182 I think you get to a stage when you're on your
own, I don't want to repeat myself, but I think
what it doesn't matter if something really happens
to you, as long as it is quick.

183 I think it is the people who are depending on you.

184 I was somebody who was afraid of dentist.

185 *Interviewer: anything else about your life,
concerned with your hip?*

186 Participant: No, not really. I feel I was lucky to get
it done.

187 Interviewer: Thank you very much. You really
helped me to understand more.

188 Participant: Really?

189 *Interviewer: Yes, thank you very much.*

Participant H:

Memo 1: I think she had this impression that she used a phrase "old self" which was not appropriate, whereas I wanted to explore the term and get more of her insights. I think she felt I was testing her and was very nervous in case she said anything that wasn't appropriate. It was a moment that I got very nervous as well.

Memo 2: She has this special pride about her life that it was some how difficult for her to be the subject of any misfortunate and difficulty in life.

Memo 3: She really meant these sentences and it showed by the way she said them. She wasn't afraid of dying, but was afraid of being dependent on others to be looked after.

Participant L: Intra-personal comparison:

007	memo 2	I mean when I think about it, uh I did have a lot of pain, but I had to use these sticks, but after three weeks I was really fine, you know	Intra-personal comparison (4)
031		If I'd been younger, yes I would, but	intra-personal comparison (4) (intra-pc)
061		Participant: That mine was all right. When I came out I had crutches, then that was for a week then I had a stick, that was for a fortnight. I didn't need anything after that. I was fine. So I am lucky, aren't I? (she laughs).	(4) (7)
072		I put weight on (sniffs). I used to be as thin as a lath. I put weight on, doing a bit and having sit a lot, you know and I can't get rid of it, the weight.	(4)
170		and I've never had any illness really. I think I went in hospital when I was young and I had my tonsils out that is about that all	(4)
191		Participant: I'm 79 and I seem to have got on and battled it, but	(4)
192		you never know later on dear, you know (short pause)	
193		I mean as you get older, you get more () don't we?	
206		Actually when I came out I had no pain. From waking up (sniffs) in the hospital I had no pain since.	(4)
207		I just normally can walk up and down stairs, just do anything, bend	(4)
208		first time I told you, didn't I? First time I could bend I washed the kitchen floor three times (they laugh)	(4)
209		I was pleased to be to get down.	(4)
241		Participant: Oh, yes, yes. I mean I couldn't carry a lot.	(4)
243		but I couldn't if I wanted to.	(4)
244		But I could now. You know I'm just really normal, yeah (short pause)	(4)

Participant L: Inter-personal comparison:

032		I've got a cousin, she's 85 and she's marvellous for her age.	inter-personal comparison(5) (inter-pc)
059	memo 7	I am really really pleased with my hip, because I know people who had it done before me and still on sticks, so I'm very lucky, aren't I? When I look back ((laughs)) I am.	(5)
065		Participant: Oh, yes. Two sisters. Yeah, I know one or two and I had a friend over around X Road and she still had a lot of pain when she came out, but she's got better you know (short pause)	(5)
066		so I'm lucky (she laughs).	
078		My husband he was 62 or 3 before he learnt to swim, but I always loved it.	(5)
141		there are thousands like it, aren't they? So you have to put up with it.	(5)
			(7)
168		A lot of people do, don't they? They worry about that, but	(5)
			(7)
181		I've have small problems like anybody, but no I don't have () and that's all you know, yeah.	(5)
196		No, no, but I just wondered, because some people do have both done, don't they?	(5)
200		and she had a hip operation 5 years ago and then she had to go in again for the other one last year, but	(5)
201		she had hers done private	(5)
202		but she's good now, but	(5)
203		hers it took her 6-7 weeks to get over it, which isn't bad, is it? It is not bad.	(5)
204	memo 18	<i>Interviewer: And you were quicker?</i>	(5)
205		Yeah, 3.	(5)
215	memo 20	Participant: It's a pity everybody's not like me.	(5)
259		She's on her own, but	(5)
260	memo 22	she's got a son lives there and his wife and grand children, so (short pause)	(5)

7. Appendix Seven

7.1. Participants' scores on the SF-36

Patient	Gender	Age	Marital status	Employment	PF1	RP1	RE1	GH1	VT1	SF1	BP1	MH1
					PF2	RP2	RE2	GH2	VT2	SF2	BP2	MH2
C	Female	64	Married	Retired (PE teacher)	30	0	33	60	50	50	55	64
T	Male	51	Single	Employed	85	100	100	65	65	100	77	72
E	Female	62	Married	Retired (News agent)	65	25	100	85	50	75	44	92
V	Male	69	Married	Retired (bus driver)	100	100	100	85	100	100	100	100
W	Female	79	Married	Retired (housewife)	30	0	33	65	70	75	66	100
O	Male	73	Married	Retired (policeman)	5	0	33	50	35	37	22	76
M	Male	50	Married	Employed (Business)	10	0	66	60	40	37	44	80
F	Male	67	Married	Retired	15	0	0	60	25	25	22	72
Q	Female	83	Widow	Retired (housewife)	15	0	0	70	30	25	22	76
I	Female	44	Married	Employed	0	0	0	70	45	75	44	72
D	Female	50	Married	Teacher	75	100	100	60	50	100	100	80
H	Female	75	Widow	Retired (hairdresser)	45	25	100	50	65	100	44	92
L	Female	79	Widow	Retired (housewife)	65	100	100	40	60	100	66	88
U	Male	61	Married	Retired (Factory worker)	0	0	0	60	65	12	11	20
R	Female	60	Married	Housewife	20	0	33	20	50	12	44	36
X	Female	77	Widow	Retired (shopkeeper)	0	0	0	70	50	12	11	76
S	Female	71	Widow	Retired (housewife)	5	0	0	50	40	25	88	56
P	Female	74	Married	Retired (housewife)	15	0	33	60	35	25	11	32
Y	Female	69	Married	Retired (hospital worker)	75	50	100	90	50	100	77	80
K	Male	49	Married	Employed (Mechanic)	30	0	100	50	25	12	0	80
					100	100	100	80	90	100	100	96
					0	0	0	35	20	37	22	64
					50	0	100	60	70	75	44	88
					35	100	100	60	40	50	44	48
					100	100	100	100	100	100	100	100
					25	0	0	75	40	37	11	76
					30	0	0	80	40	37	22	76
					15	25	0	30	35	25	22	52
					30	0	0	45	35	100	44	64
					20	0	0	45	50	50	11	68
					75	100	100	65	50	87	88	52
					45	0	0	85	45	37	33	76
					0	0	0	70	20	62	22	84
					10	0	33	90	45	87	33	88
					35	0	66	50	35	100	77	68
					40	0	0	50	50	50	44	56
					40	0	33	60	50	62	55	60
					0	0	0	55	15	37	33	84
					60	100	66	75	70	87	100	96

Table 1: Participants' scores on eight dimensions of the SF-36 ranging from 0 (worst possible) to 100 (best possible) before and after the operation

PF1: Physical functioning
 RP1: Role functioning
 RE1: Role emotional
 GH1: General Health
 CH: Change in Health

VT1: Vitality
 SF1: Social functioning
 BP1: Bodily pain
 MH1: Mental health

PF2: Physical functioning
 RP2: Role functioning
 RE2: Role emotional
 GH2: General Health

VT2: Vitality
 SF2: Social functioning
 BP2: Bodily pain
 MH2: Mental health

Patient	Gender	Age	Marital status	Employment	CHI CH2
C	Female	64	Married	Retired (PE teacher)	3 3
T	Male	51	Single	Employed	2 5
E	Female	62	Married	Retired (News agent)	4 5
V	Male	69	Married	Retired (bus driver)	3 3
W	Female	79	Married	Retired (housewife)	2 2
0	Male	73	Married	Retired (policeman)	3 4
M	Male	50	Married	Employed (Business)	3 5
F	Male	67	Married	Retired	3 3
Q	Female	83	Widow	Retired (housewife)	3 3
I	Female	44	Married	Employed	3 5
D	Female	50	Married	Teacher	3 5
H	Female	75	Widow	Retired (hairstylist)	3 5
L	Female	79	Widow	Retired (housewife)	3 5
U	Male	61	Married	Retired (Factory worker)	3 4
R	Female	60	Married	Housewife	2 3
X	Female	77	Widow	Retired (shopkeeper)	2 3
S	Female	71	Widow	Retired (housewife)	3 3
P	Female	74	Married	Retired (housewife)	3 3
Y	Female	69	Married	Retired (hospital worker)	3 4
K	Male	49	Married	Employed (Mechanic)	2 4

Table 2: Change in Health (CH), identified by the SF-36 transfer question

7.2. Participants' scores on the Oxford Hip Score and the PGI

Patient	Gender	Age	Marital status	Employment	Oxf.1	Oxf.2	PGI
C	Female	64	Married	Retired (PE teacher)	29	15	64%
T	Male	51	Single	Employed	40	14	?
E	Female	62	Married	Retired (News agent)	34	12	80%
V	Male	69	Married	Retired (bus driver)	51	35	38%
w	Female	79	Married	Retired (housewife)	50	41	67%
0	Male	73	Married	Retired (policeman)	46	17	30%
M	Male	50	Married	Employed	36	23	64%
F	Male	67	Married	Retired	46	28	19%
Q	Female	83	Widow	Retired (housewife)	56	29	9
I	Female	44	Married	Employed	49	18	85%
D	Female	50	Married	Teacher	44	12	89%
H	Female	75	Widow	Retired (hairdresser)	51	23	?
L	Female	79	Widow	Retired (housewife)	42	12	?
U	Male	61	Married	Retired	50	30	24%
R	Female	60	Married	Housewife	51		40%
X	Female	77	Widow	Retired (shopkeeper)	39	12	90%
S	Female	71	Widow	Retired (housewife)	31	36	?
P	Female	74	Married	Retired (housewife)	44	24	44%
Y	Female	69	Married	Retired (hospital worker)	40	26	75%
K	Male	49	Married	Employed	46	16	94%

Table 3: participants' scores on the Oxford Hip Score before and after the operation and on the PGI at one year follow-up.

7.3. Areas of life identified by the PGI

Patient	Gender	Age	Marital status	Employment	Important areas of life identified by the PGI
C	Female	64	Married	Retired (PE teacher)	- mobility - pain - areas affected by other health problems
T	Male	51	Single	Employed	- no areas was identified
E	Female	62	Married	Retired (News agent)	- areas affected by other health problems
V	Male	69	Married	Retired (bus driver)	- limited mobility - very light amount of gardening - walking - areas affected by other health problems (arthritis) - non-health areas of life
w	Female	79	Married	Retired (housewife)	- walking - housework - feeling tired - pain - ? - non-health areas of life
0	Male	73	Married	Retired (policeman)	- areas affected by other health problems (arthritis)
M	Male	50	Married	Employed	- not able to play squash - areas affected by other health problems (arthritis) - non-health areas of life
F	Male	67	Married	Retired	- unable to walk far - worry about future - limping - unable to play sport - areas affected by other health problems (feet and back) - non-health areas of life (depression)
Q	Female	83	Widow	Retired (housewife)	?
I	Female	44	Married	Employed	- worried about future - sporting and activities - areas affected by other health problems - non-health areas of life
D	Female	50	Married	Teacher	- leisure time - work - home work - teaching of sport - shopping - non-health areas of

					life
H	Female	75	Widow	Retired (hairdresser)	- being independent - areas affected by other health problems (back pain)
L	Female	79	Widow	Retired (housewife)	- ?
U	Male	61	Married	Retired	- work - walking distance - getting out of bath - kneeling - climbing steps and decorating - areas affected by other health problems - non-health areas of life
R	Female	60	Married	Housewife	- tired - not being active - areas affected by other health problems - non- health areas of life
X	Female	77	Widow	Retired (shopkeeper)	- walking - change in life - areas affected by other health problems - non-health areas of life
S	Female	71	Widow	Retired (housewife)	?
P	Female	74	Married	Retired (housewife)	- walking - kneeling - climbing - areas affected by other health problems (arthritis)
Y	Female	69	Married	Retired (hospital worker)	- areas affected by other health problems - non-health areas of life
K	Male	49	Married	Employed	- social activities - work - non-health areas of life

Table 4: Areas of life identified by the participants on the PGI

7.4. Coping strategies and life domains identified through narrative interviews

Patient	Gender	Age	Living status	Employment	Coping strategies	Identified areas of life
C	Female	64	Married	Retired (PE teacher)	<ul style="list-style-type: none"> - problem focused -emotion focused -comparative 	<ul style="list-style-type: none"> - physical - emotional - social - pain -family/relationship - multiple health problems -job - previous experience of arthritis - medications and painkillers - having choices in life - hip causing other problems - post-op long term care - inheritance
T	Male	51	Single	Employed	<ul style="list-style-type: none"> - self-oriented - emotion focused - comparative 	<ul style="list-style-type: none"> - physical - emotional - social - pain - family/relationships - operation experience -job - the effect of time on pain and functional performance - satisfaction with hospital care

E	Female	62	Married	Retired (News agent)	- self-oriented - problem focused - emotion focused - comparative	- physical - emotional - social - pain - family/relationships - operation experience - multiple health problems -job - satisfaction with hospital care - having choices in life - security - appearance - independency - operation experience - post-op long term care
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V	Male	69	Married	Retired (bus driver)	- self-oriented - problem focused - emotion focused - comparative	- physical - emotional - social - pain - family/relationships - operation experience - future - independency - beliefs - multiple health problems -job - satisfaction with hospital care - post-op long term care - inheritance - work-related health condition
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W	Female	79	Married	Retired (housewife)	- comparative	- physical - pain - family/relationships - operation experience - multiple health problems -job - satisfaction with hospital care
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0	Male	73	Married	Retired (policeman)	- problem focused - emotion focused - comparative	- physical - social - pain - family/relations - operation experience - post-op long term care - multiple health problems -job - satisfaction with hospital care
M	Male	50	Married	Employed	- problem focused - emotion focused - comparative	- multiple health problems -job - satisfaction with hospital care
F	Male	67	Married	Retired	- problem focused - comparative	- physical - emotional - social - pain - future - multiple health problems - operation experience
Q	Female	83	Widow	Retired (housewife)	- problem focused - emotion focused - comparative	- physical - emotional - social - post-op long term care - pain - family/relations - operation experience - multiple health problems -job - satisfaction with hospital care
I	Female	44	Married	Employed	- problem focused - comparative	- physical - appearance - pain
D	Female	50	Married	Teacher	- self-oriented - emotion focused - comparative	- physical - social - pain - operation experience - future -job - the effect of time on pain - satisfaction with hospital care

H	Female	75	Widow	Retired (hairdresser)	- emotion focused - comparative	- physical - social - emotional - post-op long term care - family/relations ships - multiple-health problems -job - medications and painkillers - operation experience - independency - work-related health condition - having choices in life
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L	Female	79	Widow	Retired (housewife)	- problem focused - emotion focused - comparative	- physical - emotional - social - post-op long term care - pain - family/relations ships - multiple health problems -job - the effect of time on pain - satisfaction with hospital care - operation experience - independency - inheritance
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U	Male	61	Married	Retired	- comparative	- physical - social - pain - operation experience - multiple health problems - hip causing other problems -job - the effect of time on pain and functional performance - satisfaction with hospital care - medications and painkillers
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R	Female	60	Married	Housewife	- emotion focused - comparative	- physical - emotional - post-op long term care - previous experience of arthritis - pain - family/relations ships - inheritance - multiple health problems -job
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X	Female	77	Widow	Retired (shopkeeper)	<ul style="list-style-type: none"> - self-oriented - problem focused - emotion focused - spiritual - comparative 	<ul style="list-style-type: none"> - physical - social - appearance - pain - family/relationships - operation experience -job - the effect of time on pain and functional performance - satisfaction with hospital care - work-related health condition - previous experience of arthritis
S	Female	71	Widow	Retired (housewife)	<ul style="list-style-type: none"> - self-oriented - problem focused - emotion focused - spiritual - comparative 	<ul style="list-style-type: none"> - physical - emotional - social - post-op long term care - previous experience of arthritis - pain - family/relationships - operation experience - future - multiple health problems -job - the effect of time on pain and functional performance - satisfaction with hospital care - medications and painkillers - independency - hip causing other problems
P	Female	74	Married	Retired (housewife)	<ul style="list-style-type: none"> - problem focused - emotion focused - comparative 	<ul style="list-style-type: none"> - physical - social - post-op long term care - family/relationships - multiple health problems -job - satisfaction with hospital care

Y	Female	69	Married	Retired (hospital worker)	- self- oriented - problem focused - comparative	- physical - emotional - social - previous experience of arthritis - pain - family/relation ships - inheritance - multiple health problems - hip causing other problems - job - he effect of time on pain and functional performance - satisfaction with hospital care
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K	Male	49	Married	Employed	- problem focused -emotion focused -comparative	- physical - emotional - pain - future - the effect of time on pain
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Table 5: Coping strategies and various life domains identified through narrative interviews

8. Appendix Eight

SHEFFIELD HALLAM UNIVERSITY
School of Health and Social Care

NORTHERN GENERAL HOSPITAL

Total Hip Replacement Outcomes Study

Information for Participants

You are invited to take part in a study that is looking at how much the information that is routinely collected when people have hip replacement surgery actually tells us about the effect of the operation on people's lives.

"Why have you asked me to take part in this study?"

Patients' views of treatment are very important to the modern NHS and we need evidence that the treatments we use help improve their lives. You have already provided information for the Exeter Study on the scales that measure the physical and functional impact of hip replacement surgery. However, we also know from people with osteoarthritis and rheumatoid arthritis who have taken part in other *research* that loss of independence and social roles is very important to them. Therefore, we consider that the extent to which the surgery can be deemed a success is dependent not only on a patient's ability to walk and undertake other activities but also on how it has improved the quality of their lives. Consequently, we are asking patients like you to tell us how hip replacement has affected important areas of their lives and whether the outcome has lived up to their expectations.

"How is this study different from the Exeter Study that I have already agreed to take part in?"

This study records patient's' views of the outcome from surgery and compares them with the measurements collected for the Exeter Study to give a bigger picture of effects of hip replacement.

"How long will the study last?"

The whole study will last over a year but your involvement will be for about 2 months.

“What will it involve?”

You will be asked to fill in a questionnaire at the assessment when you come for your 1-year follow-up appointment. First of all, you will be asked to name five important areas in your life that were affected by your hip condition. You will be given a list to choose from if you find it difficult. Then you will be asked to give each area a score from 0-10 on a scale of importance to you. Finally, you will be asked to give points for how these areas have improved.

While the researcher is assisting you to fill in the questionnaire, she will tape record what you say in order to understand your experiences as a patient. She will send you typed copies of what is recorded so that you can make changes if you wish.

“What if I do not wish to take part?”

This will not affect your treatment in any way.

“What if I change my mind during the study?”

You are free to withdraw from the study at any time without affecting your management.

“What will happen to the information from the study?”

All information will be kept strictly confidential to the researcher and her supervisors. The tapes will be numbered and kept in a locked drawer away from the list of names. They will be destroyed at the end of the study. You will be informed of the results of the study if you wish.

“What if I have further questions”

Telephone Nasrin Nasr(0114 225 2554)

or let the arthroplasty specialist nurse know

or leave a phone message with Mr Stockley's secretary (0114 271 4955), Mr Hamer's secretary (0114 226 6260) or Mr Kerry's secretary (0114 226 6259).

Participant number:

SHEFFIELD HALLAM UNIVERSITY
School of Health and Social Care

NORTHERN GENERAL HOSPITAL

Total Hip Replacement Outcomes Study

Patient Consent Form

I have read the information sheet and understand that I am being asked to take part in research which will compare data being collected for the Exeter Study with my views of how the hip replacement operation has affected my life. I acknowledge that compensation will not be offered or provided for participation.

I understand that my participation is voluntary and that I may withdraw from the study at any time without affecting the quality of the health care I will receive. I understand also that my participation will not affect the length of time I wait for any treatment.

I understand that I will be able to see copies of the information I provide and, if necessary, change what I am recorded as saying. I understand that the information will be kept on paper and computer database and that access will be restricted to the researcher and her supervisors. I understand also that they will treat all information in the strictest confidence and will not use it for any other purpose than the study.

I agree to take part in the study.

Patient's name:..... Signature:.....

Date of birth: Date of signature:.....

Witness's name: Signature:

Relative/Friend/Other:..... Date of signature:

North Sheffield Ethics Office

1st Floor Vickers Corridor

Direct Line: 0114 271 4894 or 271 4011

Fax: 0114 256 2469

Email: Sue.Rose@sth.nhs.uk

Northern General Hospital

Herries Road

Sheffield

S5 7AU

CMHN/SR/2/7/01

NS200171056

(Please quote in all correspondence)

5 September 2001

Nasrin Nasr
PhD Student
348 Exeter Drive
SHEFFIELD
S3 7TY

Dear Ms Nasr

**Re: Evaluation of the goodness of fit of standardised outcome measures to the patients' perceptions of outcomes from arthroplasty of the hip joint (total hip replacement)
NS200171056**

Thank you for your letter of the 3 September 2001 and enclosed copy of indemnity arrangements.

All outstanding issues have now been satisfactorily addressed and I can confirm that the project has full approval on behalf of the North Sheffield Research Ethics Committee.

Yours sincerely

PP C M H Newman
HONORARY SECRETARY - RESEARCH ETHICS COMMITTEE
Senior Lecturer in Cardiology/Honorary Consultant Physician

Cc Professor A Parry