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**A Grounded Theory Study of the Role of
Disclosure in the Management of Long-Term
Conditions: Who Needs to Know?**

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A thesis submitted in partial fulfilment of the requirements for
the degree of Doctor of Philosophy in Nursing

University of Warwick, Department of School of Health and
Social Studies

January 2009

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Acknowledgements

I could not have completed this thesis without the help and support of many people. In particular I would like to thank Professor Kate Seers for her guidance and enthusiasm for this project. I would also like to thank Dr Liz Tutton for her support. I would like to thank all of my colleagues at the RCN Institute: Dr Carol Edwards, Dr Sophie Staniszewska, Jackie Chandler-Oatts, Dr Claire Hawkes, Rachel Taylor, Kate Monks, Jo Brett, Marina Fontenla, Annelie Guard, Tracey Mitchell, Dr Sandra Carrivick and Emma Nawrocki. I am most grateful to the health professionals and patient support group leaders who assisted with the study and whose names I have not included to preserve the confidentiality of the participants. I would also like to thank Dr Brian Williams, Professor Joachim and Professor Acorn for allowing me to reproduce their work in this thesis.

On a personal level I am grateful to the many people who have supported me on the journey: George, Chris and Margaret Henderson, Lesley, Louis and Simon Carter, Dee Stanfield, Dr Sarah Ledingham, Mr Howard Straughen Simpson, Roz Coombes, Jen Simmons, Liz Miller, Stavros Petrou, Helen Azer, Steve Bruster, Chris Huntingford, Katie Howat, Caroline Jenkinson and many others. Lastly I am particularly grateful to those who participated in the study.

Declaration

This declaration states that the thesis is my own work. This thesis has not been submitted for a degree at another university.

Abstract

A high and increasing proportion of people in the United Kingdom are living with a long-term condition (DH, 2005a). The National Health Service is facing the challenge of increased pressure on its service provision. Government Policy has placed emphasis on supporting individuals to self-care (Department of Health, 2005a, c). However, there are specific challenges associated with living with a long-term condition, and in particular the psychosocial aspects of illness when set alongside a clinical approach to care (Gabe et al, 2004, Bury et al, 2005) It has been argued that disclosure of illness may in itself be a self-care strategy (Munir et al, 2005). However, to date individuals' experiences of disclosure of long-term conditions are neither clearly defined nor its role in managing a long-term condition fully understood. The aims of the study were to explore the role of disclosure in the management of a long-term health condition. The study drew on constructivist grounded theory (Charmaz, 2006) undertaking thirty-five in-depth qualitative interviews (fifteen people living with epilepsy, and twenty people living with type 1 diabetes) recruited from patient support groups and clinical nurse specialist's clinics. This study identified that strategies of disclosure are not necessarily fixed but may be subject to change over time. "Learning about disclosure" is an integral part of living with a long-term condition. Three key disclosure roles were identified: (1) access to self-care and social support, (2) non-disclosure (concealment) of the condition to protect one's identity from stigma. (3) redressing myths about the condition in advance: to avoid perceived stigma.

The findings provide important insights that could enable health care professionals to develop more of an emphasis on including disclosure as an issue when talking to

patients about managing type 1 diabetes and epilepsy and this is also relevant to a broad spectrum of long-term conditions.

1.0 CHAPTER ONE: INTRODUCTION

1.1 Introduction

Disclosure, the act of telling others about one's health condition may at first appear to be a simple process, yet "who" to tell, "when" to tell and "how" to tell are complex decisions for those people who are living with long-term conditions. The current role which disclosure plays in the lives of those living with a long-term condition is poorly understood and this thesis addresses this gap in understanding.

The introductory chapter presents an overview of the rationale for the study, the research objectives, and the structure of the thesis.

1.2 The Rationale for the Study

1.3 Long-term Conditions

There are a large number of people in the UK living with a long-term health condition. It was recently reported that as many as seventeen and a half million people in the United Kingdom are living with long-term health conditions such as diabetes and epilepsy (Department of Health, 2005a). As a consequence of these high numbers, it has been argued that the National Health Service is facing a new challenge as to how its services will cope to meet the: *"needs and expectations of increasing numbers of people with long-term medical conditions"* (Department of Health, 2005b, p7). Recent Government Policy has placed increasing emphasis on self-care approaches to manage long-term conditions (Department of Health, 2005a, c). Indeed as many as 70-80% of those living with a long-term condition are arguably able to self-care (Department of Health, 2005a). It has been proposed that a feature of self-care may include gaining appropriate social support (Clark et al 1991, Gallant, 2003, Munir et al, 2005).

Living with a long-term condition can be particularly challenging for individuals because they are unlikely to be “cured.” As a consequence, daily management of long-term conditions may be required (LTCA, 2005; Gabe et al, 2004, Holman and Lorig 2000). As Holman and Lorig (2000) note: “*with chronic disease, the patient’s life is irreversibly changed*” (p.527).

1.4 Disclosure of Long-term Conditions Research

Despite the relatively high number of people living with a long-term condition and the resulting challenges which they face, there is little understanding of disclosure of long-term conditions. The means by which individuals decide to disclose their condition and how they cope with the responses to such disclosure, particularly for those with conditions which may not be immediately obvious to others, is not evident (Joachim and Acorn, 2000). For example, a gap has been left in terms of: “*the decision and experience of disclosing one’s illness to...friends, family or work colleagues*” (Williams and Healy, 2001 p109). As a consequence, the nature and role of disclosure remain unclear.

1.5 The Research Gap

Choosing whether to disclose one’s illness to another is an important decision to take for those with long-term conditions (Joachim and Acorn, 2000). However, many of the studies on disclosure have adopted a quantitative approach to determine factors which may influence decisions to disclose (Beatty, 2004, Munir et al, 2005,). As a consequence, the decisions and rationale for disclosure remain unclear. Furthermore, previous studies on disclosure of illness are often set within specific contexts such as the workplace (Fesko, 2001, Beatty, 2004, Munir et al, 2005), yet it is important to explore the role of disclosure across different settings. There have

been a number of studies of disclosure in the field of psychology (Jourard, 1971, Pennebaker et al, 1986, 1988, 1990, 1999, Derlerga et al, 1993). However psychological research has focused upon the area disclosure in relation to revealing personal information about the “self” rather than disclosure of illness. Psychological studies have also predominantly adopted objective measurement approaches such as questionnaires to study disclosure, leading to a gap in subjective understanding (Jourard, 1971, Derlerga, 1979, Pennebaker et al, 1988, 1990, 1999). There is therefore a need for additional research on individuals’ experiences of disclosure of illness. Several studies have called for additional research on disclosure within the field of health care research (Joachim and Acorn, 2000, Williams and Healy, 2001). The aim of this study is to contribute towards filling this gap in research.

As managing long-term conditions are now considered to be a key challenge for the National Health Service, understanding how individuals cope with this and the role which disclosure plays in assisting in this process may lead to an improvement in patient care. In the context of current policy which stresses the importance of self-care and the provision of “patient-centred” care, clarification and theoretical development of the role of disclosure would be particularly timely.

1.6 Research Objectives

This study has been designed to address and explore the following research question:

What is the role of disclosure in managing a long-term condition?

1.7 Structure of the Thesis

The remaining thesis chapters have been organised as follows:

Chapter Two presents the literature review. It begins with a review of government policy on long-term conditions, then presents existing evidence on disclosure, and

identifies gaps in the research. The chapter concludes by arguing that exploratory research is required into the role of disclosure in managing a long-term condition using an inductive, qualitative approach.

Chapter Three presents a consideration of the most appropriate research methodology to address the aims of the study. Previous studies on disclosure have focused upon objective measurement, rather than subjective understanding; in other words using questionnaires rather than qualitative interviews (Munir et al 2005, Beatty, 2004). Here it is argued that an exploratory, qualitative research methodology is best suited to the study because it will provide insight into the role of disclosure of illness from the individual's perspective. Grounded theory is identified as an appropriate approach to adopt in the current study. An overview of the debates within grounded theory is presented. Following this it is concluded that constructivist grounded theory is the most appropriate methodological framework for the current study (Charmaz, 2006).

Chapter Four presents the methods. The methods employed in this study are open-ended, qualitative interviews conducted with participants living with either type 1 diabetes (insulin dependent) or epilepsy. Interviews with twenty members of patient support groups, and fifteen attendees at clinical nurse specialist clinics were undertaken. The process of conducting the interviews is discussed and the implications for fieldwork issues are considered.

Chapter Five presents the findings of the study concerning the role of disclosure as follows. The study findings provide valuable insights into the nature of disclosure, the process by which disclosure occurs and the role of disclosure in the lives of those living with type 1 diabetes or epilepsy. **Section one** presents the nature and the

process of disclosure across both conditions illustrating that it is deemed to be a highly personal matter, the process of disclosure illustrating that disclosure may occur in a broad range of ways. **Section two** presents mediating issues around disclosure which influence decisions to disclose or not. **Section three** presents an overview of the challenge of disclosure: “who needs to know?” identifying the role of disclosure as facilitating access to self-care and social support. The role of disclosure in the workplace is set out. **Section four** presents findings which identify a process of “learning about disclosure”: disclosure is a dynamic process subject to change over time. Firstly patient support group findings are set out illustrating the role of strategic disclosure and redressing myths about the condition in advance. Secondly, nurse specialist findings are set identifying the role of non-disclosure in order to avoid perceived stigma. Finally, **Section five** set outs views on information needs, sources of information and the role of patient support groups and nurse specialist clinics in the provision of information on disclosure.

In summary, three roles for disclosure are identified: (1) access to self-care and social support, (2) redressing myths about the condition in advance: “preventive telling” to avoid perceived stigma and (3) non-disclosure (concealment) of the condition to protect one’s identity from stigma. The generic findings are further explored in the discussion chapter.

Chapter Six presents the discussion and study conclusions as follows: there are two parts to this chapter. **Part one** of this chapter sets out a discussion of the findings, within the context of current evidence and health care agenda. A conceptual framework of disclosure is presented.

The conceptual framework of disclosure has six elements: 1. **Nature:** the essence of disclosure, (what?). 2. **Process:** the manner in which disclosure occurs, (how?), 3. **Context:** in which disclosure occurs, (where?), 4. **Mediators** which are taken into account when considering disclosure, 5. The **Role** of disclosure, (why?) its purpose and role, 6. **Living with a long-term condition:** the overarching challenges of living with a long-term condition including: the enduring nature of the condition, managing the medical, managing the social elements of the condition, and managing disclosure: namely the process of “learning about disclosure” over time.

Part two of this chapter sets out the credibility of the current study, the lessons learned from the study and reflects upon the process of adopting constructivist grounded theory as the methodological framework for this study. The specific implications of the study findings for health care practice, policy, education and future research are presented. Finally the study conclusions are set out noting that living with a long-term condition is an increasingly common feature in individuals’ lives and a crucial element of managing a long-term condition includes the process of “learning about disclosure”.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter argues that to date disclosure of long-term conditions is neither clearly defined as a concept nor fully understood and so its role in relation to living with and managing a long-term condition requires additional exploration. In this chapter I review the literature on disclosure of long-term conditions and in particular illustrate the need for further research of the role which disclosure plays in the field of health care research.

Firstly, this chapter sets the scene for the study noting that a high proportion of people in the United Kingdom (UK) are living with a long-term condition (Department of Health, 2005a). The Government's policy response to long-term conditions is set out including the rationale for individuals to increase levels of self-care. Secondly, there are particular challenges associated with living with a long-term condition and so key features of enduring conditions are discussed, and in particular the relevance of understanding the psychosocial aspects of illness set alongside a clinical approach to care (Gabe et al, 2004, Bury et al, 2005a). It has been argued that disclosure of illness may in itself be a self-management strategy (Munir et al, 2005). Whilst there has been considerable sociological research on living with long-term conditions, the role of disclosure has been arguably neglected. Thirdly, the limitations of existing studies of disclosure of illness with respect to the measurement and definitions are also discussed. Finally the argument is presented for the need for further research on the role of disclosure within the lives of those living with epilepsy or type 1 diabetes.

2.2 Sources of Literature

The role of the literature review in this study is to set out the broad parameters of the study and in order to: “*critique earlier studies and theories and to make comparisons*” (Charmaz, 2006, p164.). This includes a review of studies across disciplines.

The following electronic databases were searched: EMBASE, MEDLINE, PSYCHINFO, CINAHL, BRITISH NURSING INDEX, AMED, INDEX TO THESES and DISSERTATION ABSTRACTS. This is set out in further detail in the appendix (Appendix 1). The term disclosure is used to identify studies but additional terms were also used and referred to as MESH terms and free text terms. For example: Self-Disclosure, Concealment, Truth-Disclosure, Secrets.

The bibliographies of all the articles/books were reviewed to identify relevant material. The keywords used in relevant journal articles were noted to assist accessing relevant information in the future. Hand searches of relevant journals were undertaken (Journal of Advanced Nursing, Social Science and Medicine, British Medical Journal). Relevant websites were also searched; MIND UK, Disability UK, Diabetes UK, Epilepsy Action, and the Department of Work and Pensions in order to identify information on workplace legislation for those living with long-term conditions.

2.3 Setting the Scene: The Context for Further Research on Long-term Conditions

2.4 The Rise in the Number of People Living with a Long-term Condition

It has been recently reported that as many as seventeen and a half million people in the UK are living with a long-term condition (Department of Health, 2005a). Long-

term conditions are on the rise not only within the United Kingdom and are among the leading reported causes of illness and deaths globally (Horton, 2005). The World Health Organisation suggests that such conditions will be the leading cause of disability by the year 2020 (Department of Health, 2004). There may be several reasons for this increase. The UK population is ageing and at the same time fertility rates are decreasing leading to significant demographic changes (Department of Health, 2008, Gabe et al, 2004). Older people are more likely to have a long-term condition: as many as 75% of those aged over seventy-five years old. Furthermore, 45% of those aged over seventy-five years old are likely to have co-morbidities: more than one long-term condition (Department of Health, 2005a, 2004). As a consequence of people living longer, long-term conditions associated with the elderly such as arthritis, stroke, dementia, Parkinson's disease, heart disease and cancer have increased (Gabe et al, 2004, Department of Health, 2001a,b). Estimates suggest that the proportion of people aged sixty-five years and over living with a long-term condition will double by the year 2030 (Department of Health, 2004). However, long-term conditions are not confined solely to older people. Younger people are affected by long-term conditions. For example, Multiple Sclerosis affects around 85,000 people each year and is most likely to be diagnosed in individuals between the ages of twenty and forty-years old (Multiple Sclerosis Society, 2008, Department of Health, 2001a). Furthermore, 1.5 million children are living with asthma and around 14,500 children living with arthritis (Department of Health, 2001b). People of all ages and backgrounds are affected by a range of conditions (LTCA Website, 2005). The Long-term Conditions Alliance (LTCA) a charity whose remit is to represent the needs of those with such conditions, and advise policy makers has over one hundred member organisations representing diverse

conditions including: Acquired Immune Deficiency Syndrome (AIDS), cancer, stroke and diabetes (LTCA Website, 2005).

The increase in those living with long-term conditions has had an impact upon health services and therefore treatment costs, as they are higher users of both primary and secondary care (Department of Health, 2005a, 2008) and this also applies to both social and community care services, such as community nurse services (Department of Health, 2008). These trends are likely to increase in line with the rise in the number of older people in the population (Department of Health, 2008). Indeed, around 80% of visits to General Practitioners and eight of the top eleven causes of hospital admissions concern people living with long-term conditions (Department of Health, 2004, 2005a). A significant proportion of health care resources are therefore spent upon those living with long-term conditions: around 69% of the health and social care budget in England (Department of Health, 2008). The high costs of caring for large numbers of people with such conditions has led to a number of policy initiatives being developed to manage the financial implications of this rise on the health care budget.

2.5 The Challenges of Living with a Long-term Condition

Long-term conditions can be particularly challenging because they are unlikely to be “cured” and therefore likely to remain a “long term” and enduring feature of the individual’s life (Gabe et al, 2004, LTCA Website, 2005, Bury et al, 2005a). Long-term conditions are defined by the government as: “*those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies*” (Department of Health, 2008, p10). As Holman and Lorig (2000) note: “*With chronic disease, the patient’s life is irreversibly changed*” (p.527). The focus shifts

therefore from curing the condition to learning how to manage it. Daily management of long-term conditions may be required such as taking medication and lifestyle adjustments.

2.6 The Policy Response to the Rise in Long-term Conditions

The rise in the numbers of people experiencing long-term conditions has become an area of concern for policy makers and it has been argued that the National Health Service is facing a test as to how its services will cope: “*The NHS faces the challenge of responding to the needs and expectations of increasing numbers of people with long-term medical conditions*” (Department of Health, 2005d p7.). In order to meet the challenge of long-term conditions there have been numerous legislative documents published on this subject (Department of Health, 2001b, 2004, 2005a,d,e,f, 2008). The following policy documents relate to legislation in England and Wales. The publication of the policy documents, *Saving Lives; Our Healthier Nation* (Department of Health, 1999) and, *The NHS Plan* (Department of Health, 2000) were key documents which set out the Government’s agenda for a National Health Service and argued that health services should be: “*designed around the patient*” (Department of Health, 1999, 2000, 2005b). The White Paper, *Our health, our care, our say: a new direction for community services* (Department of Health, 2006) sets out to give people greater participation by involving their views in the provision of services and the NHS Plan and White Paper legislative documents are relevant to long-term conditions because they underpin the need to provide care to this group. In the context of legislation which places increased emphasis upon addressing the needs of service users, research which can further explore the means by which they manage such conditions may be particularly timely. In the next section I go on to discuss the introduction of policy supporting the self-care of long-

term conditions.

2.7 The Rationale for Self-Care

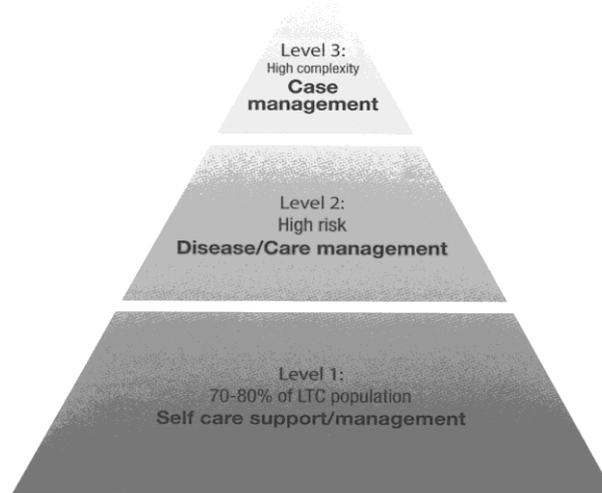
A key element of *The NHS Plan* (Department of Health, 2000) included the promotion of self-care to aid the development of patient-centred services. *The National Service Framework for long-term conditions* (2005) and *The NHS Improvement Plan* (Department of Health, 2004) further set out an agenda to improve self-care of long-term conditions (Department of Health, 2005d). Self-care is defined in policy documents as related to daily living: “*It is the care taken by individuals towards their own health and well being, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities*” (Department of Health, 2005f p.1). Government policy also defines self-care to include eating healthily, exercising regularly, limiting alcohol consumption and refraining from, or giving up smoking (Department of Health, 2005f). However, the extent to which these goals are achievable is **questionable** given that the symptoms of many long-term conditions may limit their ability to undertake these actions. For example conditions such as chronic pain may sometimes prevent individual’s from participating in exercise (Diamond and Coniam, 1997).

Self-care is presented in government policy in terms of “enabling” those living with long-term conditions: “*Promoting independence, empowering patients and allowing them to take control of their lives, and prolonging and extending the quality of life*” (Department of Health, 2005a, p.7). The underlying message of this definition of self-care is that those living with long-term conditions have a role to play in improving their quality of life. Through learning skills to assist them to manage their

condition, they have the potential to improve and extend their quality of life with the possibility of minimising the deterioration of the condition (Department of Health, 2001a). However this generic approach may not be applicable to the diverse range of conditions and individuals' experiences of living with long term conditions. Despite the renewed focus of policy makers the concept of self-care is not new but rather has existed for many years in the lives of those living with long-term conditions (Bury et al, 2005a). The increasing number of people living with long-term conditions has also led to a call for greater recognition of the key role which the patient plays in the management of their health care. As Holman and Lorig (2000) note: "*health care can be delivered more effectively and efficiently if patients are full partners in the process*" (p526). The Government's policy on self-care appears to be resource driven and emanating from financial concerns over the increase in the use of health services rather than as a consideration from the patients perspective. The Government has set targets to reduce the number of contacts people living with long-term conditions have with services; visits to general practitioner by 24% to 69% and hospital admissions by 50% (Department of Health, 2008). However, the diverse range and symptoms of long-term conditions have not been fully taken into account in such policy documents which have a generic approach yet strongly argue the relevance of "self-care" in the daily lives of individuals (Department of Health, 2005a, e).

Different interventions are thought to be appropriate for those living with long-term conditions and a three-tiered model was developed and outlined in the Department of Health (2005a) policy document: *Supporting People with Long-term conditions, An NHS and Social Care Model* (Figure 1).

Figure 1 The NHS and Social Care Long-term Conditions Model (Department of Health, 2005a)



“**Level 3: Case management** - requires the identification of the very high intensity user of unplanned secondary care. Care for these patients is to be managed using a community matron or other professional using a case management approach, to anticipate, co-ordinate and join up health and social care.

Level 2: Disease-specific care management - This involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Frameworks and Quality and Outcomes Framework.

Level 1: Supported self-care - collaboratively helping individuals and their carers to develop the knowledge, skills and experience to care for themselves and their condition effectively”.

(Figure reproduced from: Supporting People with Long-term conditions, An NHS and Social Care Model, Department of Health, 2005a, p10).

A new nursing role has been specifically developed implying that long-term conditions are an area of concern for the government. The new post of ‘community matron’ was set out in the *NHS Improvement Plan* (Department of Health, 2004) and created to explicitly address the management of long-term conditions. The role is to provide advanced clinical nursing skills and a case management approach for those with long-term conditions at risk of hospitalisation, co-ordinating both health and social services care (Department of Health, 2005d, University of the West of England, 2007).

The intention is that community matrons will be in regular contact with those individuals who are considered to be high users of health care and their role is to enable patients to be treated at home rather than in hospital (Department of Health, 2007a). An evaluation of the delivery of the national pilot education programme to prepare nurses to take up the role of community matrons has been conducted (University of the West of England, 2007). The evaluation found that patients reported to nurses that the community matrons’ role had improved their quality of life. However the community matrons stated that they faced organisational challenges when seeking to co-ordinate both health and social care services (University of West of England, 2007).

Policy documents have placed an increasing focus on supporting the majority of those living with long-term conditions to self-care: 70-80% of the population (Department of Health, 2005a). Given that there are many different kinds of long-term conditions it is questionable the extent to which such a large group might be able to self-care or be informed as to what self-care constitutes.

Against the backdrop of proliferation of policy on self-care, public attitudes to self-

care, and what it means to individuals, remains poorly understood (Ellins and Coulter, 2005). Indeed, there is a lack of consensus regarding what the terms self-management or self-care constitute (McGowan, 2005, Coulter and Ellins, 2006). These terms are frequently employed interchangeably yet they are not the same (Coulter and Ellins, 2006). As McGowan (2005) notes: *“to date there is no “gold standard” universally accepted definition of self-management...several terms are used (and) include: self-management preparation/training: patient empowerment; and self-care...the terms imply varying specification regarding attributes, roles and responsibilities of both people with chronic health conditions and health care providers (p1).*

Studies suggest that self-care of a condition may not be a straightforward process because it involves understanding and reacting to symptoms as well as adopting medication regimes (Clark et al 1991, Gallant, 2003). Large scale quantitative surveys of public attitudes to self-care suggest that whilst some groups want to self-care, certain groups may need additional assistance in this area (Department of Health, 2005c, Ellins and Coulter, 2005). These may be groups such as the elderly, ethnic minorities and those of low socio-economic status who may be in poor health (Department of Health, 2005c). Overall, Ellins and Coulter, (2005) note: *“relatively little is known about the capacity of patients and the public to be successful managers on their health and healthcare” (p31).* A telephone survey to explore public attitudes to self-care was conducted although it had a low response rate (19%) and so the results may not be generalisable (Ellins and Coulter, 2005). Furthermore the format of the questions was pre-fixed and so the breadth of individuals’ subjective experiences of self-care may not have been fully captured (Ellins and

Coulter, 2005). However it is one of the few studies which has examined public attitudes to self-care.

There does appear to be a gap between the policy agenda and the everyday experiences of living with a long-term condition. For example, the policy documents have presented a generic approach to the management of all long-term conditions and does not acknowledge their diversity such as complex medication regimes, diverse range of symptoms, ages and access to services (Department of Health, 2005a,e). It may be important to do so however, given that the self-care needs of an individual with diabetes may differ substantially to those of an individual living with epilepsy. The complex and evolving symptoms of managing certain long-term conditions do not appear to have been taken into account yet they may limit an individual's ability to self-care.

2.8 Self-management Training Programme

The policy document *The Expert Patient: a New Approach to Chronic Disease Management for the 21st Century* recommended the introduction of a self-management training programme the *Expert Patient* to the NHS (Department of Health, 2005b).

The *Expert Patient Programme* is a six week course teaching self-care skills and is an adapted version of the Chronic Disease Self-management Programme developed by Kate Lorig and colleagues at Stanford University, California, (Lorig et al 1999). It is a lay-led rather than health professional-led programme that follows a scripted course and is open to anyone with a long-term condition: it is not condition specific.

It sets out to provide “*confidence, skills and knowledge*” in order to assist the patient to manage their condition (Expert Patient Website, 2005). One of the areas which it

covers is “communication” with family, friends, and health professionals. However the intention of the communication training is unclear, for example if it is to garner social support or whether it covers areas such as how to disclose one’s condition to others.

The self-management training is underpinned by Bandura’s (1997) psychological concept, “self-efficacy” the intention of which is to build confidence and help individuals to set goals and achieve tasks (Bandura, 1997). However the group settings in the *Expert Patient Programme* may not be appropriate for all those living with long-term conditions. Also, setting psychological goals may bear little relation to the practical challenges they face in living with the condition on a daily basis.

Overall, the evaluation of the self-management courses has been conducted primarily in the United States in the form of large randomised controlled trials (Lorig et al 1999). Limited work was undertaken within the United Kingdom health care context prior to their introduction. Studies which have evaluated the effectiveness of such courses have focused only upon the short term, rather than the long-term outcomes (Bury et al, 2005a). Therefore there is limited evidence to support the introduction of such courses to England. Furthermore those who join the groups are not necessarily typical of those living with a long-term condition because they are “self-selecting” and so evaluations may not capture the diverse range of views of what it means to live with a long-term condition.

Since the introduction of the courses the report of the evaluation of the *Expert Patients Programme* in England has been published, highlighting a number of limitations to the courses (Rogers et al, 2006). The qualitative research element of the evaluation found that attendees felt that the course did not assist them in the

development of new self-care approaches but rather re-affirmed their current self-care strategies. Participants also criticised the generic approach of the course, arguing that a condition specific approach would have been more helpful.

The findings from the randomised controlled trial element of the evaluation found no significant reduction in the use of primary or secondary care services amongst course attendees (Rogers et al, 2006). Overall, the evaluation notes the narrow nature of the course and the fact that it: *“does not currently acknowledge the broader social issues and needs relevant to living with a long-term condition”* (Rogers et al, 2006, p5).

The introduction of the courses does however suggest that policy makers accept that individuals need to be supported in managing their condition. Whilst the courses may prove beneficial to some, they may also exclude large sections of those living with long-term conditions. For example, those who are unable to travel as a result of their condition, and those undergoing intensive treatment. Furthermore, some people living with a long-term condition may not wish to attend a group meeting. Also it is unclear the extent to which disclosing to others about long term conditions is covered and since the course is scripted there may be little opportunity to diverge from key topics.

In summary, overall, policy documents suggest that a range of tools and strategies are required to manage one's health. These involve making decisions, planning ahead, managing symptoms, making use of support, and being a “partner” with one's clinician, such as discussing and making joint decisions. However, the policy documents tend to represent a generic approach to the management of all long-term conditions and as such do not take into account that individuals living with such conditions may require different approaches.

The sociological literature on long-term conditions (in contrast to the work cited in policy documents) is primarily qualitative and does acknowledge the psychosocial impact of living with such conditions and takes broader contextual issues into account. As Bury et al (2005a) note, “*awareness of the varied social processes underpinning everyday life warn against...normative statements about what patients should do*” (p20). Therefore such “normative statements” set out in policy work adopt a prescriptive approach to individuals’ health behaviours, yet the broader contextual issues question this approach to changing individuals behaviour. In the next section I will argue that it is also important to consider the psychosocial aspects of living with such conditions.

2.9 The Psychosocial Impact of Living with a Long-term Condition

A number of studies concerning the psychosocial aspects of living with long-term conditions have been conducted within the social sciences. Indeed, some have argued that it is precisely because of the non-curable and therefore enduring nature of long-term conditions that it is a serious topic of study for medical sociologists (Gabe et al, 2004). As Strauss (1975) noted some time ago: “*Chronic illness... is here to stay. It will not vanish*” (p.7). Psychosocial studies suggest that aside from the medical difficulties, the social impact of living with a long-term condition is equally important to take into account (Strauss, 1975). Studies have illustrated that the symptoms of long-term conditions can have a serious impact on the individual’s ability to participate in daily activities which in turn may have a negative impact on their identity (Radley, 1989, Bury, 1982, 1991, Charmaz, 1991). Indeed, Radley (1989) has argued, the unpredictable symptoms of long-term conditions may limit the everyday activities of individuals and so influence psychosocial aspects of their lives: “*the unpredictable yet pressing demands of the body which dictate the terms in*

which that day shall be lived and personal relationships engaged in” (p.232). Furthermore, having a long term condition can affect others around them for example partners, family or work colleagues. The symptoms of the condition can also lead to being misunderstood by others, which in turn can result in social isolation (LTCA Website, 2005).

2.10 Identity

Charmaz (1983) has described the limitations which long-term conditions may place on an individual to constitute “loss of self” because the condition changes how they view themselves. She argues that living with pain and the subsequent limiting effect it has on an individual’s ability to participate in everyday life constitute a form of “suffering” and individuals fear “becoming a burden” to others around them (Charmaz 1983). In one key sociological study, Bury (1982) has argued that the impact of living with a long-term condition is so significant it completely changes individuals’ lives, not only clinically but the entire context of their lives. Bury (1982) describes the impact of living with a long-term condition to constitute: *“biographical disruption.”* In other words the condition completely disrupts what individuals previously considered to be their “normal identity.” This concept has been widely adopted in studies and reviews of long-term conditions within the sociological field (Williams, 2000). Bury (1982) conducted qualitative interviews with individuals recently diagnosed with rheumatoid arthritis to explore how people deal with and acknowledge the condition. Specifically Bury (1982) argues that being diagnosed with a long-term condition had three key impacts on the individual: an awareness of symptoms, which led to seeking clinical intervention, the condition changed how people viewed themselves because they were now “sick”; and “disruption” which indicated the new limitation the condition had placed on the

individual's everyday, "taken for granted life" spanning all areas including relationships (Bury, 1982). More recently, however, the term "biographical disruption" has been critiqued by Williams (2000) who questions the relevance of the term for the diverse group of people living with a long-term condition. Williams (2000) cited three potential limitations which need to be taken into account:

- the model focuses upon the disruption experienced only by those who are in adulthood and thus excludes younger people and those born with a condition who may not consider it to be a disruption
- the model excludes a consideration of class, age, gender and ethnic minority views on disruption
- it does not take into account that issues of timing and context, norms and expectations may affect how individuals perceive long-term conditions.

In summary, the symptoms of a long-term condition may limit individuals' ability to participate fully in everyday activities. Furthermore, such conditions are unlikely to be cured and so individuals must adapt to living with them throughout their lives. Sociological studies have set out to further explore the psychosocial impacts of living with long-term conditions and highlighted that it may have a major impact on an individual's identity. This suggests that not only is it difficult to live with a long-term condition but individuals may employ strategies to manage it. Psychosocial studies highlight how individuals' perceive that the broader social aspects of their lives must be taken into account as well as the medical aspects of the condition. For example, several studies have argued that having access to social support is beneficial to one's health (Davison et al, 2000, Wang et al, 2005, Magliano et al, 2006). Whilst there has been considerable research on the sociological aspects of

living with long-term conditions what is arguably neglected however is the role of disclosure. The link between self-care, social support, and disclosure as they relate to health is now discussed.

2.11 Self-Care, Social Support and Disclosure

It has been argued that a feature of self-care may include gaining appropriate social support (Clark et al 1991, Gallant, 2003, Munir et al 2005). For example, a recent study of disclosure of illness in the workplace states: *“disclosing an illness may elicit social support from colleagues and line managers by increasing their understanding of the effects of the illness”* (Munir et al 2005, p.1398).

Studies which have investigated the link between social support and long-term conditions, suggest it is beneficial to have people with whom you can converse (Davison et al, 2000, Wang et al, 2005, Magliano et al, 2006). Social support may play a positive role in physical and emotional health (Wang et al, 2005). Yet, access to social support may not be straightforward as factors such as gender, level of education, earnings and employment may influence access to social networks (Magliano et al, 2006). However, individuals with a similar condition may be able to offer social support. For example, the support group “Alcoholics Anonymous”, recommended that an important route to recovery is through the shared experiences of others with the same condition (Davison et al, 2000).

A relatively new source of social support for those with long-term conditions is the Internet. Online forums offer the opportunity to discuss symptoms and other issues with those who have similar conditions. A major advantage of these forums is that, in contrast to group settings, they are accessible at all times (White and Dorman, 2001). They may also offer one of the few opportunities for those living with a rare

condition to discuss issues with others in a similar situation (White and Dorman, 2001).

Whether on the Internet or through a self-help group, talking about the condition is clearly important. Williams and Healy's (2001) study of those with mental conditions also suggests that it is beneficial: "*talking to friends, family members or seeking professional help avoided some of the problems of burden*" (p111). Davison et al (2000) argue that individuals make sense of their condition through talking to others such as friends and family or clinicians. This may offer a key source of support. Yet this feature of self-care, such as accessing social support or talking to others about one's health, has not been explicitly outlined in the definition of governmental self-care policy documents or community self-management programmes.

2.12 Stigma and Disclosure Research

A key factor which may preclude disclosure of condition and access to social support is the stigma associated with certain long-term conditions such as mental health or Human Immunodeficiency Virus (HIV), (Williams and Healy, 2001, Fesko, 2001). A number of studies of long-term conditions have identified fear of stigma to be a reason for not disclosing their condition to others (Williams and Healy, 2001, Fesko, 2001, Joachim and Acorn, 2003, Chapple et al, 2004). Stigma has been associated with long-term conditions because one of the difficulties of living with them is the negative impact they have on an individual's identity: being "discredited" or perceived as "different" to others around you (Goffman, 1963, Charmaz, 1983, Scambler, 1989, Rogers et al, 1999, Mason et al, 2001, Gabe, et al, 2004). The origins of research on stigma lie with the sociologist Erving Goffman who conducted

a seminal study of patients in a psychiatric hospital in the 1960s (Goffman, 1963). Goffman, (1963) has defined stigma as: “*an attribute that is deeply discrediting within a particular social interaction*”(p3). The original meaning of stigma stems from the Greeks and referred to those with physical marks on their body such as brandings. Such marks were seen as a token of shame or disgrace and thus denoted people to be avoided in public (Goffman, 1963). He argues that the majority, “the normal” group, perceives groups who are labelled with stigma as “inferior:” “*by definition, of course, we believe the person with a stigma is not quite human*” (Goffman, 1963, p.15). In contrast “the normals” are those people who fit societies’ expectations of a “normal identity.”

Goffman (1963) refers to: “the discredited and the discreditable.” In his view the people with stigma are “the discredited” and everyone knows about their limitation. In contrast, the “discreditable” controls who knows about his limitation which is not directly obvious to others. Goffman (1963) argues that there is a decision to be made concerning disclosure of information to others: “*To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where*”(p.57).

He refers to the process of hiding something discreditable as “passing” the intention of which is to remain part of the “normal” group. He refers to “covering” as a process of not concealing the condition completely, but attempting to minimise its importance (Goffman, 1963).

To relate this to the current topic of disclosure of long-term conditions, those living with such conditions may therefore face a dilemma, to risk disclosing or not. Several studies have described the decision to disclose to others to be a “double-edged

sword” (Williams and Healy 2001, Fesko, 2001). On the one hand, it may lead to not only a diagnosis but better social support, yet on the other hand it comes at the cost of disclosure which may result in one being stigmatised. Decisions as to whom to interact with are, he argues, a key issue for those with long-term conditions associated with stigma in order to: *“minimize the obtrusiveness of their stigma”* (Goffman, 1963, p127). In other words, the “normals” are those who do not have a long-term condition and so fit into societies’ expectations of a normal “identity.”

However, Goffman’s (1963) work on stigma is relatively dated now and it is important to consider whether perceptions of stigma have evolved over time, in terms of others reactions to disclosure. Furthermore it is questionable as to whether his terms can be applied universally, given that those living with long-term conditions are not a homogenous group.

A study of mental health service users highlighted such dilemmas for those considering disclosure of illness to others: *“seeking help may result in a diagnosis...at the cost of disclosure and potential labelling and stigma”* (Williams and Healy, 2001, p.115). Others have argued that in order to cope with the stigma associated with a long-term condition, strategic decisions must be made concerning disclosure of illness to whom and how much to tell others (Joachim and Acorn, 2000). A study of the rare disease scleroderma suggested that disclosure of illness was strategic because individuals selected whom to tell about their illness based on the assumption of positive responses: *“most participants strategically decided when to tell and when not to tell about the illness”* (Joachim and Acorn, 2003, p602).

Perceptions of the means by which the person contracted the long-term condition may influence others’ reactions to the disclosure. Chapple et al’s (2004) qualitative

study explored how participants living with lung cancer perceived and experienced stigma. They found that others' views of the manner in which they had contracted lung cancer, for example through smoking, caused them to be stigmatised. This was particularly distressing for respondents, as some had contracted the disease through passive smoking, and not by actively smoking. Their study also found that such stigma may influence decisions to disclose to others and have far reaching effects that may lead to not seeking appropriate clinical support: "...*fear of disclosure may... prevent them from seeking support*" (Chapple et al, 2004, p4). However, the topic of disclosure emerged as an unanticipated area of concern rather than the main focus of the study. Therefore whilst the issue of disclosure was raised, it was not discussed in-depth in the paper and further exploration of perceptions of disclosure may prove beneficial in the context of clinical support.

A study of mental health service users similarly argues that the stigma attached to such conditions may prevent individuals disclosing that they have the condition because they fear others' reactions (Williams and Healy, 2001). They argue that there is a need to explore the influence of social responses to a condition and its impact on people seeking clinical assistance for their conditions (Williams and Healy, 2001).

2.13 Difficulties of Disclosing Illness to Others

Despite the relatively high number of people living with a long-term condition and challenges which they face, studies suggest that disclosure to others may be a difficult, and complex decision (Joachim and Acorn, 2000, Fesko, 2001, Dyck and Jongbloed, 2000). A number of studies of illness in the workplace suggest that decisions to disclose were mediated by several concerns: the impact of the disclosure

on identity, stigma, fear of discrimination and the fear that others may see them as a poor worker. Individuals also expressed fears that disclosing their illness to others may have significant financial implications such as losing their job, impact on their social security entitlements, and reduce their employment prospects (Fesko, 2001, Dyck and Jongbloed, 2000, Beatty, 2004). These studies highlight that there are a number of additional factors to take into account when disclosing, aside from stigma, thus highlighting it is arguably not a simple process. However, several of the studies of disclosure of condition are set within the workplace in the United States or Canada and so the findings may not be generalisable to the UK setting which has different employment laws regarding discrimination (Fesko, 2001, Dyck and Jongbloed, 2001, Beatty, 2004, Disability Discrimination Act, 1995).

2.14 Visible and Invisible Conditions

The issue of disclosure is further complicated as some long-term conditions have been referred to as “visible” or “invisible” (Joachim and Acorn, 2000). Those with “visible” conditions arguably have no control over whether or not to disclose their condition because others can see the existence of the long-term condition (Joachim and Acorn, 2000). This has been described by Goffman (1963) as: *“the special indignity of knowing that they wear their situation on their sleeve”* (p.152).

In contrast, conditions which do not have visible symptoms are therefore described as “invisible” because there are no obvious signs of illness. A study of the rare condition scleroderma found that those with “invisible” symptoms had a choice as to whether to disclose or not because they appear “normal” to others (Joachim and Acorn, 2003). Decisions to disclose may be problematic because it may result in additional stigma and an alternative strategy would be to try to hide the condition

and be perceived as “normal” (Joachim and Acorn, 2000). Some have argued that when the condition is “medically controlled” it is invisible to others. For example Trosters’s (1997) study of “information management” in people living with epilepsy states: *“As long as their seizures are under control, they can choose to conceal their epilepsy or disclose it (p1227).* However, there is a need to explore whether other issues aside from medical control are taken into account when deciding to disclose their condition or not.

Overall, studies have indicated that fear of stigma is a reason not to disclose a condition which in turn may have far reaching effects on the individual’s ability to cope with it. It is also notable that an individual “becomes stigmatised” as a consequence of the disclosure and specifically as a result of the reaction of others to them. Therefore further research should take into account the link between disclosure of a long-term condition and the consequences of social interaction.

2.15 Non-Disclosure

Despite the risks involved in disclosing, the decision to conceal illness from others may have a negative impact on one’s health. A study exploring disclosure of the long-term condition HIV found that non-disclosure to family or partners led to negative outcomes including depression, lack of support, isolation, and anxiety (Fesko, 2001). He argues that those who chose not to disclose their condition did so due to: *“concern for their own safety and protection”* (Fesko, 2001, p239). They feared others’ responses to the knowledge of their condition. Yet a consequence of not telling others was that they lacked support and felt socially isolated. For example, individuals felt unable to give an account for why they were having an unproductive day at work. Some stated they: *“wished they could be more frank”*

(Fesko, 2001, p.239). A study of disclosure of epilepsy in the workplace found that some chose to conceal their condition perceiving it to be a “private” and “personal” issue (Beatty, 2004). Those living with potentially “transferable” long-term conditions who do not disclose may affect the health of others. A study of disclosure of HIV infection to sexual partners found that 51% had not disclosed their status to one or more partners (Marks et al, 1991). This study suggests that depending on the type of condition, there may be both a legal and a social responsibility to disclose the condition.

2.16 The Limitations of Studies of Disclosure of Illness

It is difficult to ascertain the role of disclosure in long-term conditions due to the limited number of subjective studies on experiences of disclosure within the field of health care research. Previous studies have sought to measure disclosure using questionnaires; but these do not facilitate an exploration of what the role or components of disclosure are. The limited conceptual or theoretical development of disclosure of long-term conditions is discussed in the following section.

2.17 The Measurement of Disclosure

There is a need for more exploratory subjective accounts of the rationale for disclosure because the concept requires further clarification. Many of the studies on disclosure have adopted a quantitative approach to determine factors which may influence decisions to disclose or not (Munir et al, 2005, Beatty, 2004, Marks et al, 1991). The underlying reasons for non-disclosure of HIV infection to sexual partners were unclear due to the limitations of using a questionnaire as the participants were responding to closed questions (Marks et al, 1991).

A further limitation regarding the measurement of disclosure is that studies have primarily used conditions specifically associated with stigma for example HIV and Acquired Immune Deficiency Syndrome (AIDS), mental health and epilepsy (Beatty, 2004, Williams and Healy, 2001, Fesko, 2001, Marks et al, 1991). Although stigma appears to be a significant mediator in decisions to disclose this focus on particular “stigmatised” groups has limited the generalisability of the findings. The relevance of disclosure to long-term conditions not traditionally considered to be stigmatised as yet remains unclear. The review has also highlighted limitations in terms of the generalisability of samples adopted to conduct studies upon disclosure of long-term conditions. For example many studies of HIV/AIDS focus upon perceptions of disclosure among predominantly gay men within an American context (Edward Rutledge, 2007, Marks et al, 1991, Sheon and Crosby, 2004, Green and Sobo, 2000). Whilst other studies of disclosure have considered a broader range of long-term conditions such studies have predominantly included women (Dyck and Jongbloed, 2000, Beatty, 2004, Joachim and Acorn 2003). However long-term conditions also affect men.

Overall the majority of studies examining disclosure have been conducted in the United States of America (Jourard, 1971, Pennebaker et al, 1988, 1990, Beatty, 2004, Fesko, 2001). There may be cultural differences in terms of what one may disclose. Primarily studies of disclosure are set within the context of the workplace (Beatty, 2004, Munir et al 2005, Dyck and Jongbloed, 2000, Fesko, 2001). Some of these studies of disclosure have included in their sample those who were no longer employed and so the relevance of these findings may be limited (Dyck and Jongbloed, 2000, Fesko, 2001). Thus the picture of disclosure is not complete.

Munir et al's (2005) quantitative study of disclosure of condition in the workplace argues that disclosure may be a self-management strategy: "*We implicate a strategy employed by chronically ill employees, in that such employees control the level of information disclosed, according to their self-management needs*" (p.1405). However such views on disclosure were gauged from respondents by asking them to indicate whether or not they had disclosed by ticking "yes" or "no." In using this quantitative measurement approach the barriers to disclosure remain unclear. As previously stated the quantification of disclosure does not provide insight to the rationale for disclosure and how it may link to the self-management of the condition.

2.18 Measurement Issues: Psychological Studies of Disclosure

There have been a number of studies of disclosure in the field of psychology (Jourard, 1971, Pennebaker et al, 1986, 1988, 1990, 1999, Derlerga et al, 1993). However much of the research and its links to health have focused upon objective measurement rather than subjective understanding (Jourard, 1971, Derlerga, 1979, Pennebaker et al, 1988, 1990, 1999).

The roots of research on self-disclosure can be traced to the work of the psychotherapist Sidney Jourard (1926-1974) in the field of humanistic psychology (Jourard, 1971, Archer, 1979). He conducted a number of studies on self-disclosure, which are regarded to be influential within the field of psychology (Jourard, 1971). He developed the "Real Self Questionnaire" which set out to explore which topics individuals had disclosed to those whom he describes to be: "target-persons" such as partner, mother, father or close friends. He conducted studies on college students and work colleagues to examine whether self-disclosing has a causal effect on others to disclose and whether "liking" someone, influences how much they

disclose. This is referred to as the “*dyadic effect: the reciprocal nature of self-disclosure.*” He argues that the degree to which one tells another information relates to factors which include: “*closeness*” of the relationship, and of the affection, love, or trust that prevails between the two people” (Jourard, 1971 p.13). He sought to capture their views on disclosure using pre-fixed questions as set out in questionnaires and so this methodological approach does not facilitate an exploration of their rationale for disclosure or non-disclosure. From a measurement perspective the study has a relatively low sample of twenty-five people and was completed by college students.

The samples in such studies were relatively small and included largely high school or college students (Pennebaker et al, 1986, 1988, 1990, 1999, Jourard, 1971). Therefore, the generalisability of their findings on disclosure to the broader population and in particular those with long-term conditions may be limited. The limitations of measurement approaches within psychological literature have been acknowledged as Baxter and Sahlstein (2000) note: “*Traditionally, research on self-disclosure and privacy has been dominated by experimental designs and self-report questionnaires*” (p.299).

Some psychological studies have taken a sample group of students who responded to hypothetical questions about disclosure of long-term conditions. For example, Greene (2000) conducted a quantitative study to examine individuals’ disclosure of cancer or AIDS to members of their family. They found that people living with these conditions were most likely to disclose to their partner or friend and least likely to disclose to their brother or father. However as stated earlier, the study was hypothetical so recorded potential attitudes towards disclosure. Therefore, their

responses may not reflect the views of those living with the condition and the real life choices they have to make.

I now go on to review key studies of disclosure of long-term conditions within the field of health care research and argue for the need to conduct further exploratory research in this area.

2.19 Definitions of Disclosure

The literature review highlighted that the term disclosure has been applied across many disciplines displaying a range of different associated meanings and interpretations. Table 1 presents a multi-disciplinary comparison of definitions of disclosure. These include studies in the field of psychology, philosophy, social sciences and organisational studies as well as health-care. The range of these definitions are now presented

Table 1 Multi-disciplinary Comparison of Definitions of Disclosure

Discipline	Author	Definitions of Disclosure
Sociology	Charmaz (1991)	<p>Disclosure is ongoing: <i>“Telling does not end.”</i> (p109).</p> <p>Protective Disclosing: <i>“Designed to control how, what, when, and who people tell about their illness. They intend to protect others and themselves from shock, anger, and fear about their illness and its future implications...protective disclosure typically necessitates planning”</i> (p119).</p> <p>Spontaneous Disclosing: <i>“Full expression of raw feelings, open exposure of self, and minimal or no control over how, when, where, what, and whom to tell. People spontaneously disclose when they receive startlingly bad news or perceive dramatic changes”</i> (p119).</p>
Social Sciences	Schneider and Conrad, 1980	<p>Preventive Disclosure: <i>“Intended to influence other’s actions/ and ideas toward self and towards epileptics in general...when actors think it probable that others, particularly others with whom they share some routine will witness their seizures...others then know “what it is” and “won’t be scared”</i> (p40).</p>
Organisational Studies	Beatty (2004)	<p>Instrumental Disclosure: <i>“Intended to influence other’s actions and ideas toward the person with illness”</i> (p134).</p>
Psychology	Troster (1997)	<p>Preventive Telling: <i>“The persons with epilepsy strive to counteract stigmatisation not only through nondisclosure and active concealment but also by purposeful mention of the disease”</i> (p1229).</p>
Organisational Studies	Munir et al (2005)	<p>Partial Self-disclosure: <i>“Employees informing line managers about the presence of a chronic illness”</i> (p1397).</p> <p>Full Self-disclosure: <i>“Employees informing line managers how that chronic illness affected them at work”</i> (p1397).</p>
Social Work	Dyck & Jongbloed (2000)	<p>Disclosure: <i>“Making a diagnosis known”</i> (p344).</p>
Nursing	Joachim & Acorn (2003)	<p>Strategic disclosure: <i>“[Deciding] When to tell and when not to tell about the illness...telling was perceived as letting others in”</i>(p602).</p>
Mental Health	Williams and Healy (2001)	<p>Disclosure: <i>“The process of revealing one’s illness to others”</i> (p108).</p> <p>Informal expression: <i>“For people with minor mental health problems typical symptomatology is likely to manifest itself as informal expression e.g. social withdrawal, apathy, irritability and generally behaving in a depressed mood”</i> (p111).</p> <p>Formal expression: <i>“Acts directed towards some aim such as seeking help or understanding”</i> (p111).</p>
Psychology	Jourard (1971)	<p>Self-disclosure: <i>“The act of revealing personal information to others”</i> (p2).</p>
Psychology	Derlerga & Grzelak (1979)	<p>Self disclosure: <i>“Objectively defined as any verbal message that formally begins with the word “I” (for instance, “I think”, “I feel” or any other verbal message about the self)”</i> (p152).</p>
Psychology	Rosenfield (2000)	<p>Disclosure: <i>“The process that grants access to private things and secrets”</i> (p6).</p>
Philosophy	Burnard & Morrison (1992)	<p>Self-disclosure: <i>“As we communicate with others we reveal ourselves to others in various ways and to varying degrees”</i> (p60).</p>

Disclosure is defined by the Oxford English Dictionary (2001) as: “*to make secret or new information known.*” However definitions of disclosure within health care research are less clear since the review of disclosure has identified few exploratory qualitative studies. A qualitative study of individuals living with long-term conditions entitled, “*Good days, Bad days*” (to indicate the variable nature of living with long-term condition) identified two types of disclosure (Charmaz, 1991). Firstly, “protective disclosing” a strategy adopted to manage the disclosure in terms of both the information provided and the selection of to whom it is told. The purpose of this disclosure is to protect the disclosee and to allow others to adjust their expectations of them.

Secondly, “spontaneous disclosing” denotes a form of disclosure, which is not pre-planned or managed. This can occur on receipt of particularly negative news or information such as the perception that there has been a significant downturn in the prognosis of their condition. However, whilst long-term conditions was the focus of the study, disclosure of condition was not, but rather emerged as an area of concern (Charmaz, 1990).

Disclosure has been defined as: “*the process of revealing one’s illness to others*” (Williams and Healy, 2001, p.108). It is one of the few studies conducted within health care research which defines disclosure. Although it is not clear whether this definition has been devised by the researchers rather than grounded in participants’ data. Also there is a lack of clarity as to the dimensions of the term disclosure and its context.

Aside from “verbal” disclosure, studies have indicated that a condition may be disclosed through behaviour. One study found that “coughing” may constitute a

form of disclosure of cystic fibrosis (Lowton, 2004), and others have argued that “acting differently” may reveal mental conditions (Williams and Healy, 2001).

Schneider and Conrad’s (1980) classic sociological study of epilepsy focused upon exploring how those living with epilepsy: “*manage information to control the stigma potential of epilepsy*” (p32). Their study based on eighty in-depth qualitative interviews; illustrated the variable nature of disclosure and refers to it as a: “revolving door.” This study whilst useful would benefit from a more recent exploration of views on disclosure as disclosure took place nearly thirty years ago.

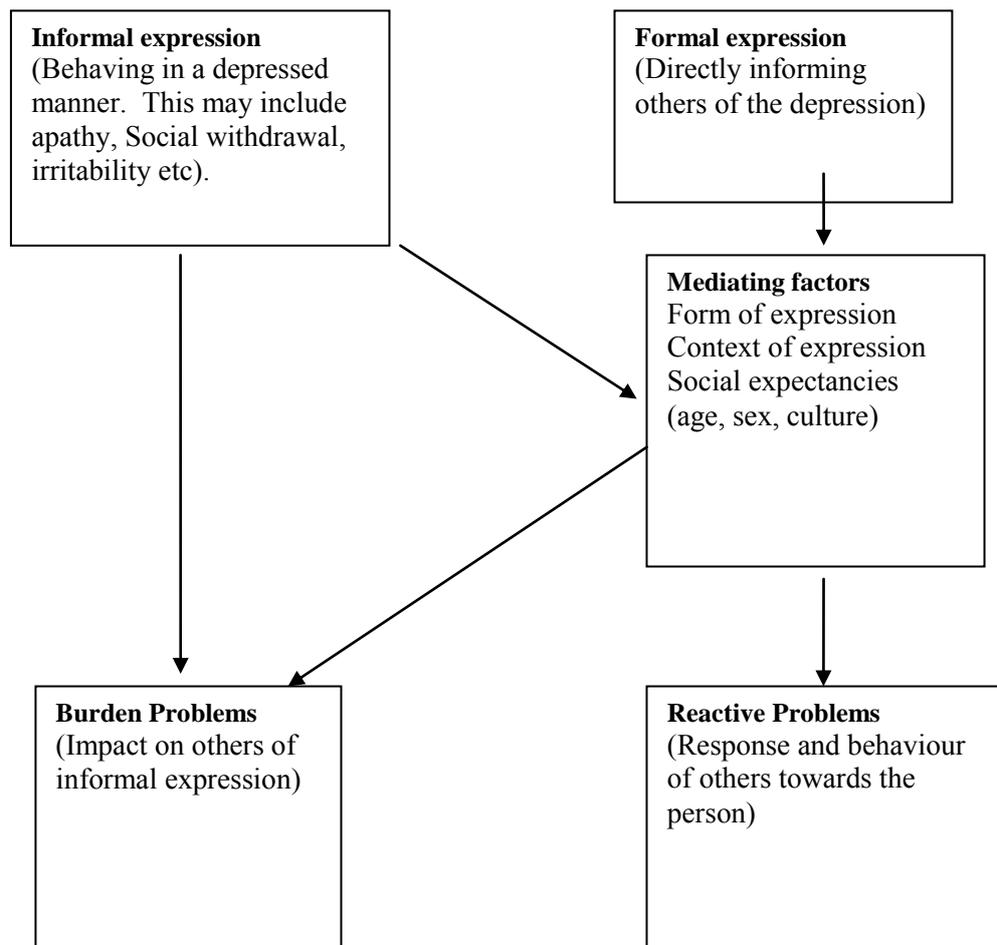
Lowton’s (2004) qualitative study of thirty-one adults aged eighteen to forty-years old set out to explore how adults living with cystic fibrosis make decisions around disclosure. The rationale for the study stemmed from cystic fibrosis no longer being a fatal childhood condition. Since people with this condition are living longer, this has led to a gap in research on adults living with cystic fibrosis and their experiences of disclosure in the workplace or within intimate relationships (Lowton, 2004). She identified three settings for disclosure and argued that they were strongly related to risk: “low risk situations,” a short period of social contact with individuals; “medium risk”, a higher level of contact leading to greater concern over how others may react to the disclosure, and “high risk” which referred to disclosure to employers or potential partners where negative reactions carry greater consequences (Lowton, 2004). However this study has limitations because the data have been drawn from a larger study focussing upon issues of infertility and potentially reduced life span as they relate to cystic fibrosis and this is the underlying rationale for this categorisation of risk rather than being grounded in participants’ data.

2.20 Models of Disclosure

Two models of disclosure have been developed and their relevance are now discussed.

Figure 2 Model of Types of Expression and Subsequent Disclosure Problems

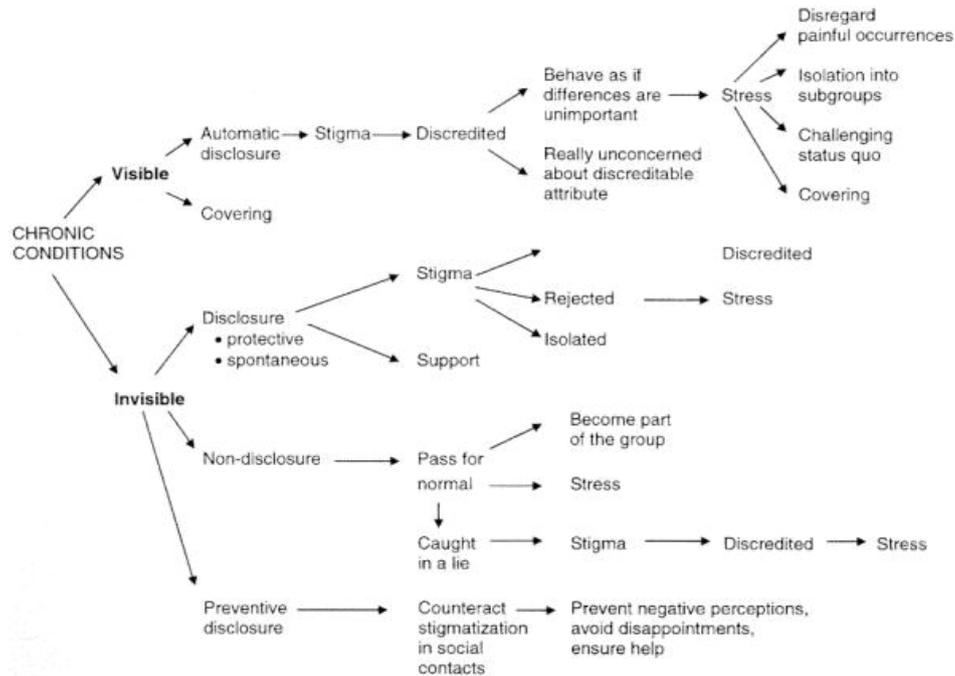
(Williams and Healy, 2001).



(Figure reproduced with kind permission from: “Disclosure of Minor Mental Health Problems: An Exploratory Study”, Williams and Healy, 2001)

Williams and Healy (2001) conducted a qualitative exploratory study of disclosure of minor mental conditions. They developed a model of the relationship between types of expression and subsequent disclosure problems (figure 2). Their study examined disclosure from the approach of the person “to whom” one discloses rather than from the perspective of the “disclosee.” Two types of disclosure were identified: “informal expression” and “formal expression.” Informal expression refers to acting or stating how one feels such as: “*social withdrawal, apathy, irritability and generally behaving in a depressed mood.*” This form of disclosure was perceived to “burden others” (Williams and Healy, 2001, p111). Formal expression involved directly disclosing to others and was deemed to be more beneficial. Qualitative interviews were conducted with forty-seven users and non-users of community mental health services. Perceptions of “burden” and “reactive problems” were identified as two areas of difficulties which emerged from the disclosure in terms of the response of others. Almost half of the study sample constituted those who were not current users of the community mental health service. Thus, in these instances participants were responding to hypothetical questions around their views on disclosure. This may account for the study’s focus on the difficulties associated with disclosure and does not illuminate any of the potential benefits. Since the study’s focus is upon disclosure of minor mental conditions which are strongly associated with stigma, the relevance of findings to other long-term conditions may be limited. I now go on to discuss the model developed by Joachim and Acorn (2000).

Figure 3 The Elements of Stigma with the Factors that Influence Disclosure and Non-disclosure in Chronic Illness (Joachim and Acorn, 2000).



(Figure reproduced with kind permission from: Stigma of Visible and Invisible Chronic Conditions, Joachim and Acorn, 2000).

Joachim and Acorn (2000) conducted a meta-study (1980-1996) of qualitative research on the “lived experience” of chronic illness and conditions as well as a review of quantitative studies on “coping” with long-term conditions. They developed a model of stigma and factors that influence disclosure or non-disclosure in chronic illness. However from a methodological perspective there are limitations to this study because it is unclear how many key studies on disclosure were identified and which studies in particular were drawn upon for the model. Their review of quantitative studies on “coping” also precludes an understanding of the individual’s decision-making process regarding disclosure. The model also suggests a clear dichotomy between invisible and visible conditions as they relate to

disclosure. However this does not take into account the role that context may play in the decision making process: disclosure may be more complex than the model suggests. Arguably their study presents a review of the key concepts identified in disclosure research to date, but the components and role of disclosure require additional exploration.

Studies of disclosure of long-term conditions within the workplace have identified a range of definitions (Munir et al, 2005, Beatty, 2004). Munir et al's (2005) study identified two types of disclosure: "partial self-disclosure" denotes telling a line manager that one has a long-term condition whereas, "full self-disclosure" denotes telling a line manager how the condition affects the discloser in the workplace. It is not clear why two separate definitions have been identified and does not address the point that in certain situations, "partial disclosure" may lead on to "full disclosure." Furthermore, the study did not consider the issue of stigma yet this has been identified as an important predictor of disclosure and so the relevance of the findings may be limited. The study tested relationships between variables and did not provide insight regarding what the reasons for "partial" or "full" disclosure were.

Studies on disclosure within the healthcare setting have drawn on definitions from the field of Psychology and these are examined in the next section (Munir et al 2005).

2.21 Psychological Definitions of Disclosure

Jourard (1971) defines self-disclosure as: "*to describe the act of revealing personal information to others*" (p.2). His research interest in disclosure stemmed from his work as a psychotherapist working with clients encouraging them to disclose, to

clarify what he describes as the parameters of “*secretiveness and openness*” (Jourard, 1971, p2).

However within the discipline of Psychology the role of self-disclosure has a different focus to studies in health care research. For example, common to psychological definitions is a sense of disclosing something personal about oneself to a trained professional which does not necessarily relate to simply one’s health status. Derlerga and Grzelak (1979) have described disclosure as a “*verbal message about the self*” (p152). More recently Rosenfield (2000) has defined it as: “*the process that grants access to private things and secrets*” (p6). This suggests that disclosure is not a decision to be taken lightly because what is being disclosed may be a “secret” and as such only disclosed under specific circumstances. In contrast to studies in the field of health care research, within psychological literature self-disclosure is clearly defined in terms of what disclosure is, and what it represents for the person disclosing. The term self-disclosure describes the process of the client’s disclosure within the counselling context (Burnard and Morrison, 1992). In “person-centred” therapy the self-disclosure of the client is fundamental to the process. They go on to argue that disclosure is essentially about communication to others around us and note that we generally disclose to a range of people from friends to colleagues at work (Burnard and Morrison, 1992). Although this disclosure may not necessarily relate to the same issues brought up in a counselling context. As Burnard and Morrison (1992) argue: “*we do not live as isolated beings. We are dependent upon others to tell us about ourselves*” (p32). This perspective is helpful because it indicates that it is through others that we may learn about ourselves: the extent to which this is relevant to disclosure of long-term conditions in health care research requires additional exploration.

2.22 The Rationale for further Research on the Role of Disclosure

Overall, the literature review of studies, which examined disclosure of illness, highlighted that primarily disclosure emerges as an unanticipated area of importance to research participants rather than being the main focus of the research study design (Charmaz, 1991, 2000, Williams and Healy's 2001, Chapple et al 2004, Lowton, 2004).

Furthermore the topic of disclosure emerges as a significant issue within the context of debates around issues of stigma associated with long-term conditions rather than being the key focus of the study itself (Williams and Healy, 2001, Chapple et al, 2004). For example studies which appear to be discussing issues of disclosure refer to the process of "information management" about one's condition (Schneider and Conrad, 1980, Troster, 1997, Green and Sobo, 2000, Joachim and Acorn, 2000, Munir et al, 2005). This term emanates from Goffman's (1963) study of stigma who refers to the process of "managing potentially discrediting information" which may lead to stigmatisation. Goffman's (1963) study whilst important is relatively dated now. Thus it may be timely to review how those living with long-term conditions perceive disclosure and whether disclosure does constitute "information management" particularly as studies have frequently drawn upon the term without clarifying that it has emanated from Goffman's (1963) work on stigma rather than an issue of current concern to participants in studies (Troster, 1997, Green and Sobo, 2000, Joachim and Acorn, 2000, Munir et al, 2005).

In terms of context, research on disclosure has been conducted in a variety of settings such as clients disclosing to psychologists or psychotherapists (Jourard, 1971, Pennebaker, 1999). The term disclosure also appears frequently in studies of

sexuality in terms of the process of disclosing one's sexual orientation to others particularly within the context of "coming out" (McLean, 2007). In addition the research on disclosure focuses on the dilemmas of disclosing conditions associated with sexuality such as the process of disclosing HIV/AIDS to current or potential sexual partners (Edward Rutledge, 2007, Marks et al, 1991, Sheon and Crosby, 2004, Green and Sobo, 2000). Therefore the role of disclosure in this context appears to relate most directly to issues of risk of transmission of a potentially transferable condition. However, not all long-term conditions are transferrable (Department of Health, 2005). Disclosure within the biomedical literature predominantly refers to the process of doctor patient communication (May 1993, Kirk et al 2004).

In summary, there is no single definition of the process of disclosure. It is a poorly understood concept and lacks theoretical development. The components of disclosure remain unclear since there have been few primary or exploratory studies of disclosure of long-term conditions within the field of health care research. Variations in definitions of disclosure make it difficult to assess what is really being examined. Clearly, the conceptualisation of disclosure differs between and across different disciplines.

Several studies have called for additional research on disclosure of long-term conditions within the field of health care research (Joachim and Acorn, 2000, Williams and Healy, 2001). It is regarded to be of relevance since choosing to disclose one's condition to another (particularly if it is not visible to others) is likely to be a difficult decision not least due to possible negative reactions by others (Joachim and Acorn, 2000). Furthermore, nurses are key providers of care for those with long-term conditions (Department of Health, 2005d). Therefore the role of disclosure and in particular how patients perceive disclosure has particular relevance

for clinical practice and the delivery of quality patient care. Furthermore patients may ask for specific guidance on the advisability of disclosing a condition. Policy changes have resulted in the development of specific nursing roles for those living with long-term conditions such as epilepsy (SIGN Epilepsy guideline, 2003). Nurses also play a significant role in the provision of services to those living with diabetes (Department of Health, 2007c).

As Joachim and Acorn (2000) note, many of the key studies on stigma and disclosure such as Goffman (1963) and Schneider and Conrad (1983) are now over twenty years old. Yet this literature review has identified that subsequent studies have continued to draw upon their work and so a more recent exploration of the role of disclosure would be timely in order to explore possible changes in personal and public perceptions.

The research question for this study is set out below:

2.23 Research Question

- What is the role of disclosure to others in managing a long-term condition?

Having set out the argument for the need for additional exploration of the role of disclosure in the lives of those living with a long-term condition, those living with epilepsy or type 1 diabetes were selected as appropriate participants for this study. I now set out the medical and social implications for those living with epilepsy and type 1 diabetes (both long-term conditions).

2.24 Living with Epilepsy and Disclosure

Epilepsy is the most common serious neurological condition in the UK (NHS Direct Website, 2006). The condition affects 382,000 people in England, one in every 131 people has epilepsy. For example from a medical perspective, epilepsy is a

neurological condition which is typically caused by sudden changes in the brains electrical activity between cells which may cause individuals to have a seizure (Epilepsy Action, 2006, National Society for Epilepsy, 2007).

Self-care of epilepsy involves a process of taking medication. This is not a straightforward process as it often involves a period of trying a range of medications and dosages to determine the most appropriate treatment. There are also a number of side effects associated with taking such medication which can be difficult to cope with as they may affect the central nervous system (Epilepsy Action, 2006). Other elements of self-care include seeking to control the frequency of seizures by making lifestyle changes (Shaw et al, 2007). Dilorio et al's (2003) study suggests there may be a link between stigma and self-management. They found that those with higher levels of perceived stigma had low levels of self-efficacy regarding their ability to manage epilepsy.

Studies suggest that those living with the condition not only have to cope with a biomedical diagnosis, but the "social" judgements of others to the condition. From a sociological perspective stigma is strongly associated with epilepsy (Scambler, 1989, Prinjha et al, 2005). For example powerful misconceptions concerning epilepsy related the condition to religious perceptions of being "possessed" by demons: *"seizures are dramatic, public and frightening...The forced cry, the loss of consciousness, the fall, the twitching and the foaming at the mouth suggest possession by a spirit"* (Eisenberg, 1998, p42). Historically people living with epilepsy were regarded to be "mad", and treated as "criminals" who should be locked away from society (Eisenberg, 1998).

Schneider and Conrad (1981) have argued that people living with epilepsy should not be judged by the type of seizures and the medical terms which define it, but rather by the strategies of managing the condition apart from the medical diagnosis. A classic study on epilepsy describes two types of stigma: *“felt”* and *“enacted”* (Scambler 1989). “Enacted” stigma is defined as those instances when individuals have been penalised or treated differently because of having the condition. “Felt” stigma refers to anxiety associated with enacted stigma as well as a sense of embarrassment related to living with epilepsy.

This review identified few studies specifically examining the role of disclosure as it relates to the everyday lives of those living with epilepsy. Instead the question of disclosure emerges predominantly within the context of discussion of stigma management (Schneider and Conrad, 1980, Troster, 1997). Schneider and Conrad’s (1980) seminal study of epilepsy refers to the process of “preventive telling” which they defined as follows: *“Intended to influence others’ actions/ and ideas toward self and towards epileptics in general...others then know “what it is” and “won't be scared”*(p40). However subsequent studies have borrowed their term “preventive telling”, sometimes referring to it instead as “instrumental telling” (Troster, 1997, Beatty, 2004). The current relevance of the strategy of “preventive telling” from the perspective of those living with epilepsy would be particularly timely.

2.25 Living with Type 1 Diabetes and Disclosure

A long-term condition which is particularly prevalent among younger people is type 1 diabetes (Commission for Healthcare Audit and Inspection, 2007). The rates of people being diagnosed with type 1 diabetes are increasing and the condition is estimated to affect around 25,000 people aged under 25 in the UK (Department of

Health 2007b). From a medical perspective type 1 diabetes occurs when the body's immune system destroys the cells which produce insulin. This may occur suddenly. When there is insufficient insulin in the body this leads to higher levels of glucose in the blood which can cause potentially serious medical problems such as a coma (hypoglaecema) (NICE, 2004). Several policy documents have been published by the Government setting out the integral role of self-care and diabetes. For example *The National Service Framework for Diabetes* (Department of Health, 2001c) states that self-care is fundamental for those living with diabetes. A recent report by Diabetes UK (2006) also notes the key role of self-care in managing diabetes: "*Self-care is the cornerstone of diabetes care as 95 percent of managing the condition is self-care*" (p12). However, living with diabetes is not only a medical diagnosis but has broader social implications such as employment, life expectancy, lifestyle and health since it: "*impacts upon every aspect of life*" (Department of Health, 2001c, p6). Self-care is required on a daily basis for those living with type 1 diabetes. They must manage their diet carefully. They must also learn how to check their blood glucose levels and require daily injections of insulin in order to live (Department of Health, 2001c). Adopting a strategy of taking insulin is vital, the aim being to achieve: "*best glucose control with the fewest problem...that suits you best*" (NICE, 2004, p20).

However, relatively little is known on how those living with type 1 diabetes perceive disclosure and how this may impact on the self-care of the condition. The review identified surprisingly few studies examining disclosure of type 1 diabetes. Studies do refer to stigma and the process of injecting insulin but they do not specifically examine the role of disclosure in this process. For example, a qualitative study of type 1 diabetes did identify fears around social stigma as a barrier to self-

management (Tak-Ying Shiu et al, 2003). However this study sample was perhaps atypical of those living with type 1 diabetes as they recruited those with high anxiety levels around having a hypoglaeaemic episode. Furthermore, the management of diabetes among younger people differs to that of adults (Department of Health, 2007b). These differences in perceptions of stigma and its management need to be explored further, particularly in relation to the area of self-care and the role of disclosure.

2.26 Summary and Conclusion

In summary, additional exploratory research on the views of those living with long-term conditions such as epilepsy and type 1 diabetes regarding their experiences of disclosure would be timely. As stated earlier, limitations in measurement issues have led to difficulty in ascertaining the role of disclosure. This study therefore sets out to fill the research gap by exploring the role of the social process of disclosure for those living with a long-term condition. Research which has been conducted on the topic of stigma in particular suggests that the reaction of others to disclosure has a vital role to play in stigmatisation of a condition. In light of this review, an exploratory qualitative research methodology which can provide valuable insights into the role of disclosure to others would be beneficial. The selection of an appropriate research methodology is set out in the following chapter (Chapter three).

3.0 Chapter Three: Philosophical and Methodological Framework

3.1 Introduction

Chapter two reviewed the literature on disclosure, illustrating that the majority of research on disclosure has been conducted using survey techniques within the positivist paradigm. The extent to which the individual perspectives of those living with long-term conditions have been included remains unclear and so the concept is relatively poorly defined. A qualitative methodology has been adopted to clarify the role of disclosure. This is based on Blumer's (1969) assumption that disclosure of a long-term condition is a subjective individual experience made sense of through others' reactions.

It is also based upon the assumption that disclosure is a social process.

In this chapter I set out the rationale for adopting constructivist grounded theory as the philosophical and methodological framework (Charmaz, 2006). This decision has been based upon two key issues: the methodological limitations of existing work within the field of research on disclosure of illness, and the researcher's constructivist philosophical stance. Since its development, grounded theory has been subject to considerable debate and has evolved both philosophically and methodologically. The underlying reasons for the selection of this particular approach is placed within an historical overview of grounded theory and the debates surrounding it.

3.2 Consideration of Research Paradigm

3.3 Methodological Limitations within Existing Research on Disclosure of Illness

In considering the most appropriate paradigm to select I took into account the aim of the study and the type of knowledge required. As Weaver and Olson (2006) state: “...*the purpose of the inquiry, in conjunction with the state of knowledge development in the substantive area*” (p466). Thus firstly I consider the relevance of the positivist paradigm to the current study, reflecting upon the existing knowledge of disclosure of long-term conditions and the research gaps identified in the literature review.

3.4 Consideration of the Positivist Paradigm

The term positivism was developed by the French philosopher Auguste Comte (1798-1857) (Schwandt, 2001). The philosophical and epistemological underpinnings of the positivist paradigm perceives “knowledge” as identifiable, objective and therefore measurable predominantly using questionnaires: “*there is a reality out there to be studied, captured and understood*” (Denzin and Lincoln, 2000, p9).

I considered the existing knowledge of disclosure of long-term conditions and the research gaps identified in the literature review in terms of the type of knowledge required to gain insight into individuals personal experiences of disclosure. The review of the literature (chapter two) illustrated that the majority of studies concerning disclosure have used questionnaires to identify individuals’ views on disclosure (Jourard, 1971, Troster, 1997, Marks et al, 2001, Greene, 2000, Munir et al 2005, Beatty, 2004, Pennebaker, 1999). The predominant focus of using

questionnaires to measure disclosure has arguably led to a research gap in terms of capturing the individuals subjective experiences of disclosure. As Denzin and Lincoln (2000) suggest: “*quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes...within a value-free framework*” (p8). Such quantitative studies are designed to test relationships between variables rather than seeking to describe and understand social processes (Denzin and Lincoln, 2003). This has resulted in methodological limitations within existing research on individuals’ personal experiences of disclosure of illness. It is my contention that disclosure is a social process and my philosophical stance does not operate within a: “value-free framework” as I go on to discuss later in this chapter. Research located within the positivist paradigm therefore focuses upon an objective understanding of disclosure of illness. There is a need to explore and clarify subjective knowledge of disclosure as perceived by the individual living with the condition, in order to identify, explore and build concepts for further research. This study has therefore been designed with this purpose in mind by drawing upon and exploring individuals’ views and accounts of disclosure.

Applying the positivist approach to this study would not facilitate access to the potentially dynamic nature of disclosure as a social process for the individual, since it focuses on the quantification rather than the exploration of the role of disclosure. Within the positivist theoretical perspective disclosure of illness would be positioned as an observable “fact”, which is fixed and quantifiably measurable.

3.5 Consideration of the Constructivist Paradigm

In this chapter I argue that the constructivist paradigm is best suited to the study, noting that it is appropriate for developing areas of inquiry where further exploratory

research is required. The key principles of qualitative research within the constructivist paradigm are:

- to shed light upon the: *“phenomena in terms of the meanings people bring to them”*(Denzin and Lincoln, 2003, p.13)
- to tap into the subjective personal accounts of individuals (Schwandt, 2004)
- the inclusion of the researcher’s knowledge and experience of the research area
- co-construction of the data: *“Both the research and the participant together generate meaning for example, I ask and interpret together I need their account to understand”* (Denzin and Lincoln, 2003, p.35)
- there are many different views of “reality” in terms of what constitutes “knowledge” (Denzin and Lincoln, 2003)

In order to access the participant’s perspective of the role of disclosure of illness I judged an exploratory approach located within the constructivist paradigm was appropriate: *“Constructivism assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed and aims toward interpretive understanding of subjects meanings* (Charmaz, 2000a, p510). The constructivist perspective also fits with my philosophical stance and epistemological beliefs as I now go on to outline.

3.6 Why Constructivist Grounded Theory? Philosophical Stance

The researchers’ perception of what constitutes “knowledge” (epistemology) influences the theoretical perspective, methodology and methods applied to a study (Schwandt, 2001, Crotty, 2003). My view of the world and the nature of being

(ontology) and the ways in which this may be understood through means of enquiry (epistemology) have influenced the study alongwith my decision to use a qualitative approach specifically within this constructivist grounded theory (Charmaz, 2006). Ontologically, I perceive meaning in the social world to be socially constructed, that is to say, there are multiple realities as opposed to a single “truth” (Crotty, 2003). It is my contention that the data gathered in the current study will not constitute “reality” because true knowledge does not exist independently to be “discovered” but rather is socially constructed. As part of this approach it is proposed that the researcher’s views and experiences be taken into account (Schwandt, 2001). Indeed as I go on to argue one of the reasons why Charmaz’s (2006) version of grounded theory has been selected is because philosophically it is explicitly located within the constructivist paradigm in contrast to other approaches within grounded theory such as Strauss and Corbin’s (1990,1998) approach whose philosophical stance has been subject to much interpretation (Macdonald and Schreiber, 2001, Annells, 1997a) Philosophical clarification is important since it influences the methods adopted in grounded theory studies as well as the researchers’ stance to the data (Charmaz, 2006). The constructivist version of grounded theory therefore takes into account that I, the researcher, am not “neutral” in my approach to this study (Charmaz, 2006). That is to say, I have selected the topic of disclosure, and brought my interest in long-term conditions to this area of inquiry. Social processes such as disclosure of illness are likely to involve a range of subjective experiences including personal emotions and interactions with others. As a health care researcher, trained in the Social Sciences, I believe that access to personal subjective accounts is vital when exploring the diverse issues surrounding an illness which may in certain cases last for many years or throughout ones’ lifetime.

My main experiences of long-term conditions in both my personal and professional life are as result of observing others. As a qualified social scientist and academic researcher in the field of health services research for the past thirteen years, I have interviewed many people living with both acute and long-term conditions. At that time the focus of the interviews concerned individual's experiences of seeking treatment and care from health care professionals. As patients were largely recruited from hospital waiting lists or outpatient appointments, the nature of their condition had already been identified and so there was no necessity to disclose it. However, on occasions during interviews some disclosed information on conditions additional to the illness which had led to the hospital appointment. I have also experienced "spontaneous" disclosure whilst attending a large international conference on self-management of long-term conditions. On explaining the focus of my PhD topic several individuals were moved to disclose that they or their relatives had a long-term condition. There were no visual cues that those present had a long-term condition and I felt privileged that they had confided in me. Within my personal life, one person revealed to me on our first meeting that she had a long-term condition and requested that I kept it a secret. This disclosure elicited a change in behaviour towards her as I sought to offer her empathy and support whilst taking particular care not to tell others within the same social group. On reflection it may be that identifying myself as a researcher on patient's experiences may have facilitated such disclosures. Within my personal life several relatives and close friends are living with long-term conditions. One friend has frequently disclosed to me her symptoms and difficulties in managing her long-term condition. The purpose of this disclosure was I felt in order to garner social support. In contrast, a relative seldom discusses his long-term condition, despite having to follow a new and intensive daily treatment

regime. Disclosure has also impacted on me personally as I became unwell during the process of conducting this thesis and I was led to make personal decisions regarding to whom, how and when I should disclose. This will be explored further in the discussion and conclusions chapter (Chapter six).

3.7 Summary

Having reflected upon my personal and professional experiences of disclosure of illness, I perceive that individuals adapt to long-term conditions in different ways, and furthermore, are likely to produce diverse strategies regarding their management. In considering the appropriate methodological framework to adopt I also explored the applicability of adopting either phenomenology or ethnography which are both qualitative, inductive approaches (Cresswell, 1994). I now go on to discuss these approaches and their limitations with regard to the current study in the following section.

3.8 Consideration of Possible Qualitative Methodologies

3.9 Phenomenology

The central focus of phenomenology is to explore individual experiences of everyday phenomena: *“human experiences are examined through the detailed descriptions of the people being studied”* (Cresswell, 1994, p12). The intention of this approach is to access the “essences” of the lived experience: *“a description of ‘things’ (the essential structures of consciousness) as one experiences them”* (Schwandt, 2001, p191). There are two predominant strands of phenomenology, “descriptive phenomenology” developed by Edmund Husserl (1838-1959) and “hermeneutic phenomenology” as developed by his former pupil Martin Heidegger (1889-1959) (Maggs-Rapport, 2001). Hermeneutic phenomenology was considered

to be particularly relevant to the current study since it is also located in the constructivist paradigm and also acknowledges the researcher's perspective (Omery, 1983). That is to say the researcher's worldview should not be excluded from the analysis of the phenomenon but be taken into account. In contrast, the "descriptive" phenomenological approach excludes the researchers "taken for granted" understanding of phenomena, a process termed "bracketing." The intention of bracketing is to exclude the researchers understanding of the phenomena so that we can go "*back to the things themselves*" in order to access new understandings or confirm previously held meanings of phenomena (Crotty, 2003, Schwandt, 2001). Phenomenology shares several procedural steps with grounded theory, it uses open, in-depth qualitative interviews to gather data but there are key differences. For example, phenomenological studies typically interview a smaller number of participants compared to grounded theory (Cresswell, 1994). These participants are described as "key informants" who give an individual account of their experience of the phenomenon disclosure of illness.

To summarise I have reflected that a hermeneutic phenomenological approach would not fit the broader remit of the research question: what the role of disclosure is in managing a long-term health condition? A descriptive phenomenological approach would set out a rich description of disclosure of illness but not explore or capture the meaning of social interactions or social processes. The phenomenological focus on experiences offers insights into the lived experiences of disclosure of illness but does not provide an explanation of the role of disclosure, nor assist in its theoretical development. Since I have judged disclosure to be a social process my selection of a theoretical framework is based upon the need to take the role of others in making sense of disclosure into account (Blumer, 1969). This is viewed to be particularly

important in order to move understanding forward from not simply experiences, which a phenomenological approach would offer, but towards the development of an inductive theory thus contributing a body of knowledge to the field. I now go on to discuss ethnography in relation to the current study.

3.10 Ethnography

Ethnographic studies observe, question and listen to participants of interest to uncover a sense of “what is going on?” (Hammersley and Atkinson, 1983). The stance of the researcher is that of a stranger seeking to understand taken for granted meanings for members of the culture of interest in order to acquire: “*inside knowledge of it*” (Hammersley and Atkinson, 1983, p8). The foundations of ethnographic research lie in the field of anthropology, notably the early work of anthropologists such as Malinowski who conducted observational studies of non-western societies (Fitzgerald, 1997). Participant observation is a key method adopted in ethnography drawn from the perception that in order to fully understand a particular group of people, it is necessary to observe and participate in everyday activities over a period of time. Other methods include conducting in-depth interviews and the use of field-work diaries (Hammersley and Atkinson, 1983). The researcher’s personal views and experiences about the area of research are deemed to be relevant and may become part of the data.

3.11 Summary

Having noted these key features I have elected not to adopt an ethnographic approach for the following reasons. Its focus is upon explaining participants “shared values” and “taken for granted” meanings that participants within it hold (Hammersley and Atkinson, 1983). Whilst a cultural understanding of disclosure

may prove to be of interest, this is not the focus of my research question which seeks to define and provide a broader insight into the role of disclosure across the individual's life (as set out in the literature review).

Disclosure of illness may occur in a group sense such as within the setting of a patient support group or "expert patient" group. Participant observation is a key method adopted in ethnographic research. However, since disclosure can be spontaneous and occur in diverse settings this approach would be unlikely to capture all types of disclosure and perceived reactions to disclosure would prove difficult to observe. Using this approach would also fail to capture individual personal experiences of disclosure. For these reasons an ethnographic approach with its slant on cultural meaning does not address the research question and its focus upon social processes.

In the following section I reflect upon my reasons for selecting grounded theory as the methodological framework for the study. I set out the broad parameters of the methodology followed by the debates surrounding grounded theory and the rationale for adopting constructivist grounded theory.

3.12 Why Grounded Theory?

Grounded theory is a particularly appropriate methodology to adopt in my study with its focus upon social processes (Glaser and Strauss, 1967, Strauss and Corbin, 1990). Also it fits the nature of the research question: "*Grounded theory questions...tend to be oriented toward action and process*" (Strauss and Corbin, 1990, p38). This study of disclosure is "action" orientated because it seeks to explore subjective understanding by taking into account the role which interaction with "others" plays in developing "meaning" (Blumer, 1969, Schwandt, 2001). A fuller explanation can

be found later in this chapter where I set out the philosophical roots of grounded theory. Disclosure of illness is a social process and elements of it are likely to involve social interaction. Grounded theory's inductive approach facilitates greater understanding of the phenomenon of interest as Strauss and Corbin (1990) note "*one does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge*" (p.23). As discussed in the literature review disclosure is poorly defined, and grounded theory presents particular utility to the current study through the clarification of concepts relevant to disclosure.

3.13 The Key Tenets of Grounded Theory

Grounded theory has a number of distinguishing procedural features compared to other qualitative approaches (Charmaz, 2006). It is considered to be a rigorous approach because it outlines a series of steps concerning how to gather, collect and analyse the data (Glaser and Strauss, 1967). Its intention is to develop a theory which might be recognisable to those involved with the phenomena and in which they can identify a degree of "fit" with their experience (Glaser and Strauss, 1967). A distinguishing feature of grounded theory is the constant comparative technique of analysis: examples of the phenomena identified by participants are coded then compared and contrasted throughout the data collection phase of the study (Glaser and Strauss, 1967). Key issues raised by the participants are followed up in subsequent research interviews (Glaser and Strauss, 1967). Unstructured, open interviews are used to gather the data, to ensure that the participant's subjective views are allowed to emerge. The resulting theory is therefore said to be grounded in the data and discovered, not preconceived by the researcher (Glaser and Strauss, 1967, Charmaz, 2006). The subsequent debates concerning this process referred to

as the emerging versus forcing are set out in further detail later in this chapter. The theory must be developed prior to conducting an in-depth literature review (Glaser and Strauss, 1967). An essential element of the theory is the development of a core category which explains the phenomenon under consideration and is intended to be a central product of the participant's accounts (Glaser and Strauss, 1967, Anells 1997a).

3.14 Summary

The choice of approach was based on the following considerations. Firstly, the need for an exploratory methodology which can develop understanding of the phenomenon of disclosure of illness. Secondly, an inductive qualitative methodology to allow data to emerge from the participants rather than testing a hypothesis. Thirdly, an approach explicitly setting out the author's philosophical stance, acknowledging the researcher's role in the analysis and thus the construction of the theory which emerges (Charmaz, 2006). Constructivist grounded theory has been selected for this study because the approach fits all these criteria (Charmaz, 2006). In the next section I set out the rationale for adopting constructivist grounded theory within the context of an historical overview of grounded theory.

3.15 Why Constructivist Grounded Theory? Historical Overview

Charmaz (2006) developed her own strand of grounded theory, entitled "Constructivist Grounded Theory", setting out a new approach for the future: "*...we look back into the history of grounded theory in the twentieth century and look forward into its yet unrealised potential for the twenty-first century*" (p1). I therefore contextualise the decision to adopt constructivist grounded theory in this study by setting out an overview of the origins and the philosophical underpinning of

grounded theory. I also set out the key debates about grounded theory which were taken into account in my decision to adopt constructivist grounded theory (Charmaz, 2006).

3.16 The Origins of Grounded Theory

In this section the origins and philosophical underpinning of grounded theory are set out. Table 3 sets out a chronology of key relevant methodological texts on grounded theory, beginning with the original textbook on grounded theory (Glaser and Strauss, 1967).

Table 3 Chronology of Key Methodological Texts on Grounded Theory by Glaser and Strauss, Glaser, Strauss and Corbin and Charmaz

<ul style="list-style-type: none"> • 1967 Glaser and Strauss <i>The Discovery of Grounded Theory Strategies for Qualitative Research</i> • 1978 Glaser <i>Advances in the Methodology of Grounded Theory, Theoretical Sensitivity</i> • 1987 Strauss <i>Qualitative Analysis for Social Scientists</i> • 1990 Strauss and Corbin <i>Basics of Qualitative Research Grounded Theory Procedures and Techniques</i> • 1992 Glaser <i>Emerging Versus Forcing Basics of Grounded Theory analysis</i> • 2000 Charmaz <i>Objectivist Versus Constructivist Grounded Theory</i> • 2002 Glaser <i>Constructivist Grounded Theory?</i> • 2006 Charmaz <i>Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis</i>
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Grounded theory was developed in reaction to the predominant positivist approaches at the time (Glaser and Strauss, 1967). Both Glaser and Strauss each went on to modify the approach (Glaser, 1978, Strauss and Corbin, 1990). Glaser’s (1992) book entitled: “*Emerging versus Forcing*” was written in response to, and strongly challenged Strauss and Corbin’s (1990) modifications. Glaser (2002) also critiqued Charmaz’s (2000) constructivist grounded theory, arguing that this approach again “forces the data”.

The origins of grounded theory lie in Sociology, particularly the Sociology of Health and Illness (Glaser and Strauss, 1967). It was the American sociologists Glaser and Strauss who developed the research approach grounded theory in the seminal book, *Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser and Strauss, 1967). When Glaser was employed by Strauss to work on a study of “dying

in hospital" (Glaser and Strauss, 1965) the need to formulate an explicit, methodical system to code the data was identified (Glaser, 1992, Strauss, 1990). The methodology as presented in *Discovery of Grounded Theory* was a reaction to the challenge of the dominance of the quantitative approaches which posited that qualitative research was less rigorous (Glaser and Strauss, 1967). As a reaction to this, Glaser and Strauss (1967) developed a technique within the context of social research with the purpose of "*discovery of theory from the data.*" Their intention was to close what they described as: "*the embarrassing gap between theory and empirical research*" (p7). That is to say they set out to legitimise the generation of theory within the qualitative paradigm by outlining methods to develop theory. During the 1960s when grounded theory was developed, the dominant view was that knowledge was regarded to be "true" or "false" only if it had been "tested" and deemed a verifiable "fact." The intention was to offer an alternative approach to the prevailing consensus that sociologists could only conduct research in the vein of "verification." Verification is defined as: "*the activity of determining whether a statement is true or accurate*" (Schwandt, 2001, p270). The prevailing positivist paradigm emphasised the gathering of verifiable "facts." One difficulty with this view of knowledge was that such research limited the creative approach necessary to discover the theory (Glaser and Strauss, 1967). In contrast, Glaser and Strauss (1967) argued that a theory might be "discovered" and so in order to do this researchers should enter the field devoid of preconceptions with regards to what categories or hypotheses are likely to be of importance (Glaser and Strauss, 1967). In their view, grounded theory may be used to develop two types of theory: "substantive" and "formal." Substantive theory sets out to explore a broad area of sociological interest such as patients' treatment for long-term conditions. Whereas,

formal theory explores areas of sociological interest such as “stigma” or “deviance” and so has a narrower focus (Glaser and Strauss, 1967). The nature of the theory which emerges is not necessarily generalisable to other contexts or settings.

I now go on to present an overview of the philosophical roots of grounded theory: pragmatism, symbolic interactionism and the Chicago School of Sociology noting their influences on Charmaz leading to the development of constructivist grounded theory (Charmaz, 2006).

3.17 Philosophical Roots of Grounded Theory

3.18 Pragmatism

George Herbert Mead (1863-1931) a professor of philosophy at the University of Chicago was a key founder of pragmatism (Hammersley, 1989, Benzies, 2001). Pragmatism was particularly influential in the development of grounded theory. Pragmatists argue that: *“we cannot know anything beyond our experience...experience (is)...a world of interrelated phenomena that we take for granted in everyday life”* (Hammersley, 1989, p45). This viewpoint is reflected in its two defining features: anti-foundationalism, the view that knowledge may not be known completely in an objective positivist way and the fallibilistic view, that our knowledge of the world is limited and so cannot be fully known (Schwandt, 2001). Therefore pragmatism influenced Charmaz’s perspective that knowledge is socially constructed and we cannot know things completely, only partially (Charmaz, 2006).

Mead was interested in the role of symbolic language and the role which interaction with others plays in defining oneself. He discussed the differences between the self, I and me. In his view, “I” represents the inner voice of the individual and the notion of “me” is constructed through the responses of others to us. It is through the

process of interacting with others that the self is developed (Benzies, 2001). This construction of meaning appears relevant to the current study, as research suggests that it is interaction with others that leads to stigma (Goffman, 1963). Thus the role of others in making sense of things is important to take into account.

3.19 Summary

Pragmatism offered new ways to examine interaction between individuals within the social world. It established the socio-philosophical foundation which led to the development of the theoretical perspective Symbolic interactionism, and subsequently the Chicago School of Sociology and grounded theory (Blumer, 1969, Hammersley, 1989, Crotty, 2003, Rice 1999, Benzies, 2001, Schwandt, 2001). In the following section I discuss symbolic interactionism.

3.20 Symbolic Interactionism

Symbolic interactionism was developed by Herbert Blumer (1969). Blumer was a postgraduate student at the University of Chicago, and Mead's research assistant. In Blumer's (1969) book *Symbolic Interactionism Perspective and Method*, he notes that Mead outlined two types of social interaction: "the conversation of gestures" and "the use of significant symbols." The "conversation of gestures" is the description of the process of interaction as in what may cause things to "act" and whether it is individuals themselves who have caused others to act: "*when our gestural meanings take on identical meanings to ourselves and to others, then we have the "significant symbol"*" (Hammersley, 1989, x111). Blumer (1969) renames them: "non-symbolic interaction" and "symbolic interaction." Symbolic interactionism sees individuals as "actors" who must "act" as a consequence of being in a particular situation which warrants "action." "Meanings" he suggests play their part in action through self-

interaction, in other words through a process of communication with oneself. Objects are also regarded as playing an important role. These are defined as: *“anything that can be indicated or referred to. The crucial point however is that it is through others that the meaning of the object is conferred (Blumer, 1969, p5).*

Blumer (1969) states there are three key tenets to symbolic interactionism:

- *“The first premise is: human beings act toward things on the basis of the meanings that the things have for them*
- *The second premise is: the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows*
- *The third premise is: these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters” (p.2).*

3.21 Summary

In summary grounded theory is underpinned by symbolic interactionism and as noted earlier was heavily influenced by pragmatism (Strauss and Corbin, 1990, Benzies, 2001, Charmaz, 2000, 2006). One of the co-founders of grounded theory, Strauss was particularly influenced by Blumer whom he described as: *“my intellectual hero” (Baszanger, 1998).* The interactive and dynamic nature of symbolic interactionism are of relevance to the current study. Disclosure of illness inherently involves others and thus represents a form of interaction as well as conveying the notion that disclosure is a dynamic process (Charmaz, 2006). As Charmaz (2006) notes, the symbolic interactionist’s perspective assumes that: *“interaction is inherently dynamic and interpretive and addresses how people create, enact and change meanings and actions” (p7).*

The meaning of disclosure from a symbolic interactionist perspective posits that the responses and reactions of the person to whom the individual has disclosed play an important role in the development of meaning. Therefore it is through a social process of interaction with others that meaning may be created. The meaning attributed to interactions with others is the focus of my study. Disclosure of illness inherently involves others and it is through telling others that meaning is generated. Symbolic interaction perceives the individual to self-interact with themselves in processing the meaning generated through others responses (Blumer, 1969). Symbolic interaction also fits with my study because it suggests that individuals do not live in isolation. Charmaz (2006) argues that her version of grounded theory seeks to build upon the pragmatist Chicago School roots of grounded theory and so an overview of this is now presented.

3.22 The Chicago School of Sociology

The University of Chicago's Department of Sociology built up a significant reputation for conducting qualitative research (Hammersley, 1989). It became known as the "Chicago School of Sociology" emphasising the importance of seeking understanding of social interaction and social processes: "*at the centre of their attention*" (Strauss, 1987, p.6). They conducted ethnographic fieldwork in Chicago seeking to identify: "*a slice of life*" (Denzin and Lincoln, 2000, p13). The "Chicago School" strongly influenced Strauss with its interest in the dynamic nature of human experiences (Strauss and Corbin, 1990). Its preferred method was to use interviews and observations to gather data, rather than survey techniques. As Strauss and Corbin, (1990) note: such influences fed into the development of grounded theory in several ways, by highlighting the importance of:

- The necessity of conducting research in the natural setting of the people being investigated
- The significance of theory, based on real life, and its ability to advance an area of academic thought
- The view that knowledge is subject to continual change
- That individuals are engaged in and can influence “the world”
- The focus on the dynamic and temporal nature of the social world
- The relationship between meaning and action

Charmaz (2006) argues that she has realigned the focus of grounded theory returning it to the philosophical roots of pragmatism and the Chicago School of Sociology by:

- *“examining processes*
- *making the study of action central*
- *creating abstract interpretive understandings of the data”* (p9).

In the next section I set out an overview of the debates on grounded theory considering which approach is most relevant to the current study and the rationale for adopting constructivist grounded theory (Charmaz, 2006).

3.23 Debates on Grounded Theory

Over time there have been several modifications to the grounded theory approach and extensive debate as to: *“who’s got the real grounded theory?”* (Charmaz, 2000, p513). Firstly, I present a consideration of Glaser’s (1978, 1992) version of grounded theory with reference to the current study. Secondly, I present a consideration of Strauss and Corbin’s version of grounded theory with reference to

the current study setting out why I have elected not to adopt these approaches. Thirdly, I set out an overview of the key “emerging versus forcing” debate between Glaser (1992) and Strauss and Corbin’s (1990) versions of grounded theory. Finally I set out the rationale for adopting Charmaz’s (2006) constructivist grounded theory as the methodological framework for this study taking the debates into account.

3.24 Consideration of Glaserian (1978, 1992) Grounded Theory in this Study

The table below sets out the key tenets of Glaserian (1978) grounded theory.

Table 4 Key Tenets of Glaserian (1978) Grounded Theory

- | |
|--|
| <ul style="list-style-type: none">• Theoretical Sensitivity – remain open: <i>“as few predetermined ideas as possible”</i> (p3).• Theoretical Sampling• Theoretical Saturation of Categories• Substantive (open) Coding• Theoretical (selective) Coding• Constant Comparative Data Analysis• Writing of Theoretical Memos• Inductive and Deductive Process of Coding: <i>“derive or induce logic from data then apply it to data after ideas emerge”</i> (p11).• Identify a Basic Social Process (BSP) which: <i>“explains a considerable portion of the action in an area (and) integrative of all the categories needed in a theory”</i> (p5). |
|--|

Glaser (1978) argues that one should not enter the field with a preconceived notion or deductive hypotheses of what the important concepts or phenomena might be: *“the problem emerges, and questions regarding the problem emerge by which to guide the theoretical sampling”* (p25). Glaser (1978) advocates allowing the phenomenon to emerge from the data, thus ensuring “theoretical sensitivity” (Glaser, 1978). Applying a Glaserian perspective to the current study would not initially

identify disclosure as a phenomenon of importance; instead one would wait to see what emerges in the data once fieldwork has commenced. The first step is open coding which Glaser (1978) describes as: “*coding the data in every possible way*” (p56). The researcher codes different occurrences into categories which may “fit” until theoretical saturation occurs. The key aim is to allow the data to emerge and not force it into predefined categories. Open coding also plays a role in decisions regarding theoretical sampling. A range of questions inform the process of open coding: “*what is this data a study of?*” (Glaser, 1978). This highlights the fact that unexpected data may be discovered in the study. The researcher then embarks on a process of “constant comparison” of categories, posing the question: “*what category or property of a category, of what part of the emerging theory, does this incident indicate?*” (Glaser, 1978, p.57). He suggests that it is important to ask these questions in order that the codes: “*earn the right*” to be part of the theory and so are grounded in the data (Glaser, 1978). Theoretical selective coding is used to identify the core variable, that is the “basic social process.” This process involves coding the data to identify key variables which appear to bear particular significance and so may form part of the emergent theory. Theoretical selective coding sets out to link substantive codes and examine the relationships as they relate to one another in the form of hypotheses which may then become part of the theory. Two types of code emerge, substantive and theoretical, which are defined as follows: “*substantive codes conceptualize the empirical substance of the area of research. Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into a theory*” (Glaser, 1978, p55). Finally, the “basic social process” which explains the key constituents of the theory is identified. The emergent theory

should “fit” and “work” providing a relevant account of the area of interest (Glaser, 1978).

3.25 Summary

Having outlined Glaser’s (1978) procedures and considered their relevance to the current study I have elected not to adopt his approach. This decision is based on both philosophical and procedural decisions. Philosophically, Glaser’s (1978, 1992) approach is arguably positivist in its underpinnings: the researcher adopts a neutral stance using a set of procedures to render the data into identifiable knowledge (Charmaz 2000a). Procedurally, whilst Glaser (1978) presents insights into the methods of grounded theory, due to their complexity these are arguably not easily implemented: *“the abstract terms and dense writing Glaser employed rendered the book inaccessible to many readers”* (Charmaz, 2000a, p512).

I now go on to present a consideration of Strauss and Corbin’s (1990) version of grounded theory with reference to the current study.

3.26 Consideration of Strauss and Corbin’s (1990) Grounded Theory in this Study

In time Strauss (1990, 1998) developed his own guide to conducting grounded theory: *“Basics of Qualitative Research, Grounded Theory Procedures and Techniques.”* His book was co-authored by Juliet Corbin, an American nurse and colleague of Strauss (Strauss and Corbin, 1990). The key additional procedural techniques suggested by Strauss and Corbin (1990, 1998) are presented below (table 5) and later compared and contrasted with Glaser (1978) (table 7).

Table 5 Key Additional Procedures Strauss and Corbin (1990, 1998) Grounded Theory

- Open coding
- Axial coding
- Selective coding
- Theoretical sensitivity permits literature
- Constant comparative techniques: Waving the red flag, Flip-flop technique
- Use of matrices: Paradigm model, Conditional matrix

As the title of the book suggests, it outlines a series of additional procedural steps and techniques which are intended to enhance “theoretical sensitivity.” The additional procedures and techniques stemmed from discussions with students requesting clearer guidance on methods of translating data into “theory.” (Strauss, 1998) They recommend additional “constant comparative” techniques and the use of matrices in analysis, in order to improve the quality of grounded theory studies (Strauss, 1987). As Strauss and Corbin (1990) note: “*we need theoretical sensitivity, the ability to “see” with analytic depth what is there*” (p76). These recommendations mark a divergence from both the original version of Glaser and Strauss’s (1967) grounded theory and Glaser’s (1978) subsequent modifications. New additions include the proposition of three levels of coding: open coding, axial coding and selective coding (not necessarily sequential). Open coding sets out to identify from the data concepts, their properties and dimensions (Strauss and Corbin, 1998). Axial coding examines the relationship between categories of the phenomenon in the data according to: “*who, when, where, why, how, and with what consequences?*” (Strauss and Corbin, 1998, p.127). The results of such questions serve to illuminate how and why the phenomenon occurs (Strauss and Corbin, 1998).

Selective coding is an important stage, the purpose of which is to identify the “core category: *“the central phenomenon around which all other categories are integrated”* (Strauss and Corbin, 1990, p116). Theoretical memos are used throughout the process to track the ongoing analysis and offer guides for areas which may require additional sampling. Strauss and Corbin (1990) also permit the use of literature to inform the research process and enhance theoretical sensitivity. In particular, they set out to enhance a creative approach to analyzing the data including the researcher’s perspective who interacts with the data to explore: *“what is going on?”* (p145). The findings of this process influences subsequent sampling as examples are compared and contrasted with existing data. This is crucial they argue, in order to gain fresh understanding of phenomena. Strauss and Corbin’s (1990) approach focuses upon social process. Its focus is on process and meaning as defined through interaction with others: *“meaning is defined and redefined through interaction”*(p9). They define process to mean: *“sequences of action/interaction pertaining to a phenomenon as they evolve over time”* (Strauss and Corbin, 1998, p.123). Process is regarded to be dynamic and fluid changing as individuals move in and out of interaction in different situations and context. Indeed, Strauss and Corbin (1990) describe process to be similar to music because it changes in terms of tempo and style.

3.27 Summary

Having outlined Strauss and Corbin’s (1990) procedures and considered their relevance to the current study I have elected not to adopt their approach, the reason being that Strauss and Corbin’s (1990) epistemological position is not explicitly set out in their text and so has been subject to much interpretation (Glaser 1992, Annells, 1997a,b, Charmaz 2000a, Macdonald and Schreiber, 2001). Annells

(1997a) states that their stance is relativistic because the theory which they develop reflects: *“a local and constructed reality”* (p202). Although Annells (1990) had earlier described it as “neo-positivist” because the researcher must adopt a prescribed number of steps in order to analyse and judge the utility of the findings. As Strauss and Corbin (1998) state, there is an element of construction of the data: *“Although we do not create data, we create theory out of data...enabling (participants) to speak in voices that are clearly understood”* (p56). There is a mix of subjective and objective approaches to the data as they argue it is difficult to suspend prior views of the data (Strauss and Corbin, 1990). The range of perceptions of their philosophical stance seem to support Macdonald and Schreibers (2001) assertion that it open to interpretation: *“people can find support in it for any ontology they wish”* (p45).

I now go on to set out an overview of the “emerging versus forcing” debates concerning Glaser’s (1992) critique of Strauss and Corbin (1990) grounded theory.

3.28 The “Emerging versus Forcing” Debate: Glaser’s (1992) critique of Strauss and Corbin (1990)

As noted earlier, since its inception in 1967 there have been several modifications to grounded theory and extensive debate often referred to as the “Emerging versus forcing” debate (Glaser, 1992, Strauss and Corbin 1990, Charmaz, 2000). Charmaz (2000) notes: *“grounded theory methods have come under attack both within and without...What grounded theory is and should be is contested”* (p510). The key differences between the procedures used by Strauss and Corbin (1990) and Glaser (1978, 1992) to develop a grounded theory are set out in this section with reference to the emerging versus forcing debate. I go on to clarify the contribution of Charmaz (2000, 2006, 2007) to this debate in the following section.

The differences between Strauss and Corbin (1990) and Glaser's (1978, 1992) versions of grounded theory can be summarized into three points (see table 7).

Firstly, procedural differences Strauss and Corbin (1990) advocate the use of additional procedures such as, "waving the red flag", "the flip flop", technique and the use of "matrices" to maximise theoretical sensitivity and ensure the development of a grounded theory which is dense and precise (Strauss and Corbin, 1990). Glaser (1992) challenges these additional procedural techniques arguing that constant comparative methods are sufficient in themselves to develop a grounded theory: "*and that is all there is to it*" (p43). Thus arguing that they are "forcing" the data rather than allowing what is important to emerge.

Secondly, the researcher's stance to the data. Strauss and Corbin's (1990) approach permits the inclusion of the researcher's views and experiences, since coding the data is essentially a creative process and argues that previous experience or reading of an area is beneficial to the development of the theory. In contrast, Glaser (1992) argues that one should not approach the data with preconceived ideas, and the use of literature should be delayed until the theory has been developed. This he states facilitates the emergence of what is likely to be important in the study.

Thirdly, philosophical differences exist between the authors. The divergent procedural techniques may be traced to philosophical perspectives (Annells, 1996, Charmaz, 2000). The philosophical differences between Glaser and Strauss may stem from their earlier training and intellectual influences: Glaser's quantitative and Strauss's qualitative influences. Glaser studied at Columbia University, New York United States of America and was influenced by the work of Paul Lazarsfeld who was renowned for developing quantitative survey methods (Strauss, 1990, Charmaz,

2006). Glaser's (1992) philosophical stance has been described as "critical realist" whose perspective posits that: "*the social and natural worlds have differing realities, but that both forms of reality are probabilistically apprehensible, albeit imperfectly*" (Annells, 1996, p385). By contrast, Strauss trained at the University of Chicago, whose Department of Sociology had built up a significant reputation for conducting qualitative research.

Having set out an overview of the key debates and consideration of approaches within grounded theory in the next section I go on to discuss the role of constructivist grounded theory as applied to the current study.

3.29 The Role of Constructivist Grounded Theory in this Study

3.30 Constructivist Grounded Theory as an Emergent Technique

In essence I have elected to adopt constructivist grounded theory for the following reasons. Firstly, its philosophical approach fits my constructivist philosophical assumptions as set out earlier in this chapter. Secondly, the flexible approach to the methods and thirdly, the central role of the researcher in the analysis process and theory which facilitates an emergent approach to the data. The key tenets of constructivist grounded theory are set out below in table 6.

Table 6 The Key Tenets of Constructivist Grounded Theory Charmaz (2000, 2006)

- Constructivist Epistemological Assumptions (include the researcher's perspective)
- Theoretical Sensitivity: Emergence is Accessed via the Researcher who is not a "*distant observer*" (p178).
- Methods are Flexible and thus "Emergent" to access the Unanticipated and Facilitate the Creative Process of Coding
- Initial Coding: "*remain open to exploring whatever theoretical possibilities we can discern in the data*" (p47).
- Theoretical Coding: "*Clarify and sharpen your analysis but avoid imposing a forced framework on it with them*" (p66).
- The End Product of Constructivist Grounded Theory is not Pre-ordained: "*the finished work is a construction –yours.*" (Charmaz, 2006, px1).

Charmaz (2000) published a key paper entitled objectivist versus constructivist grounded theory in which she sets out her constructivist approach which: *reclaim these tools from their positivist underpinnings to form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements* (p510). Glaser (2002) responded to Charmaz's (2000) paper by arguing that: *the researcher's interactive impact on the data (is) more important than the participants. Constructionism is used to legitimate forcing* (p4). That is to say, including the researcher's perspective is intrusive and unnecessary since the process of conducting constant comparative methods are: "*all that is required*" (Glaser, 2002). However I have elected to adopt the constructivist grounded theory because I disagree with Glaser's (2002) point and believe that: "*more is required*". For example, Charmaz's constructivist grounded theory (2000,2006, 2007) is an "emergent" technique which will allow further exploration and so facilitate fresh

insight into the area of disclosure of illness on which there is limited research to date. I now go on to set out its relevance to this study in detail.

Charmaz (2006) presents grounded theory as an emergent, approach whose methods can be adopted flexibly: *a set of principles and practices, not ...prescriptions or packages* (p9). Procedurally, Charmaz (2007) states that the methods should be seen as “flexible” rather than “prescriptive” in order to facilitate the emergence of unanticipated data. Indeed Charmaz (2006) argues that one can adopt the procedures of grounded theory set out by Glaser and Strauss (1967) and later modified by Glaser (1978) because the procedures are essentially neutral (Glaser and Strauss, 1967, Glaser, 1978). As Charmaz (2006) states: *We may think our codes capture the empirical reality. Yet it is our view: we choose the words that constitute our codes* (p47). In this study the participants’ views will not be “forced” into pre-defined categories but rather their data will emerge and I, the researcher, will be highlighting the data and constructing the codes. Therefore, this approach fits my study well since emphasis is placed upon the significance of the role which I play in terms of the theory which “emerges” from the data. Charmaz (2007) argues that the constructivist version of grounded theory draws its emergent nature from the researcher in terms of the questions they pose and means employed to analyse the data as well as the choice of topic itself. I have also selected constructivist grounded theory because this approach puts participants’ views to the fore by arguing that there is no “pre-ordained” end product of grounded theory. Whereas Glaser’s (1978, 1992) approach is actively seeking to identify the endpoint of: *“basic social processes”* as a means by which to illustrate the emergent nature of the data (Charmaz, 2007).

Philosophically, Charmaz's (2006) approach is constructivist because she argues that the researchers' perspective is integral to the process of collecting data and influences the theory which emerges because it stems from both the participants accounts and the researcher: *"neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our theories from our past and present involvements and interactions with people, perspectives and research practices"* (p10). In contrast Glaser and Strauss's (1967) classic version of grounded theory sets out to "discover" the theory entirely independent of the researchers' stance. Charmaz (2000) argues that Glaser's (1978, 1992) approach is positivist since his intention is that the researchers perspective must be excluded, and a set of procedures are recommended to render the data into identifiable knowledge. She argues that Strauss and Corbin's (1990) approaches are also inherently positivist: *"Both...assume an external reality that researchers can discover and record. Glaser through discovering data, coding it and using comparative methods step by step; Strauss and Corbin through their analytic questions, hypotheses and methodological applications"* (Charmaz, 2000, p513). However, Charmaz (2000) goes on to argue that Strauss and Corbin's (1998) second edition of *Basics* suggests a "post-positivist" philosophical stance.

3.31 Chronicity

Charmaz's (2006) grounded theory is further relevant to my study aims to explore ongoing, long-term conditions which may evolve over time because it regards interaction to be dynamic and subject to change. Indeed, as an approach it is well suited to exploring long-term conditions and disclosure in particular because the theory "emerges" and is not "generated" (Charmaz, 2000, 2006). Furthermore, according to Charmaz (2006) it is important to code for "actions" rather than

“themes” to identify potential temporal sequences in the data. Grounded theory has been useful in aiding theoretical understanding of long-term conditions. It has also provided insight into the meanings that individuals attach to such conditions: *“Grounded theory can illuminate how people learn the difference between having a diagnosis and an illness. By studying how people learn about chronicity, we also gain ideas about what having the illness means to them”* (Charmaz, 2006, p152). Charmaz has conducted much qualitative work on living with long-term conditions (Charmaz, 1983, 1991, 2000). Her book “Good Days, Bad Days: The self in chronic illness and time” was notable because it sets out the changing nature of living with a long-term condition and the difficulties participants faced. She has also written on the topic of disclosure of long-term conditions noting that issues around disclosure emerged unexpectedly in participants qualitative accounts and so she explored it further: *“Ill people attached such significance to these issues, which, in turn, caused me to look at them more systematically and to raise new questions about them”* (Charmaz, 1990, p1169).

3.32 Summary and Conclusion

In this chapter I have set out my rationale for adopting constructivist grounded theory as the methodological framework for my study. In summary the selection of an inductive, qualitative research approach located within the constructivist paradigm has been guided by the specific aims of the current research study. Firstly, philosophically, Charmaz’ s (2006) approach is particularly relevant to the current study because she provides explicit clarification on her constructivist stance, in contrast to Strauss and Corbin’s (1990) approach which is open to interpretation. Secondly, constructivist grounded theory facilitates a flexible approach to the methods of conducting grounded theory with the intention of developing exploratory

work in the field of disclosure of illness. Thirdly, her approach takes into account the importance of the role of the researcher in the development of the theory. Fourthly, her approach is deemed to be emergent by focusing upon the need to return to the pragmatist roots of grounded theory by studying action and process which are relevant to disclosure of illness. In the next chapter (Chapter four) I go on to present the methods adopted in the study.

Table 7 Comparison of Glaser (1978) (1992) and Strauss & Corbin (1990)

Procedural and Philosophical Differences

	Glaser (1978*) (1992)	Strauss and Corbin (1990,1998*)
Philosophical Differences (Annells 1996, Charmaz, 2000)	Critical realist: "Generated grounded theory really exists in the data" (p53).	Open to Interpretation: Relativist search for: "A reality that cannot actually be known, but is always interpreted" (p22). Positivist search for: argues: "an external reality that researchers can discover and record...through their analytic questions, hypotheses and methodological applications" (Charmaz 2000 p513)
Researchers Stance to the Data	Positivist (etic) The theory should "emerge" and not be overly influenced by the researcher. A common understanding of the phenomenon is "out there".	Open to Interpretation: "We create theory out of data enabling them (participants) to speak in voices that are clearly understood and representative" (* p56). Positivist search for:"an external reality that researchers can discover and record...through their analytic questions, hypotheses and methodological applications"(Charmaz, 2000, p513). Postpositivist: "giving voice to their respondents, representing them as accurately as possible, discovering and acknowledging how respondents views of reality conflict with their own, and recognizing art as well as science in the analytic product and process (Charmaz
Research Question	An emerging account is there to be "discovered": "The research question is not a statement that identifies the phenomenon to be studied...out of open coding, collection by theoretical sampling, and analysing by constant comparison emerge a focus for the research" (p25).	The phenomena is identified: "Underlying this approach to qualitative data is the assumption that all of the concepts pertaining to a phenomenon have not yet been identified or, if so, the relationships between the concepts are poorly understood or conceptually undeveloped"(p37).
Common Procedures	<ul style="list-style-type: none"> • Theoretical sampling • Constant comparative technique • Theoretical sensitivity • Writing of memos 	<ul style="list-style-type: none"> • Theoretical sampling • Constant comparative technique • Theoretical sensitivity • Writing of memos • Theoretical saturation
Theoretical Sensitivity	"The first step in gaining theoretical sensitivity is to enter the research setting with as few predetermined ideas as possible" (*p3). "It is hard enough to generate one's own ideas without the "rich" derailment provided by the literature in the field" (p31). Delay use of literature until	"To discover theory in data we need theoretical sensitivity, the ability to "see" with analytic depth what is there" (p76). "One can come to the research situation with varying degrees of sensitivity depending upon previous reading and experience with or relevant to an area" (p4). Literature may be used throughout the process: "an actual interplay of reading literature and data analysis"(p56). • Use of fieldwork diaries
Timing of Coding	Coding does not begin immediately: the researcher should linger with the data what is important what is important will "emerge"	Coding begins immediately

	Glaser (1978*) (1992)	Strauss and Corbin (1990,1998*)
Coding Procedures	<p>CODING</p> <p>Open coding: "coding the data in every possible way" (*p56).</p>	<p>THREE LEVELS OF CODING (not necessarily sequential)</p> <p>Open coding: "The process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p61).</p> <p>Axial coding: "specifying a category (phenomenon) in terms of the conditions that give rise to it; the context (it's specific set of properties) in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those</p>
	<p>Selective coding: "to selectively code for a core variable.. the analyst delimits his coding only to those variables that relate to the core variable in sufficiently significant ways to be used in a parsimonious theory" (*P61).</p> <p>Theoretical coding: "theoretical codes conceptualise how the substantive codes may relate to each other as hypotheses to be integrated</p>	<p>This process identifies:</p> <ul style="list-style-type: none"> • Categories: "concepts that stand for phenomena" • Dimensions: "the range along which ... properties of a category vary". • Properties: "characteristics of a category ... which defines and gives it meaning" (IOlp, 1998). <p>Selective coding: "The process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that need further refinement and development" (p. 116).</p>
Additional Procedures	<p>Additional procedures are not necessary: "constant comparison" will produce a grounded theory: "Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it" (p43).</p>	<p>Additional constant comparative procedures can enhance "Theoretical Sensitivity" and guide theoretical sampling: "We intend to provide a number of techniques to assist you, the analyst to make use of your creative capacities and to further develop the theoretical sensitivity that may already be present within you"</p> <p>Theoretical comparisons as tools: (1) "Flip flop technique:" the concept is: "turned "inside out" or "upside down" to obtain a different perspective" (p94) (2) "Waving the red flag:" "certain words and phrases...such as "never," "always"... should be taken as signals to take a closer look" (p.92). (3) "Far out comparisons:" "making striking comparisons" (p82).</p> <p>Matrices:</p> <p>(1) Conditional matrix:"A diagram useful for considering the wide range of conditions and consequences related to the phenomenon" (pi 58).</p> <p>(2) Paradigm model: "In grounded theory we link subcategories to a category in a set of relationships denoting causal conditions, phenomenon, context, intervening conditions, action, interactional strategies, and consequences ... use of this model will enable you to think systematically about data and relate them in very complex ways. Unless you make use of this model, your grounded theory analyses will lack density and precision" (p99).</p>
Outcome	<p>A basic social process is discovered which: "Explains a considerable portion of the action in an area and relates to most categories of lesser weight used in or making the theory work" (*p5).</p> <p>Generated grounded theory</p>	<p>"Generate a rich, lightly woven, explanatory theory that closely approximates the reality it represents" (p57).</p> <p>An explanatory general theory which explains how the phenomenon works in a range of contexts</p>

	Glaser (1978*) (1992)	Strauss and Corbin (1990,1998*)
Criteria for Rigorous Grounded Theory	<p>Fit": the categories of the theory "fit" or match the data</p> <p>"Work": the theory explicates, predicates and interprets what is going on in a substantive area.</p> <p>"Relevance": It is relevant to that area.</p> <p>"Modifiabiitiy": "though basic social processes remain in general, their variation and relevance is ever changing in our world" (p5*).</p>	<ul style="list-style-type: none"> • Fit • Understanding • Generality • Control

4.0 Chapter Four: Methods

4.1 Introduction

This chapter presents an overview of the methods employed in accordance with the constructivist approach to grounded theory which takes into account the need to be flexible and so adopt an emergent approach to the data (Charmaz, 2006). The research question with its focus upon a social process lent itself to this methodology. The research design, study population, and means of gathering the data are presented. The process of data analysis is described and the principles of ethics applied to the study. Finally, the procedures taken to ensure the study results are trustworthy are set out. Issues arising from the methods are presented in the discussion and conclusions chapter (chapter six) in greater detail.

4.2 Summary of the Methods

Recruitment commenced in December 2006 and was completed in August 2007. The source of data was in-depth qualitative interviews. Participants were recruited from two settings: patient support groups and clinical nurse specialist clinics. A total of thirty-five qualitative interviews were conducted (fifteen people living with epilepsy, and twenty people living with type 1 diabetes). Overall there were fewer men than women in the sample group (fourteen men compared to twenty one women). Those recruited from the nurse specialist clinics tended to be younger with the majority aged between sixteen and thirty-five years old while most of those recruited from the patient support groups were aged between forty-six and seventy-five years old. There were also differences in occupational status across the study sites. Many of those recruited from the clinical nurse specialist clinics were students, while those recruited from the patient support groups tended to be retired. The data were fully

transcribed and coded using a three step process: initial line by line coding, focused coding and constant comparative methods. The qualitative data analysis programme QSR.N5 was used to manage the organisation of the data.

Research Question: What is the role of disclosure to others in managing a long-term condition?

4.3 Aims of the Study:

The study was designed to explore the following:

- the role that disclosure plays in managing a long-term condition in the lives of those living with type 1 diabetes or epilepsy

4.4 Study Design

A qualitative grounded theory research methodology was selected to provide insight to and clarification of the role of disclosure in the management of long-term conditions (Charmaz, 2006, Strauss and Corbin, 1990). In addition, this methodology was considered to be pertinent to this study due to its focus on social processes and interactions and so particularly useful in analysing perceptions of the role of disclosure which inherently involves others (Blumer, 1969, Glaser and Strauss, 1967, Charmaz, 2006, Strauss and Corbin, 1990).

The literature review (chapter two) highlighted that research on the role of disclosure from a psychosocial perspective is relatively limited. Following the guidelines of constructivist grounded theory an exploratory qualitative approach was adopted to facilitate the opportunity for participants to raise topics relevant to them and to tap into their individual, personal accounts (Charmaz, 2006). Open ended qualitative interviews fit the study well as they facilitate the capture of the dynamic nature of

disclosure such as potential changes over time: “*An interview goes beneath the surface of ordinary conversation and examines earlier events, views, and feelings afresh*”(Charmaz, 2006, p26). This approach has been used successfully in previous grounded theory studies on long-term conditions (Charmaz, 1990).

4.5 Recruitment to the Study

4.6 Rationale for Selection of Long-term Conditions Type 1 Diabetes and Epilepsy

The decision was taken to focus on individuals living with either epilepsy or type 1 diabetes (insulin dependent) as the literature review identified that few studies explored the role of disclosure across both conditions. Two long-term conditions were selected to facilitate a comparison of key similarities as well as differences between and within the groups in order to build upon existing studies: earlier studies on disclosure tended to focus upon one long-term condition. Such comparisons may also identify gaps in the provision of services. As illustrated in the literature review, although both conditions are prevalent and require varying levels of self care, they remain hidden to some extent. However they become visible when a diabetic has a hypoglycaemic episode, or an epileptic experiences a seizure.

4.7 Selection of Recruitment Setting

A pragmatic approach was taken as I sought access to those living with type 1 diabetes or epilepsy from a range of ages, socio-demographic backgrounds and period of time living with the condition. Participants were recruited from both patient support groups and clinical nurse specialist clinics in order to facilitate a

comparative approach across conditions and to gain access to a broad spectrum of experiences.

4.8 Clinical Nurse Specialist Clinics

Clinical nurse specialist clinics were identified as suitable recruitment sites for both pragmatic and theoretical reasons. It was a pragmatic decision to recruit those with long-term conditions within the single setting of a clinic. This study site also allowed access to patients who may not have attended patient support groups. It was a theoretical decision because as noted in Chapter two (literature review) nurses play a key role in the provision of care for those living with long-term conditions. Recruiting from the clinics allowed me to explore patients' perceptions of the role of health care professionals with regard to disclosure.

4.9 Patient Support Groups

Similarly, participants for the study were recruited from patient support groups for pragmatic and theoretical reasons. It was a pragmatic decision to recruit those with long-term conditions within a single setting and explore potential differences between attendees of support groups and clinics. It was also a theoretical decision because as highlighted in the literature review, those who attend patient support groups may not be "typical" of those living with the condition. Therefore, I sought to explore their reasons for attendance and the influence of the group, if any, on the decision making process concerning disclosure as well as exploring other issues raised during the interviews.

4.10 Description of Study Sites

4.11 Patient Support Groups: Epilepsy

Epilepsy Action is a registered charity in the UK. The aims of the charity are: “*to improve the quality of life and promote the interests of people living with epilepsy*” (Epilepsy Action Website, 2005). The Charity offers support and provides information to those living with epilepsy and to others with an interest in this condition. Patient support groups are volunteer led. Group meetings are held each month and an external speaker invited to address the group on relevant topics. These are attended not only by those diagnosed with epilepsy but also by their friends and family.

4.12 Patient Support Groups: Diabetes

Diabetes UK is a registered charity. The aim is to offer support and information, organise social events and raise awareness of diabetes. Patient support groups are run by volunteers. They meet each month and a speaker is invited to address the group on a topic of interest relevant to diabetes such as diet or exercise. They are attended by individuals not only diagnosed with either type 1 or type 2 diabetes, but also their friends and family.

4.13 Clinical Nurse Specialist Clinic: Epilepsy

The two clinics selected were held within two teaching hospitals in the South East of England. In clinic one, patients were seen twice per month. In clinic two the nurse had a higher case load, and patients were seen on a weekly basis. Patients were referred to the clinical nurse specialists by consultant neurologists and on occasions by general practitioners. The purpose of the clinic was to provide counselling,

information and support to those living with epilepsy on topics such as: seizures, surgery, medication, employment, and pregnancy.

4.14 Clinical Nurse Specialist Clinic: Diabetes Clinic

The clinic was set within a hospital in the South of England, and attended by those aged sixteen years and over. The function of the clinic was to provide advice specifically to young adults on the management of diabetes in areas such as diet, exercise, insulin control and any other issues of concern. The clinic was held fortnightly.

4.15 Research Access

4.16 Clinical Nurse Specialist Clinics

This element of the study was set in three NHS teaching hospitals in the South of England (see table 2). Since patients were being recruited from nurse specialist clinics, a number of procedural steps were required to facilitate this. Firstly, an application was made to the NHS Research and Development Department seeking approval for the study to take place, as set out in the *Research Governance Framework for Health and Social Care Act* (Department of Health, 2005g). Secondly, an application for an honorary contract was submitted to each NHS Trust. One trust stipulated that as part of this process I should also obtain clearance from the Criminal Records Bureau. Thirdly, as I was directly in contact with patients I was asked to complete an occupational health questionnaire.

Permission to proceed with the study was obtained from the nurses. However their stipulation to gain permission from the consultants in two of the proposed study sites (one Epilepsy, one Diabetes) led to delays. As a consequence of these delays, and in

order to supplement recruitment, it was necessary for me to seek alternative study sites.

4.17 Epilepsy

I met with the clinical nurse specialist in epilepsy at a major teaching hospital to request permission to conduct the study in the clinic. She acknowledged that disclosure of illness was an important topic and agreed to participate, pending ethical approval and permission from the relevant neurology consultants.

4.18 Diabetic Clinic

I met with the clinical nurse specialist in diabetes at a major teaching hospital to discuss the aims of the study and to request her permission for it to be conducted within the department. She agreed to participate, pending approval from the lead consultant. Permission was granted on the proviso that the study should not add to the workload of the clinic staff. This was taken into account when planning the process of recruitment.

4.19 Summary

The study raised a number of issues regarding access to study sites by means of clinicians, despite having ethical approval in place. Gaining research access to clinic attendees proved to be a time consuming and potentially sensitive process and raised interesting questions as to who is the ‘gate keeper’ to patient access (reflections on this process are set out in chapter five). As access was dependent upon an agreed process of recruitment the researcher had little control over this.

4.20 Patient Support Groups

In this section I discuss the identification of patient support groups and issues regarding access.

4.21 Epilepsy

As there were no patient support groups in the local area, they were identified via the national charity Epilepsy Action. An application was made to the Charity's research co-ordinator regarding the study. This was a necessary process in order to obtain contact details of patient support group leaders. Completing the application form was a detailed process requiring professional references and a copy of the letter giving ethical approval. The application for research access was successful. The Charity wrote to group leaders directly, and as a result I was invited by three support groups to present my study to potential participants at a group meeting.

4.22 Diabetes

The charity Diabetes UK was contacted to obtain details of the local group co-ordinators. Following a telephone discussion with the co-ordinators, information regarding the aims of the study was forwarded to them. The study was then discussed at their committee meeting. Permission to recruit from three diabetes groups was granted and I was invited to present my study at each group's meeting.

4.23 The Recruitment Process

This section presents the process of recruitment to the current study. A pragmatic approach was taken in line with the wishes of the leaders of the patient support groups and the nurses. Due to the different settings and issues over access, a range of methods of recruitment were employed (Table 2) presents an overview of the

process of recruitment. Recruitment took place in two key settings: patient support groups and clinical nurse specialist clinics. I will now discuss the process of recruitment to the patient support groups (epilepsy and diabetes respectively).

4.24 Patient Support Group: Epilepsy

I attended four evening meetings and delivered a brief presentation on my study. Attendees were then invited to ask questions. It was emphasised throughout the meeting that they were under no obligation to participate in the study but should they wish to, they should complete and return to me the form in the information pack with their contact details (appendix 2a) along with the personal data collection sheet (appendix 2b). I reflected that having met the researcher, and been given the opportunity to raise questions on the study, that this might have allayed any fears and so made the prospect of participation less daunting. Some groups consisted largely of friends and family members of those with the condition and as such were ineligible to participate in the study: this number was higher than anticipated.

4.25 Patient Support Group: Diabetes

I attended two evening meetings of the diabetes group when I introduced my study and provided attendees with an information pack(see appendices 3a,4a). They too were invited to return the form enclosed in the pack complete with their contact details if they wished to participate in the study. Again it was emphasised that attendees were not obliged to participate. The key difference in this setting was that since there are two predominant types of diabetes (type 1 and type 2) it was necessary to clarify that the study was focussing only on type 1 diabetes. This had implications for the recruitment process at the third site where the majority of group attendees were type 2 diabetics. The group leader offered to contact those with type

1 diabetes directly to ask if they would be interested in participating in the study.

4.26 Clinical Nurse Specialist Clinic: Epilepsy

The recruitment process for the two clinics is set out. At the first clinic, the clinical nurse specialist wrote the address of the patient on the pre-paid information pack (appendices 3b,4b) and envelope provided. This was the most practical approach because it required specialist knowledge as to who was eligible for the study. The researcher contacted the nurse regularly by telephone and face to face meetings, to enquire how many patients had been contacted. She noted that she had forgotten to send the information packs due to work commitments. Potential alternatives to minimise the workload incurred by the study were discussed. However, she offered to continue to send out the packs. Both the nurse and I kept a record of the number of information packs forwarded to the patients. At the first clinic, out of fifteen information packs sent to clinic attendees, three agreed to participate.

Access to this second epilepsy clinic was negotiated on 18th July 2007: recruitment ceased 28th August 2007. The nurse assisted in the recruitment of those aged between eighteen and thirty five years as it was noted that there were few younger people in the sample group.

4.27 Provision of Gift Vouchers to Participants

Due to a low response rate, particularly in the epilepsy specialist nurse clinic, and following discussion with research colleagues, permission to offer participants a gift voucher was sought and granted by the Ethics Committee and local Research and Development Committees. Consequently, participants received a fifteen pound gift voucher to compensate them for time taken to participate in the study. Across all

recruitment settings, nine participants received a gift voucher.

4.28 Clinical Nurse Specialist Clinic: Diabetes

Recruitment commenced in this site on the 14th February 2007, and ceased on the 22nd August 2007. In order for me to prepare sufficient information packs for attendees at the clinic, I telephoned the day before it was due to be held to enquire about numbers attending. When patients arrived at the clinic, they waited on average five minutes until called forward by the nurse for their appointment. The nurse suggested that this would be the most appropriate point to approach possible participants for the study. I clarified that they were attendees of the diabetic clinic, introduced myself, and briefly explained the aims of study. I explained what being a participant would entail and invited them to take part, whilst emphasising that they were not obliged to do so and their decision would not affect their care in any way. I then provided them with an information pack requesting their contact details if they wished to participate.

4.29 Inclusion Criteria

Broadly across all study sites, those aged sixteen years or over and diagnosed with either type 1 diabetes or epilepsy were eligible to participate in the study and invited to do so.

4.30 Exclusion Criteria

Those aged under sixteen years were excluded due to legislative restrictions and those who required the services of a translator were excluded due to a lack of resources. In terms of clinical exclusions, on the advice of the nurse, those with learning disabilities and those who were not formally diagnosed with epilepsy were

excluded from the study.

Table 2 Process of Recruitment to the Study

Study sites	Location	Type of contact	Response rate
Patient Support Groups: Epilepsy	Two groups in the South of England.	Presentation to group by the researcher.	Nine participants
Patient Support Groups: Diabetes	Three groups in the South of England.	Two presentations to group by the researcher. One presentation by group leader	Eleven participants
Clinical Nurse Specialist Clinic Epilepsy	Two teaching hospitals in the South of England.	Patients receive postal invitation to participate (via the nurses).	Six patients
Clinical nurse specialist Young Adult Diabetic Clinic	One teaching hospital in the South of England.	Researcher invites clinic attendees to participate in the study.	Nine patients

4.31 Conducting the Qualitative Interviews

This section presents the process of conducting qualitative interviews in the study; the interview setting, details on the format of the questions and establishing rapport with participants.

4.32 Interview Settings

The majority of participants chose to be interviewed in their homes (n=25). Interviews were held in a health centre; the most practical option for the attendees (n=3). Some teenagers preferred the “neutral” setting of a central café (n=7).

4.33 Question Format: Open-ended Qualitative Interviews

In the interviews, participants were invited to describe their experiences of disclosure. A topic guide was used with the key questions asked of every

interviewee (appendix 5). The interviews were broadly guided by the following topics:

- experiences of disclosing illness to others in different contexts (the workplace and their personal lives),
- the outcome of telling others about the condition
- exploration of the barriers to disclosure

Participants were invited to recount their experiences of disclosure from the point of diagnosis to the present time in order to: “*try to tap his or her assumptions, implicit meanings, and tacit rules*” (Charmaz, 2006, p32)

4.34 Establishing Rapport

It has been argued that establishing rapport in the interview setting is crucial to the quality of information emerging from the data. Charmaz (2006) states: “*The interviewer is there to listen, to observe with sensitivity, and to encourage the person to respond*” (p25). The following steps were taken in an attempt to establish rapport. I dressed smartly but casually, in order to create an impression of informality. Participants’ offers of refreshments prior to and during the interview were generally accepted. Before the interviews commenced the participant was invited to discuss any queries regarding the study. It was emphasised that the purpose of the interview was for the researcher to listen to their experiences and this would be conducted in an informal manner. This appeared to be a successful course of action, because many explicitly expressed that for them, participating in the interview had been a positive experience.

4.35 Data Management

This section presents details of the manner by which data were gathered, managed and processed.

4.36 Use of a Tape Recorder

Participants were asked to complete and sign a consent form (appendix 6) giving their permission to tape record the interview. All participants agreed to this which enabled me to maintain regular eye contact with them and also concentrate on what they were saying rather than taking notes. When the interviews took place in public cafes there was a great deal of background noise. However, due to the quality of the digital recorder and because I was the one transcribing the tapes, this was less problematic than anticipated.

4.37 Transcription of Interviews

Interviews can be transcribed at different levels and so decisions need to be made about how much detail to record (Mishler, 1986). He argues that transcription is not a simple process because the non-verbal elements of the interview such as expressing or emphasising ideas through movement of the body are difficult to capture. The accuracy of the transcripts is vital in qualitative research, in terms of both the questions posed as well as participants' responses as Mishler (1986) notes: "*...the analysis of speech is central to the use of interviews as research data...an accurate record is needed of the questions that interviewers ask and the responses that interviewees give* (p.36). In this study all the interviews were transcribed verbatim by the researcher as soon as was practical following the interview, in order to record an accurate version. The interviews varied in length but an average of four hours

was spent per interview on their transcription (approximately one hundred and forty hours altogether). To preserve participants' confidentiality and anonymity any identifying features mentioned in the interviews were removed.

4.38 Use of Computer Package QSR N5

A number of computer packages have been developed to assist in the organisation and analysis of qualitative data. However there is some debate between qualitative researchers as to whether computer packages should be adopted (Seale, 2005). Some qualitative researchers have expressed fears that they will impose a rigid framework upon their analytical process given that they originated in the statistical quantitative paradigm (Seale, 2005). The benefits of using such packages in grounded theory studies are being increasingly recognised (Seale 2005, Corbin 2008). Seale (2005) notes that their assistance in the process of data management facilitates theoretical sampling and "constant comparison" across cases and Corbin's (2008) updated version of Strauss and Corbin's (1990) grounded theory textbook "*Basics*" includes a new chapter setting out the relevance of computer software to conduct grounded theory analysis.

Computer packages designed by Social Scientists can also facilitate management of the data by drawing together and highlighting data not initially apparent to the researcher when employing manual approaches to coding. A further advantage of such packages is their transparency, allowing others to see the manner in which the coding process has been conducted and analysis reached (Green and Thorogood, 2004). For this study, the data package *QSR N5 for Qualitative Data Analysis* (QSR International Pty Ltd 1980-2000's) was selected for practical reasons. The transcripts were transferred onto the computer package *QSR N5*. This data

management package was particularly useful in the process of analysis because it enabled the management of large amounts of data in a standardised and transparent way, thus contributing to the “credibility” of the study (Charmaz, 2006)

4.39 Methods of Data Analysis

This section sets out details of the methods of data analysis reflecting on the researcher’s role in this process.

Compared to other models of grounded theory (Glaser and Strauss, 1967, Glaser, 1978, Strauss and Corbin 1990), constructivist grounded theory offers flexibility in the methods employed to analyse data. This perspective takes into account the role of the researcher in this process, allowing one to adopt an open, flexible, and therefore “emergent” approach to the data, thus facilitating fresh insights into the phenomenon of disclosure (Charmaz, 2006).

4.40 Reflections upon my Role in the Analysis Process

4.41 Theoretical Sensitivity

A key tenet of constructivist grounded theory is that researchers must adopt a reflexive approach and consider their contribution to the theory (Charmaz, 2006). The methods of grounded theory are considered to be “neutral” but by contrast the researcher is not. The researcher plays a key role in the coding process by identifying relevant data (Charmaz, 2006). By using a constructivist approach, I was able to reflect upon and consider my role in the process of gathering the data in terms of coding, interview questions and analysis. In this study, whilst the participant is the key informant, I pose the questions, and identify specific areas to be explored. Consequently my role is not “neutral” but rather my perspective is integral to the

analysis process and emerging data: “*researchers are part of what they study, not separate from it*”(Charmaz, 2006, p178). The theory which emerges from the study is itself a “construction” developed by the researcher and the participants (Charmaz, 2007). In other words there is no single, end product which is “arbitrarily preordained.”

4.42 Researchers Positionality

As Cresswell (2003) notes it is important for the qualitative researcher to reflect upon their own role in the research and set out how they think this may “shape the study” (p182). I therefore now briefly set out my personal biography and reflect upon on how it may have shaped the study. My academic background is not clinical but rather lies in the field of Sociology of Health and Illness and Health Services Research. At the point of commencing this research I had worked in the field of health services research with a particular focus upon patient experiences for over eight years. I had conducted over one hundred qualitative interviews with participants living with long term or acute conditions. However whilst I had spent much of my working life interviewing research participants living with illness I had limited personal experience as to what it is like to live with a long term condition or consider the question of disclosure. During the course of conducting this research, I unexpectedly encountered health difficulties and for the first time had to consider the question of disclosure from a personal perspective. I began to have to consider “who needs to know?” about my health condition, to what extent? and for what purpose? The methodological implications of this were, that I was not only interviewing participants as a researcher, I was interviewing them with an increasing personal experience of the challenge of disclosure myself. Due to my interest in disclosure I

was able to acknowledge that I was following up particular points that participants made. Put simply, my personal experience on disclosure is that it is not a straightforward or easy process and so I acknowledge that I was able to empathise with those who encountered difficulties in this area. On one occasion after disclosing to someone that I was unwell, their response to me was: “You don’t look ill!” Participants in my study had also cited similar reactions. Thus, unexpectedly, disclosure has come to have both a professional and socially profound impact upon my life. This affected how I worked with respondents meanings by acknowledging my personal experience of disclosure and not trying to exclude these but using them to explore and build upon respondents accounts.

Overall I believe my personal experiences of disclosure led me to a greater depth of empathy and possibly rapport with participants than may have otherwise been the case. However my personal experiences of disclosure were relatively limited and newly acquired compared to the majority of the participants. The participants whom I interviewed were diverse in terms of their age and length of diagnosis compared to myself. As a white female researcher in her mid thirties I used my personal experiences of disclosure as important insights which I could draw upon whilst ensuring I still remained open to participants’ perspectives.

This section outlines the method of ongoing data analysis employed in this study in accordance with Charmaz’s constructivist grounded theory (2006). She notes that in the process of conducting analysis there is a desire to follow a “step by step” procedure.” She warns however that this must be tempered by the need not to stifle the creative process (Charmaz, 2007). I conducted all thirty-five interviews, and transcribed each once as soon as was possible following the completion of the

session. Listening in detail to the recorded interviews, whilst conducting the process of transcription, was fundamental to the overall analysis process because it allowed me to immerse myself in the data. Transcribing the interviews also gave me the opportunity to reflect upon not only the questions I posed, and the responses given, but also to note pauses or changes in the emotional pitch of the interviewee's voice. I therefore set out to look out for such cues in subsequent interviews.

4.43 Theoretical Memos

The writing of memos plays an integral part in the development of grounded theory since they can be used to note reflections on the data and compile questions in order to allow one to build upon and explore different ideas (Charmaz, 2006). Memos can: *“form the core of your grounded theory. Following up on ideas and questions that came up while you wrote them will push your work forward”* (Charmaz, 2006, p94). In my study I used theoretical memos to record my thoughts on key issues which emerged during the course of the interviews. In those instances when participants referred to their condition as either “controlled” or “uncontrolled” this was noted for additional exploration. The process of writing memos was ongoing and crucial to the development of the process of data collection. The following section deals with the process of gathering field notes throughout the study.

4.44 Fieldnotes

Fieldnotes are often used to record observations and reflections on the data, as part of the reflexive approach to the ongoing analytical process (Charmaz, 2006).

Comparing fieldnotes to interviews, then line by line coding facilitates: *“the logic of discovery as you begin to code the data”* (Charmaz, 2006, p51). The recording of

field notes was particularly relevant to this study when noting “the non-verbal communication” such as reflecting upon emotional responses or body language, to gauge participants’ responses to particular questions. Others have found it useful to record fieldnotes using a tape recorder or journal (Morse and Field, 1996). As I often travelled by train to interview participants, I was able during the return journey to listen to the recording of the interview which I had just completed and note salient points on the setting, or emotions that had emerged during the session while they were still fresh in my mind. It has been contended that using a tape recorder does not capture all interaction accurately such as: “*the physical setting, the impressions the observer picks up or the non-verbal communication in an observed interaction*” (Morse and Field, 1996, p91).

The following examples indicate how field notes were used to gather non-verbal observations from the interviews. For instance two of the interviewees had suffered physical injuries as a consequence of their epilepsy: one had a bruised face, the other a burnt arm. They described how the visual marks had led to enquiries regarding these injuries and that prompted them to disclose the nature of their condition explaining that it was due to harming themselves unintentionally during a seizure.

4.45 Coding

4.46 Initial coding

In this section I set out the coding process adopted in this study. The first step which Charmaz (2006) recommends is “initial coding” the logic of which is to: “*remain open to exploring*” the data (p47). Comparing the data in this way enables the researchers to remain open to what participants perceive to be important

(Charmaz, 2006). In this study the transcripts were carefully scrutinised and each line labelled noting when participants had raised key terms such as, “being diagnosed” and “learning to inject insulin.” Once more during this process of analysis my role in this became apparent, as I selected the words to code. Charmaz (2006) notes: “*we may think our codes capture the empirical reality. Yet it is our view: we choose the words that constitute our codes*” (p9).

When reviewing the transcripts I adopted Charmaz’s (2006) strategy of coding “actions” rather than “themes” such as “*being diagnosed with epilepsy;*” “*learning about medication*” and “*learning over time.*” Charmaz (2006) states the reasoning behind this: “*focus your coding on actions, you have ready grist for seeing sequences and making connections... not on individuals, as a strategy in constructing theory and moving beyond categorizing types of individuals*” (p136). Using this approach it was possible to develop fresh insights into disclosure by focussing upon “actions” in order to examine how they relate to the overall phenomenon of disclosure.

4.47 Focused Coding

The next step was to conduct what is termed “focused coding.” Charmaz (2006) defines this process as: “*using the most significant and or frequent earlier codes to sift through large amounts of data*” (p57). This involved a process of extracting the key and “frequently used” codes and grouping them together. For instance, the following examples of focused codes illustrate participants’ perceptions of disclosure as a personal topic: “*who needs to know?*” and, “*I wouldn’t broadcast it.*” This produced numerous codes and these had to be distilled into the following major categories: “stigma”, “visibility”, “invisibility”, “disclosure”, “non disclosure”,

“information” and “identity” to facilitate management of the data.

4.48 Axial Coding

Axial coding examines the relationship between categories of the phenomenon in the data: *“in terms of the conditions that give rise to it; the context (its specific set of properties) in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those strategies”* (Strauss and Corbin, 1990, p97). Axial coding played the following role in this study. When examining disclosure I considered contexts and settings of disclosure; to whom people disclosed and why, responses to disclosure and perceived reactions to disclosure. This assisted in the process of clarifying the components or “properties” of disclosure in this study.

4.49 Diagramming

Throughout the period of data collection, a series of visual diagrams were prepared to explore the relationships between categories to discover potential links (Charmaz, 2006). For example *“the rationale for disclosure and its intention or purpose”*, and *“barriers to disclosure”* were set out in exploratory diagrams. Examples of these are set out (see appendix 7) to illustrate their relevance to the analysis process.

4.50 The Literature Review

There is much debate in the field of grounded theory methodology regarding the timing and the role of the literature review (Glaser and Strauss, 1967, Glaser, 1978, Strauss and Corbin, 1990, Charmaz, 2006). Some have argued that the literature review should be delayed until after the completion of data analysis in order to avoid being influenced by existing literature and so remain open to fresh insights (Glaser

and Strauss 1967, Glaser 1978). Such influences may result in what has been termed: “received theory” (Glaser and Strauss, 1967, Glaser, 1978).

On the other hand Charmaz (2006) notes that a literature review assists in identifying possible research gaps, thus setting out a clear rationale for the study, and also to clarify and build upon the data analysis. In this study, I completed the literature review initially to set out the broad parameters of the area of research. It was after having completed most of the analysis that I then reviewed the literature in order to remain open to new ideas and so minimise its influence on me (Charmaz, 2006). In adopting this process, I was able to clarify the contribution of this study to the field of disclosure research for example: concordance with regard to medication and young people, and the role of the internet as a source of health information.

4.51 Sampling

4.52 Theoretical Sampling

Theoretical sampling is a key element of conducting a grounded theory study and forms part of the process of theoretical saturation: “...to develop the properties of your category (ies) until no new properties emerge. Thus, you saturate your categories with data and subsequently sort and/ or diagram to them to integrate your emerging theory” (Charmaz, 2006, p12). In this study theoretical sampling was used to develop the concepts identified by participants as being relevant to disclosure, such as “visibility and disclosure”, “identity and disclosure” and “stigma and disclosure.” These categories were raised by participants and therefore noted for inclusion in subsequent interviews to facilitate their development and “saturation” (Charmaz, 2006). The process of achieving theoretical saturation is described as follows: “gathering fresh data no longer sparks new theoretical

insights, nor reveals new properties of these core theoretical categories” (Charmaz, 2006, p113). Whilst it was not possible to directly select participants for this study according to their views on disclosure the setting of patient support groups and nurse led clinics accessed a broad range of participants who varied in terms of characteristics. These included gender, age, and length of time with the condition. Throughout the analysis process field notes and memos were kept to record my reflections on whether new properties of the categories were emerging. I noted that by interview thirty five no new issues were emerging and I judged that theoretical saturation had been achieved.

4.53 Process of Constant Comparison

The process of constant comparison and the researcher’s “engagement” in the process are key elements of grounded theory studies: *“making comparisons between data, codes and categories advances your conceptual understanding because you define analytic properties of your categories”* (Charmaz 2006, p179). The process of constant comparison was applied on an ongoing basis as I compared and contrasted concepts relevant to the phenomenon of disclosure. The purpose of this was to clarify the contents of the concepts and the properties of the categories. For instance, in this study I coded “spontaneous” examples of disclosure and then compared them to examples of “unspontaneous” disclosure. I then reviewed the interview data to search for examples of disclosure, comparing and contrasting with examples of non disclosure and seeking to identify the salient characteristics of the phenomenon (Charmaz, 2006). Using the process of constant comparison in my study enabled me to compare and contrast categories such as: “who needs to know?”

In the next section I set out the principles of ethics applicable to this study.

4.54 The Principles of Ethics Applied to this Study

An application was made to the local research committee (Oxfordshire Research Ethics Committee “A” reference (06/Q1604/79). The study was approved at their meeting on May 2nd 2006. A formal letter offering a favourable ethical opinion for the research project was provided on the 27th June 2006.

There are four key ethical principles incorporated into the study design, these are: respect for autonomy, non-maleficence, beneficence, and justice (Beauchamp and Childress, 2001).

4.55 “Respect for Autonomy”

4.56 The Process of Seeking Informed Consent

Underpinning the notion of “informed consent” is the principle that those taking part in research should not feel compelled to do so. Rather, the decision should be taken voluntarily, in the complete knowledge of what the implications would be for the participant (Green and Thorogood, 2004). In this study, individuals were enabled to make an informed decision in several ways: the provision of an information pack setting out the purpose of the study; the reasons for being invited to participate; the reassurance that they were not obliged to participate; and that opting not to take part in the study would not affect any aspect of their current or future provision of health care. Those invited to participate were also given up to two weeks to consider whether or not to take part. They were also encouraged to discuss the study with others prior to making a decision. A contact telephone number was provided should they require any additional information along with a consent form confirming their agreement to participate and indicating that they had read and understood the

information sheet (appendix 4a,b). Prior to formally commencing the interviews, the consent form was discussed and participants were invited to raise any concerns about the study. The offer to note responses rather than record the interview was made, but all participants consented to the use of a tape recorder.

4.57 “Non-maleficence:” to the Participants

A second key ethical principal is “non-maleficence:” “first, do no harm” to participants (Beauchamp and Childress, 2001). The topic of disclosure of long-term conditions is one which I reflected may raise potentially distressing and sensitive issues as previous studies have identified (Jouard, 1971, Charmaz, 1990, 1991, Rosenfield, 2000, Beatty, 2004). Taking this into account, the following steps were adopted to protect the participants. As part of the consent process participants were reminded of their right to withdraw from the study at any time, that provision of health care would not be compromised and that the information they shared would remain confidential. Following the interview they were offered the opportunity to receive a copy of the interview transcript to suggest amendments if desired. If the participant became distressed during the interview, I would bring it to a close and switch off the tape recorder. I ensured that I had an information sheet with the names of relevant local and national contacts if further support or information was required once the interview had ended (appendix 8).

4.58 “Non-maleficence:” to the Researcher

Recent studies have suggested that the process of conducting interviews can have an emotional impact on the researcher (Lalor et al, 2006, Craig et al, 2000, Lees, 1993). Guidelines have been developed to protect social researchers and an enquiry conducted to assess the overall impact of conducting qualitative research on

researchers well being (Craig et al 2000, Commissioned Enquiry 2007 *Risk to well-being of researchers in qualitative research*).

The multi-disciplinary literature identified that disclosure is a sensitive topic as it involves the divulgence of something which is essentially “private” (Charmaz, 1990, 1991, Beatty, 2004, Jouard, 1971, Petronio, 2000, Derlerga et al 1993). It has been argued that an emotional investment is required by the researcher: *“the researcher, if more than merely competent, will be “in the work” emotionally as well as intellectually...others will be profoundly affected by experiences engendered by the research process”* (Strauss, 1987, p10). I found this to be the case in my study as many difficult issues emerged in the course of the interviews. On occasions, participants recounted traumatic experiences of miscarriages; stillbirths; previous suicidal feelings; depression and anger at society for being judged by their condition.

Some described how they perceived the condition to have been caused by having to cope with being bullied in school. In some extreme cases difficulties in coming to terms with, and the process of managing the condition had led to the serious deterioration of the individual’s health status such as gradual blindness or requiring a kidney transplant. This raised questions as to the role of the interviewer. My role was to listen but not exploit. Grounded theory studies encourage the use of open ended interviews from which unanticipated topics may emerge, so to a certain extent I was prepared for this (Charmaz, 2000). To minimise the impact on the researcher’s well being I debriefed interviews that I had found difficult or emotionally draining with my research supervisor.

4.59 Participants' Confidentiality and Anonymity

Participants' confidentiality and anonymity were assured. As Lees (1993) notes: *“researchers must walk a tightrope careful neither to conceal too much, nor to disclose too little (p 206).* The confidentiality of the participants was assured when collecting the data and when documenting the findings of the research. In this study all participants' names and addresses were stored in a locked cupboard. The transcripts were given an identifying number, and names or other identifying features were removed or altered in order to maintain confidentiality. The locations of the recruitment centres were anonymised to maintain confidentiality and clinicians' names removed to prevent identifying the setting of the interviews. In the next section I go on to discuss the criteria adopted to evaluate the study.

4.60 Evaluating the Research

Qualitative research has been criticised for being overly subjective and not open to scrutiny. This has led to considerable debate within the field of qualitative research concerning the most appropriate criteria and terms to adopt when evaluating such studies (Miles and Huberman 1984, Sandelowski 1993, Lincoln, 1995, Lincoln and Guba, 2000, Morse et al 2002). It is therefore important to set out the methods employed. Lincoln and Guba's (1985) key paper developed a framework assessing the “trustworthiness” of qualitative research recommending four criteria: credibility, transferability, dependability and confirmability. These are defined as follows:

- **Credibility:** the extent to which the findings are plausible and worthy of confidence
- **Transferability:** the extent to which the findings of a study can be applied to another setting

- Dependability: the extent to which future research yields similar results using the same methods
- Confirmability: an assessment of how well the findings are supported by the data collected

I have considered adopting Lincoln and Guba's (1985) criteria. However as noted earlier there has been much debate as to the appropriate means by which to assess qualitative studies and other researchers have subsequently drawn upon these terms seeking to develop their own frameworks. The methodological framework of this study is constructivist grounded theory. Therefore I have elected to follow the criteria recommended by Charmaz (2006): "credibility", "originality", "resonance" and "usefulness" to assess the value of a constructivist grounded theory study. These criteria as they apply to this study are set out in further detail in the discussion and conclusions chapter (Chapter six).

4.61 Credibility

Credibility denotes the "trustworthiness" of the entire research process: data presented; the analysis; evidence produced to support claims made; and the breadth of data gathered (Charmaz, 2006). Thus issues of credibility were considered throughout the research study to ensure the "usefulness" of the findings taking Charmaz (2006) suggested criteria into account:

1. Does the research present intimate familiarity with the setting or topic?
2. Are the range, number and depth of the data gathered sufficient?
3. Were categories systematically compared?
4. Do the categories cover a range of empirical settings?

5. Does the data gathered link rationally to the data analysis and subsequent arguments which emerge?
6. Has sufficient evidence been provided in the study to enable a detached reader to concur with the findings of the study?

This was demonstrated in the current study and set out in detail in the discussions and conclusions chapter (Chapter six).

4.62 Originality

Originality should be measured in terms of whether the study presents: “*a new conceptual rendering of the data?*” (p182) through the identification of fresh insights which challenge and extend existing knowledge of the empirical area. This was demonstrated in the current study in the following ways. Firstly, through the presentation of “fresh insights” into the process, and role of disclosure, and the development of a new conceptual framework (figure 4) of the role of disclosure in managing a long-term condition. Secondly, the social and theoretical relevance of this work are reflected in the implications of the findings for health care practice, employers, and future research and are set out in further detail in the discussions and conclusions chapter (chapter six).

4.63 Resonance

Resonance refers to an assessment of the breadth and depth of the data, whether the categories are “saturated” and thus represent: “*the fullness of the studied experience*”(Charmaz, 2006, p182). This was demonstrated in the current study by using two approaches. Firstly, by the end of the period of data collection no new issues regarding disclosure were being raised in the interviews. This is termed

“theoretical saturation” (Charmaz, 2006). Secondly, member checking was also used to assess the resonance of the study and the “fullness of the studied experience.”

Member checking is part of the overall strategy of achieving “resonance” within a study. The purpose of member checking is twofold: firstly, to gain feedback from the participants regarding the interpretation of the data collected, and secondly, to enable participants to have access to the data collected (Sandelowski, 1993). There is however, a debate concerning the most appropriate timing of member checking, as to whether it should take place during, or post data collection (Miles and Huberman, 1984, Sandelowski, 1993). Sandelowski (1993) defines it as an ongoing process throughout the study. Two key ways of member checking were employed in this study: firstly at the end of each interview the key issues which the participant had raised were summarized verbally to check that my understanding of their perspective was accurate. At this point interviewees were invited to amend or add to the summary. Secondly, participants’ were given the option to review the transcripts at a later date, to remove or add anything as they wished. Opportunities to provide feedback to participants were also built into the study design in the form of a summary of the key findings to individual participants on completion of the study, and feedback to support groups.

4.64 Usefulness

The usefulness of the study is measured according to Charmaz (2006) in terms of its contribution and relevance to existing knowledge in the substantive area of research. This was demonstrated in the current study by examining the study findings and noting that: this study has: *“built upon existing knowledge”* by illustrating that

disclosure is a key process in the lives of those living with epilepsy and type 1 diabetes. The findings were also examined to assess the extent to which they have captured “*generic processes*”. The study findings were also examined to identify: “*the need for further research in other substantive areas*”

4.65 Criteria for Rigorous Grounded Theory

Debates exist as to the criteria to employ in order to gauge the rigour of the resulting grounded theory (Glaser and Strauss, 1967, Strauss and Corbin, 1990, Glaser, 1978, Charmaz, 2006). Charmaz (2006) recommends employing Glaser’s (1978) criteria of what constitutes a useful theory: “fit”, “work”, “relevance”, and “modifiability.”

These are defined as follows:

- Fit: “*the categories of the theory “fit” or match the data*”,
- Work:” “*the theory explicates, predicates and interprets what is going on in a substantive area*”
- Relevance: the theory is relevant to the substantive area.
- Modifiability: “*though basic social processes remain in general, their variation and relevance is ever changing in our world*” (Glaser, 1978 p5).

These criteria were adopted because they are useful for assessing the theory particularly as to how: “*the constructed grounded theory renders the data*” (Charmaz, 2006, p182).

4.66 Summary and Conclusion

In this chapter I have set out the methods employed in this study in accordance with the constructivist approach to grounded theory (Charmaz, 2006). The research

design, study population, and means of gathering the data have been presented. The process of conducting the qualitative interviews, data management, method of sampling; data analysis; and the principles of ethics applied to the study. Finally, the procedures taken to ensure the credibility of the study are presented taking into account debates within qualitative research as well as grounded theory. In the next chapter I go on to present the results from the data analysis.

5.0 Chapter Five: Study Findings

5.1 Introduction

This chapter presents findings from the study data. As discussed in the methods chapter (Chapter five) the data were derived from thirty-five qualitative interviews conducted with those living with either epilepsy or type 1 diabetes.

Participants were recruited from two different settings: either nurse specialist clinics or patient support groups across the two different health conditions. To highlight commonalities or differences across conditions a comparative approach was adopted to explore a range of perceptions of the role of disclosure. Following the principles of constructivist grounded theory (Charmaz, 2006) the major categories identified in this study are drawn from participants' responses. Each quotation is labelled with the participant's number and the identifying line number referred to as text units (tu). At the end of each section is a discussion of the key issues. The data identified the following key analytical themes: visibility and invisibility; stigma; process of disclosure and non disclosure; and perceptions of reactions from others. Strategies of disclosure are not necessarily fixed but may be subject to change over time.

Section one entitled **the nature and process of disclosure** presents commonalities regarding the nature and the process of disclosure across both conditions. **Section two: mediating issues around disclosure**, presents a number of mediating issues which influence decisions around disclosure or non-disclosure. **Section three: the challenge of disclosure: "who needs to know?"** presents an overview of the challenge of disclosure: "who needs to know?" identifying the role of disclosure in this context as access to self-care and social support. The role of disclosure in the workplace is set out. **Section four: learning about disclosure: disclosure and the**

role of time presents comparative data (across both conditions and recruitment settings) illustrating differing views and strategies around disclosure namely the process of: “learning about disclosure” over time. Firstly, patient support group findings are presented identifying: the role of strategic disclosure: redressing myths about the condition in advance. Secondly, nurse specialist clinics findings are then presented identifying: the role of non-disclosure: avoiding stigma. Finally, **Section five: Disclosure and the Role of information** presents views on information needs, how information was sourced about their condition and the role of the patient support groups and nurse specialist clinics in the provision of information on topics including disclosure.

Table 8 sets out the socio-demographic characteristics of the study participants. Illustrating differences between those recruited from the patient support group and the nurse specialist clinics. Those recruited from the patient support groups had been living with the condition for a longer period of time compared to those recruited from the nurse specialist clinic. There were also differences in age and differences in employment status.

Table 8 Socio-demographic Characteristics of Study Participants

	Patient Support Group n=20		Nurse Specialist Clinic n-15	
	<i>Diabetes n=11</i>	<i>Epilepsy n=9</i>	<i>Diabetes n=9</i>	<i>Epilepsy n=6</i>
Mean Age (range)	58 yrs (33-72 yrs)	45 yrs (18-63yrs)	19 yrs (17-22 yrs)	39 yrs (28-60 yrs)
Mean Time Living with the Condition	26yrs	24yrs	7yrs	19yrs
Female	7	6	4	4
Male	4	3	5	2
Marital Status				
Single living at home	6		9	
Married/Co-habiting	14		6	
Employment Status				
Skilled Manual	2		1	
Manual	0		1	
Student	1		9	
Medically Retired	6		1	
Retired	9		1	
Unemployed	2		2	

5.2 Section One: The Nature and Process of Disclosure of a Long-term Condition

5.3 Introduction

This section presents the study findings regarding the nature and process of disclosure. It illustrates that disclosure is a personal process for many and therefore is a process which participants prefer to control its timing and its role.

5.4 The Nature of Disclosure

Analysis of the interview data illustrated that for many of the participants their health condition was something that they regarded as highly personal: a private issue, not to be discussed freely. Therefore decisions were made as “to whom to disclose” and “when”, as a female attendee at the nurse specialist clinic recounted:

It’s not really the sort of thing you tell people straight away ... It’s just not something you really come out with.

Interview 29, tu:69, Female, Aged 17, diagnosed three years ago, recruited from young adult diabetes clinic

Attendees at patient support groups also highlighted that for them too, disclosure was a highly personal issue:

It’s something that I haven’t ever felt I needed to sort of: “shout from the rooftops!” I suppose I’m a confidential sort of person in a way and ... personal things you don’t necessarily disclose.

Interview 4, tu: 211, Male, Aged 71, Diagnosed fifty-eight years ago, recruited from diabetes patient support group

Similar findings emerged for those participants living with epilepsy:

It's just not one thing that you "broadcast." You don't really tell everybody your personal business anyway!

Interview 1, tu:172, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group

I suppose I do feel it is a personal thing. You know it's just "my illness."

Interview 30, tu:92, Female, Aged 28, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

Thus living with epilepsy or type 1 diabetes was perceived by participants to be a "private" matter and not something to be disclosed indiscriminately.

Decisions then have to be made regarding whether there is a specific need to disclose and if so, to whom. Indeed, for many participants, the act of disclosure is only likely to happen with 'outsiders' if an acute episode such as an epileptic seizure or hypoglycaemic episode makes it necessary as the following extract illustrates:

If you walked down the street and everybody you'd bumped into you just said: "I'm epileptic!" they'd look back at you as if to say: "There's something wrong with that chap!" ... If he was having an attack ... you'd think there was a need for him to tell us.

Interview 2, tu: 283, Male, Aged 55, Diagnosed eighteen years ago, recruited from epilepsy patient support group.

Therefore the term: "who needs to know?" appears to relate to the visual symptoms of the condition and the need for assistance. It also illustrates that disclosure has a

role to play.

Similar findings emerged from those recruited from the diabetes patient support group:

I tell people as and when it's necessary. I would not broadcast it to the world 'cos I don't think it's necessary ... I tell people who I think might "need to know."

Interview 12, tu: 298, Female, Aged 60, Diagnosed nineteen years ago, recruited from diabetes patient support group.

Others expressed frustration at having perceived their condition to be personal, the possibility of having an acute episode (epileptic seizure or hypoglycaemic episode) took away their sense of control in terms of disclosure:

You're almost forced to tell people ... in case you have a fit, in case you have a hypo (hypoglycaemic episode). People need to be aware of it really. Sometimes you feel like you're having to bare your soul to people and let people know things that are quite private and personal.

Interview 16, tu: 511, Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group.

Most participants wanted to have control where possible, over "when" to disclose and to "whom." This may be related to cultural reluctance to cross personal/private boundaries with people outside close family and friends, as a member of a patient support group recounts:

In this country you don't ask other people about their health. That's rude! That's impolite! You still want to know, you're curious but where do you go

for the answers without ... crossing these politically correct boundaries? We don't discuss feelings, emotions, health in this country!

Interview 3, tu: 278, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group

Therefore perceptions of health as being private and personal, in turn tapped into views on disclosure.

5.5 Discussion of the Nature of Disclosure

This study found that participants perceived disclosure to be something personal: only to be divulged for a reason. This was a point also identified by Charmaz (1991) and Beatty (2004). This finding is in line with studies in the field of psychology where others have found that disclosure is inherently personal because it reveals something of the "self" (Jourard, 1971, Rosenfield, 2000). Participants reiterated that their health condition was a personal issue and so should not be freely discussed with others. Yet, some felt "forced to disclose" due to a lack of control over their condition which in turn had a negative impact on their feelings and led to a loss of privacy.

For many disclosure is not a straightforward process and typically, participants felt that disclosure had to have a functional role. This is concurrent with other studies which have examined long-term conditions and disclosure (Charmaz, 1991, Beatty, 2004, Williams and Healy, 2001).

I now go on to examine data concerning the diverse ways in which disclosure may occur.

5.6 The Process of Disclosure

This section presents data concerning how the disclosure of having epilepsy or type 1 diabetes may occur in ways other than direct, verbal disclosure such as differences in behaviour. Participants emphasized that a central concern was the issue of visibility linked to managing their condition. Opportunities to disclose emerged through indirect ways of managing the conditions, including: injecting insulin, restrictive dietary requirements or taking medication.

Issues concerning management of the condition therefore became forms of disclosure to others. For example, making a condition visible through the act of injecting insulin which for some participants was necessary as often as four times each day:

I didn't like injecting in front of people. I'd normally go into an office ... or just kind of slipped into the loos and did it quickly ... I still don't like doing it in front of people because some people react ... don't really like seeing it.

Interview 25, tu:18, Male, Aged 19, Diagnosed 14 years ago, recruited from young adult diabetic clinic

Disclosure may also be triggered in response to, or as a consequence of having to explain differences in behaviour such as dietary constraints, as a young adult with diabetes explained. This led to the necessity of explaining why they had to eat at certain times:

I say to people: "*What time are we eating? (and) "What are we eating?"*" I need to know 'cos I need to know how much insulin to take."

Interview 5, tu: 107, Female, Aged 60, Diagnosed nineteen years ago, recruited from diabetes patient support group.

(If) someone asked if I wanted some certain food then I'll say: "No I'm diabetic" ... It will come up then.

Interview 24, tu:52 Male, Aged 18, Diagnosed seven years ago, recruited from young adult diabetic clinic.

Therefore managing dietary restrictions also became a form of disclosure.

The following example illustrates how the need to take medication at a particular time became an opportunity for disclosure:

I'd sort of take my tablets at 4pm, my midday tablets and sort of just comment: "Oh you know must take my tablets 'cos I have epilepsy."

Interview 3, tu:49, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group.

Another form of visual disclosure identified in the current study was the medical bracelets worn by some participants. The bracelets were engraved with the wearer's medical condition and an emergency helpline number in order to access information on their medication regime:

I mean I wore a medical alert bracelet ... then people saw that and asked: "*Oh what's that for?*" as well so yeah, it was definitely an encouragement to tell people.

Interview 23, tu:58, Male, Aged 18, Diagnosed four years ago, recruited from young adult diabetic clinic

Therefore, on occasions the bracelets themselves became triggers for disclosure. In the event of having an acute episode they appeared to play an important role in terms of explaining the behaviour to “strangers” and also to alert others to their medical needs:

Sometimes you’re on your own with people you don’t know and the only reason they know you’re diabetic is ‘cos I’m wearing this like “Medical Alert” bracelet. It says I’m diabetic on it so if I’m having a hypo (hypoglycaemic episode) they understand what’s going on.

Interview 23, tu:63, Male, Aged 18, Diagnosed four years ago, recruited from young adult diabetic clinic.

I’ve got my “Med-Alert” bracelet which is really invaluable because if it happens (epileptic seizure) in the street people could tell what I’ve got.

Interview 15, tu:138, Female, Aged 48, Diagnosed thirty-two years ago, recruited from epilepsy patient support group.

The bracelets also appeared to play a role in providing a form of “back up” to the person and reduced fears particularly when they were alone or in the company of others who were unaware of their condition.

In the following example a young student has been provided with a fridge to store her insulin in while in university which, as she explains, symbolises an opportunity for her to disclose to others:

I wasn’t going round to people saying “Hi my name’s Emma, I’m a diabetic!” but it was fairly easy because when I moved to university they gave me a fridge in my room. So when people come round they’re like: “Why have you

got a fridge in your room?” so I just said: “cos I have to keep medication in there.” So it sort of came about that way.

Interview 35, tu: 12, Female, Aged 22, Diagnosed nineteen years ago, recruited from young adult diabetic clinic.

Thus broadening the concept of what “visibility” of a long-term condition constitutes: not only physical symptoms of the condition itself, but visible “objects” related to the management of the condition.

For those living with epilepsy additional opportunities arose during the course of conversation in relation to driving:

Things came up like if they asked me: “Do you drive?” I’d just say: “I do but actually my licence was taken off me because of this” (having epilepsy) ... If they ask me more questions I’d tell them about it.

Interview 1, tu:141, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group.

The above quotes illustrate how their medical condition overlapped into their social environment.

Sometimes disclosure emerged through the need to explain different “behaviour.” For example, within the context of school such as having to explain repeated absences. The following quote describes how someone living with diabetes that was not medically “controlled” led to dangerously high blood sugar levels (diabetes ketoacidosis) requiring emergency treatment:

More people knew about it then (at school) ... I had to explain, 'cos my diabetes was out of control and I had so much time off school going "dka" (diabetes ketoacidosis) and everything.

Interview 26, tu: 55, Female, Aged 21, Diagnosed eleven years ago, recruited from diabetes young adult clinic.

Participants speculated on the possibility of people close to them disclosing to others as the following quotation illustrates:

If they're real friends or family they're gonna know about it. If not through you, through the other close family. You know it leaks out doesn't it?!

Interview 17, tu 24, Male, Aged 67, Diagnosed thirteen years ago, recruited from diabetes patient support group

These quotations highlight that disclosure is a process which is not easily governed. Participants recounted that due to a lack of medical control over their condition others indirectly found out about their condition. Conversely others recounted how once they had disclosed to family members they effectively had little control over to whom they in turn disclosed.

5.7 Discussion of the Process of Disclosure

The data identified that the process of disclosure is diverse and not straightforward and have identified the number of ways in which the process of disclosure may occur: verbally, visually, or indirectly through the process of managing the condition. Whilst disclosure occurs in a number of different ways mainly linked to the visible symptoms of the condition, a key finding of the current study is that the condition may become visible not only through symptoms, but through the

management of the condition itself. Sometimes the process of disclosure is in response to routine questions, in relation to explaining issues of differences in behaviour, in terms of how they manage their condition. Participants raised the point that how others responded to the disclosure was important because it played a key role in how they felt about having the condition and upon their identity. This finding concurs with work which has suggested that how others perceive someone with an illness can be crucial as it may influence whether or not they see themselves as being “different” (Mason et al, 2001).

The broad range of potential situations for disclosure has illustrated that controlling disclosure may be problematic. Whilst the existing literature on disclosure has focussed upon planned, strategic, verbal forms of disclosure as a means of addressing issues of stigma (Charmaz, 1991, Joachim and Acorn, 2003), the findings illustrated that the need to disclose and the process of disclosure were inextricably linked to the practical management of the condition and in particular for those living with type 1 diabetes.

The current study identifies a broader understanding of the concepts ‘invisible’ and ‘visible’ in relation to disclosure. Studies of those without obvious “visible” symptoms have implied that individuals have a choice as to disclose or not because they appear “normal” to others (Joachim and Acorn, 2003, Vickers 1997, Joachim and Acorn 2000). While other studies on disclosure stated that participants make decisions based on whether the condition will become more visible as the condition deteriorates over time (Lowton, 2004).

The next section compares and contrasts findings from participants that attend patient support groups or nurse specialist clinics across both conditions (epilepsy and

type 1 diabetes) to further explore the different issues at play when making decisions around disclosure of one's health condition, termed: "mediating issues around disclosure."

5.8 Section Two: Mediating Issues around Disclosure

5.9 Introduction

This section presents data which illustrate that many participants found living with the condition to be challenging. I go on to present data which illustrates that issues of health status and identity are taken into account with regard to disclosure.

5.10 The Challenges of Living with a Long-term Condition

Aside from the biomedical diagnosis, participants had to cope with the psychosocial implications such as the negative impact of the condition on their identity. Both conditions (epilepsy and type 1 diabetes) are long-term and require ongoing management. This means that there is a process of adjusting to living with the condition and integrating it into one's daily life. The emotional impact of being diagnosed due to the enduring nature of the condition, and the sense of being "different" to others is conveyed.

Those participants who had been newly diagnosed expressed their sense of shock when diagnosed with a long-term condition which could not be "cured" and would therefore require long-term management as the following quotation illustrates:

It is a shock! ... The nurse said "You know, you've got to get used to it ... It's not something you have for a little while and you get better ... This is something that you have to cope with for the rest of your life!"

Interview 11, tu: 49, Female, Aged 66, Diagnosed three months ago, recruited from diabetes patient support group

I think I went through various stages after I got it. I don't think it really sunk in to start with ... I didn't take it as seriously as maybe I should have done to start with right at the beginning ... I wasn't really watching what I ate and so therefore my blood sugar was up and down ... Its really difficult when you suddenly realize how much it affects your life ... As long as you control it then it's fine but you do always have to be aware of it.

Interview 27 tu:39, Female, Aged 19, Diagnosed six months ago, recruited from young adult diabetes clinic

Participants' emotional response appeared to be strongly linked to the ongoing, enduring nature of the condition and the need to take the condition into account in their daily lives.

The following quote by a young student clearly illustrates the degree to which being diagnosed and in particular the prospect of having to perform daily insulin injections impacted on her:

I cried my eyes out! ... I just thought I couldn't do it! ... I knew that I'd have to inject ... all the time for like the rest of my life. That was the kind of the scary part

Interview 29, tu: 24, Female, Aged 17, Diagnosed three years ago, recruited from young adult diabetes clinic

When newly diagnosed with epilepsy similar feelings were identified:

I weren't too happy when I got told ... I just lost confidence in myself. I weren't very happy ...it was hard!

Interview 19, tu: 3 Female, Aged 21, diagnosed seven years ago, recruited from epilepsy patient support group

Thus being diagnosed with the condition had a negative impact upon their emotions as they struggled to adapt to their new status.

Younger participants in both groups and across both conditions highlighted that being diagnosed did not only affect them emotionally but also impacted on family members, as the following quotation highlights:

I took it quite lightly really (the diagnosis of epilepsy) ... My mum found it really difficult to deal with ... She was devastated, she was really upset!

Interview 1, tu: 192, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group

Frequently this related to family members raising concerns about the potential limitations the condition might have on their lifestyle:

My mum was really upset when she found out ... All of my family were ... My mum phones all the time and she'll always say: "What's your blood sugar today?" ... They knew the kind of lifestyle changes that I'd have to make ... also because of how young I am ... It's at a difficult time in my life when you're at that age when you want to go out and drink and do all sorts of things ... It's a difficult thing to manage with everything else.

Interview 27 tu:136, Female, Aged 19, Diagnosed six months ago, recruited from young adult diabetes clinic

Thus being diagnosed with a long-term condition affected not only the person living with the condition but those around them, and in particular parents. Parents it seemed were acutely aware of the potential restrictions that a long-term condition might have on their children and this appeared to provoke a strong emotional response.

In the next section I refer to data which illustrated participants' perceptions of the limitations of living with a long-term condition.

A number of participants highlighted that they were medically unfit to work due to their condition. One young woman whose father also has epilepsy felt initially optimistic when diagnosed due to her perceptions that he was not overly affected by the condition because he remained in employment. However she found that her condition placed greater limitations on her lifestyle than previously anticipated:

Initially when I was diagnosed it was nowhere near as severe as it is now. I suppose I thought: "Oh well my Dad's got epilepsy and most people with epilepsy are able to work or they have the odd seizure," but they're stable. Whereas with me I find because it is unstable I think it just has more of an effect I guess ... I'm finding that difficult to deal with.

Interview 33, tu: 106, Female, Aged 28, Diagnosed eighteen months ago,
recruited from epilepsy nurse specialist clinic

The following quotation illustrates the difficulties faced in coming to terms with the perceived limiting effects of their condition:

When I started having the fits ... it just shatters your confidence. I think that's the worst part of it ... It's almost like being castrated not being able to work!

You don't feel like a man you know.

Interview 21, tu: 34, Male, Aged 56, Diagnosed twelve years ago, recruited from epilepsy patient support group

Thus the limitations that the condition placed upon them had a negative impact upon their self-esteem and their identity.

Others found it exceptionally difficult to contemplate a future in which they would not be able to have full control over their mobility as one man living with epilepsy describes:

The hardest thing of all was having to give up my driving, that literally brought tears to me eyes having driven from the age of seventeen ... Several scans later they then told me that I would not be allowed to drive ever because they didn't think that they could sort of control the epilepsy.

Interview 2, tu:50, Male, Aged 55, Diagnosed eighteen years ago, recruited from epilepsy patient support group

Thus illustrates the emotional impact that such new limitations have on one's identity and the psychosocial implications of living with a long-term condition.

5.11 Discussion of the Challenges of Living with a Long-term Condition

The ongoing, persistent nature of both conditions was identified in the data and the suffering which many endured as a consequence. The data has highlighted key concepts which typically emerge in studies of long-term conditions in relation to the negative impact on identity: "loss of self" Charmaz (1983) and "biographical disruption" (Bury, 1982).

These findings concur with Charmaz's (1983) study which describes the impact of having a long-term condition and the limitations as the "loss of self" and a form of suffering. The concept "loss of self" is extended in the current study as the data illustrates that having a long-term condition may cause suffering not only for the individual but also those around them such as partners and family members also affected by the diagnosis.

Bury (1982) describes the impact of being diagnosed with a long-term condition as "biographical disruption." This was often manifested in the perceived unanticipated daily restrictions which participants faced such as being unable to work or no longer allowed to drive a car. Since the condition is long-term, decisions around disclosure are ongoing as is the potential for "disruption" which in turn may have a negative impact on identity. This study builds upon Bury's (1983) concept of "biographical disruption" by illustrating the potential ongoing nature of the "disruption."

I now go on to illustrate how issues of health status are taken into account in relation to disclosure.

5.12 Health Status, Identity and Disclosure

Participants appear to go through a complex process of assessing the impact of the condition. Those who described their condition as "controlled" linked this concept to having limited hypoglycaemic episodes or epileptic seizures and therefore felt that the impact of the condition was easier to cope with. This linked into the perception that the condition was predominantly "invisible" to others which in turn appeared to create greater choices over disclosure. Conversely those whose condition was "uncontrolled" linked this concept to having frequent hypoglycaemic episodes or epileptic seizures at unpredictable times and appeared to have less choices around

disclosure as their condition was more “visible” to others. For some, newly diagnosed, the unpredictable nature of the illness was a particular challenge. These participants described how their condition made them feel different to others:

It is unstable. I think it just has more of an effect I guess ... I’m finding that difficult to deal with.

Interview 33, tu:86, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

Some found the process of managing the extreme symptoms of their condition difficult to the extent that some perceived diabetes as “taking over” their lives as the following quote from a young woman with “uncontrolled” type 1 diabetes described:

For me it’s difficult ... got trouble with my eyes, got loss of feeling in my feet and everything and it was just constant: “Don’t eat this, take more insulin, check your blood sugar, do this, do that.” ... Things that constantly goes over and over in your head ... the diabetes is taking over!

Interview 26 tu: 267, Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Thus the constant nature of the daily management of type 1 diabetes emerged in the data as a burden for some due to the ongoing dietary considerations, the need to inject insulin, to check their blood sugar levels as well as cope with the symptoms associated with the condition. The following quotation illustrates how having a condition that is considered to be “controlled” leads to greater choices and less limitations:

I rule it!, it doesn't rule me! and I won't be ruled by it! I've never said: "I'm not going to do that because I've got epilepsy."

Interview 6, tu: 405, Female, Aged 51, Diagnosed thirty years ago, recruited from epilepsy patient support group

Perceptions of being "in control" of the condition therefore appeared to be important to participants although some stated that they were prepared to take a risk:

Sometimes I just wanna gamble on it and think If I don't tell 'em nothing will happen and it will be ok.

Interview 31 tu:107 Male, Aged 32, Diagnosed twenty-one years ago, recruited from epilepsy nurse specialist clinic

In contrast others cited difficulties around the unpredictability of the condition. Some participants highlighted that a feature of their condition was that they may have a sudden acute episode for example a hypoglycaemic episode or epileptic seizure in such cases they would require assistance from others yet the timing or location of this could not be predicted as the following quotation illustrates:

It's just the unknown isn't it? That's the hardest part to accept ... walking along the street and then suddenly it happens ... A few times I've crossed over the road and it's happened. You could get knocked down couldn't you? I was helped up by two old ladies, but I suddenly drop to the floor literally anywhere!

Interview 15, tu: 355, Female, Aged 48, Diagnosed thirty-two years ago, recruited from epilepsy patient support group

This illustrates the potential danger of having an epileptic seizure at an unpredictable

time or place.

Others highlight that they require assistance from others and frequently have no memory of an acute hypoglycaemic episode:

I've had hypos (hypoglycaemic episodes) where I can't remember it happening, ... I remember waking up but I don't remember how I've got to that position and I've only been able to come round because people have been able to help me or give me a Mars bar or give me a Lucozade or whatever.

Interview 24, tu:63, Male, Aged 18, Diagnosed seven years ago, recruited from young adult diabetic clinic

The above quotation illustrates how people living with diabetes may also have unexpected hypoglycaemic episodes in public places. How others react appears to be relevant. For example prompt assistance from others (potentially strangers) is required, to medically recover such as giving them a drink or something to eat.

5.13 Discussion of Health Status, Identity and Disclosure

The data highlight the link between issues of medical control over the condition and issues of visibility or invisibility. Living with epilepsy or type 1 diabetes which was perceived to be “controlled” was typically perceived to be invisible to others and as having less of an impact upon their daily lives in terms of limitations. Such perceptions in turn linked into decisions over disclosure and also played a role in perceptions of the limitations upon their daily lives. Many participants sought their condition to be controlled as this led to greater degree of perceived “invisibility” and greater integration with others. Similarly invisibility made the disclosure less necessary. Difficulties in accepting the condition appear to play a role in terms of

difficulties around disclosing to others. Participants who attended the nurse specialist clinics tended to cite difficulties in controlling their condition and also difficulties in disclosing their condition. For some participants this was manifested in the prospect of the practical daily management of their condition for the rest of their lives which felt at times quite overwhelming.

The long-term nature of the condition and also decisions around disclosure are thus illustrated in this section. The data suggest that those living with epilepsy experienced difficulties around the unpredictability of the condition. This has been found in existing studies on the social aspects of epilepsy which have described how fear is associated with an unpredictable condition which requires an explanation (Trostle, 1998).

In the next section I present data on how decisions around disclosure are made.

5.14 Section Three The Challenge of Disclosure: “Who Needs to Know?”

5.15 Introduction

This section presents data illustrating the challenge of disclosure described by participants as a process of considering: “who needs to know?”

It examines why participants felt others needed to know about their condition, and the perceived role which disclosure played in this context: gaining access to self-care (medical support) and social support. Decisions have to be made whether to disclose or not across a range of settings. It illustrates that in general participants felt that those close to them such as friends and family should be aware of their condition. Issues of choice over disclosure and dilemmas over disclosure are presented. The role of disclosure in the workplace is also set out.

5.16 The Role of Disclosure: Access to Self-Care and Social Support

As the following extracts highlight, the phrase “need to know” was commonly used by participants who decided strategically who needed to know about their condition:

I tell people who I think might “need to know.” ... Any organization that you belong to, especially where you’re doing a lot of activity they need to know.

Interview 12, tu: 299, Female, Aged 60, Diagnosed nineteen years ago, recruited from diabetes patient support group

I think it’s beneficial to tell people that you are kind of around a lot. My best friend ... I’m with her a lot ... if anything was to happen she’d know what to do.

Interview 1, tu: 165, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group

These quotations underline the key need for others to assist them in the case of an acute episode and suggests that by disclosing they are attempting to protect themselves and others in the case of an acute episode:

It’s important for anybody with diabetes ... to let their family, friends (and people they might meet up with) know that they have it. It could be a life saver in the end ... If they suddenly have a hypo (hypoglycaemic episode) the people around them need to know what it is!

Interview 14, tu: 410, Male, Aged 72, Diagnosed nineteen years ago, recruited from diabetes patient support group

Participants reflected that family members needed to know not only for reasons of

social support, but for reasons of medical support as they reportedly assisted in the self-care of the condition as I go on to illustrate. This was particularly the case with younger participants who relied more obviously on their parents. These participants recounted in detail how their parents (particularly the mother) took on the role of managing prescriptions and overseeing their general health in order to avoid an acute hypoglycaemic episode:

She's always making sure I'm doing the right stuff: got the right prescriptions all topped up to make sure I never run out of insulin ... Don't go out and get drunk too much! ... She's had a massive impact!

Interview 24, tu:67, Male, Aged 18, Diagnosed seven years ago, recruited from young adult diabetic clinic

Sometimes this role is reversed when the affected person is herself a parent. Indeed one mother living with diabetes had explicitly taught her young daughter what action to take should she have a hypoglycaemic episode:

My other daughter is very trained in knowing what to do ... I said to her: "If you ever find mummy asleep and you can't wake her up ... What do you do?" She said: "I ring for an ambulance!"... and "What do you say?" She says: "I tell them that Mummy's asleep and won't wake up and that she's diabetic."

Interview 10, tu: 16, Female, Aged 34, diagnosed sixteen years ago, recruited from diabetes patient support group

Partners also played a key role in self-care: both through recognising symptoms and assisting in their recovery from acute episodes. For those living with diabetes the role of partners was noteworthy as illustrated by the following quotation:

Fiona (my wife) she's often said at night-time: "You're going low." I said: "Don't be so bloody silly I'm not!" but you know she's usually correct ... I've really lost the warning signs.

Interview 14, tu: 426, Male, Aged 72, Diagnosed nineteen years ago, recruited from diabetes patient support group

This underlines the significant role of partners in self-care as the participant's wife warned him that he was at risk of having a hypoglycaemic episode, something which he was no longer able to determine. Other participants highlighted the benefits of being in a relationship with someone with the same condition who could understand and assist in the ongoing practical self-care requirements:

I'm going out with a diabetic so it's a lot easier ... because he knows you know if we go out somewhere that we have to eat at a decent time ... Checking our sugar levels ... you do it together ... It's just a bit more easy you don't feel like the odd one out all the time ... Some of my partners in my past have been very scared when I've had a really bad hypo (hypoglycaemic episode) ... My partner now he knows what it's like to have a really bad hypo. So even if I have one he takes it all in his stride and he sorts me out.

Interview 16 tu: 267, Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group

Such shared experiences also appeared to be significant in terms of identity because the individual no longer felt "different" to her partner as she had done so in the past. Others living with epilepsy highlighted that they felt safer having their partner or a

family member with them particularly in public places since they would know how to respond in the event of a seizure occurring:

I very rarely go anywhere without my wife ... the frequency that I do have fits, it makes you scared ... to go out by yourself in case something does happen.

Interview 32, tu: 96, Male, Aged 52, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

One older woman living with type 1 diabetes reflected that some men were in denial and had difficulty in accepting their condition. Their wives played a vital role in supporting them in self-care:

The men I know who have it rely on their wives. Their wives do everything you know. They remind them to have their jabs, they do their food and they tell people. But the men behave as though it's not happening to them ... I do think they're very frightened of admitting there's anything wrong with them!

Interview 12, tu: 264, Female, Aged 60, Diagnosed nineteen years ago, recruited from Diabetes Patient Support Group

These quotations raise the issue of dependence and responsibility placed upon their partners and the gendered nature of support within a family or relationship.

Others highlighted the limitations that living with epilepsy placed upon their lives which they felt not only affected them, but their partner and family around them:

I get a bit sorry for (my) husband and ... son 'cos there's some things I can't do for them ... Obviously if I have an attack or something they've gotta keep me under control ... There's times when one of them can't go out 'cos I can't be left here on my own.

Interview 18, tu:165, Female, Aged 49, Diagnosed thirty-four years ago years ago, recruited from epilepsy patient support group.

The above extract illustrated that some participants perceived the condition to place an unfair burden upon family members.

5.17 Discussion of the Challenge of Disclosure: “Who Needs to Know?”

Participants described a process of assessing “who needs to know?” about their condition which suggests that such decisions are underpinned by a desire for privacy. This process of assessing “who needs to know?” has been identified in previous studies examining disclosure (Green and Sobo, 2000). In the current study, those who needed to know were those whom participants were likely to see frequently in the course of their personal or social lives including friends and family. This finding supports previous studies which report that the decision to disclose is dependent upon levels of intimacy: how well they are known to the discloser (Lowton, 2004, Green and Sobo, 2000).

In the current study, the question of “who needed to know?” was linked to a specific role: the need to access not only social support but medical support. The rationale for disclosure was generally linked to the symptoms of their condition and wanting others to know how to respond in the event of an acute episode such as a hypoglaeaemic episode or epileptic seizure where they would require assistance. For example in the event of a potentially acute episode someone would “know what to do.”

These findings illustrate that the role of disclosure in this context is not only to inform others about having the condition, but also to minimise their concerns. This

concur with studies in the field of epilepsy. Schneider and Conrad's (1980) concept of "preventive telling," that "others know what it is" and, "what to do". The current study builds upon the concept of "preventive telling" by identifying the additional point that disclosers felt that their condition placed an unfair burden on those "who needed to know" due to the role that they play in supporting them: the concept is also relevant to those living with type 1 diabetes.

For example, studies in the field of diabetes have identified that it is important to have "allies" to assist you to manage the condition (Paterson et al 1998). In the event of a hypoglycaemic episode family members typically perform the role of "rescuers because they are also looking out for potentially dangerous signs of the condition (Paterson, et al, 1998). Charmaz (1991) has stated that this planned form of disclosure constitutes "protective telling" but her concept does not address the need for practical assistance.

Overall, disclosing to friends and family was perceived to be advantageous. This finding concurs with studies in the field of psychology which state that outcomes of disclosure are more likely to be beneficial if they assumed a positive response (Pennebaker, 1990).

In contrast difficulties around disclosure were reported more frequently outside of the context of family and friends such as the workplace. I go on to set out the study findings illustrating the role of disclosure in the workplace.

5.18 The Role of Disclosure in the Workplace

Disclosure in the workplace presented participants with particular dilemmas. Issues of legislation and disclosure are presented. The perceived reactions to disclosure

which may result in discrimination, feelings of difference, and stigma. Some disclosed for reasons of health and safety.

One woman reflected upon the complexity of disclosure in the context of workplace legislation:

You don't have to disclose your medical condition however you can get into trouble if you haven't informed the employer afterwards and then an accident happens, it's your responsibility but not theirs but then again ... big changes were made because it is now the employers responsibility to make sure you are safe in the work environment not yours.

Interview 3, tu: 356, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group

Others cited how they felt they did not have a choice over whether or not to disclose in the workplace, yet this can be a difficult process particularly as highlighted earlier, their condition is perceived by many to be a personal matter:

Something like epilepsy or diabetes ... you have to disclose it. You have to make your employers aware 'cos they need to know if you have a hypo or a fit what to do and sometimes you do feel you're baring your soul to people and (they) know things that are quite private and personal.

Interview 16 tu: 521 Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group

The nature of a long-term and sometimes unpredictable condition means that participants may disclose for simple reasons of safety. Thus as the interviewee below outlines, his fear of a sudden hypoglycaemic episode relates not only to

personal safety but also to workplace legislation which makes the individual responsible for disclosing.

Although not obliged to he felt an individual responsibility to disclose:

I felt it was something people ought to know ... It became a health and safety issue ... If I passed out at my desk, they needed to know why I'd passed out.

Interview 4 tu: 40 Male, Aged 71, diagnosed fifty-eight years ago, recruited from diabetes patient support group

Others felt that choice was not an option and they were obliged to disclose to employers for reasons of health and safety:

It was a case of having to tell them at work. I didn't have any choice ... I was working in a factory, working around sort of milling machines ... You could potentially fall into and take your head off if you weren't careful, let alone your arms or anything. So you had to be really careful."

Interview 2 tu: 49 Male, Aged 55, Diagnosed eighteen years ago, recruited from epilepsy patient support group

Despite legislation around disclosure in the workplace, some participants reported difficulties in completing a medical disclosure form when applying for jobs for fear of being rejected. One woman faced a dilemma over disclosure and attempted to reassure her employers that her condition was "controlled" and therefore she did not constitute a "risk":

I knew I'd got to declare it legally ... but it does cause a problem because if people see it, they think "No, we don't want her!" So I tended to write epilepsy and then in brackets "controlled."

Interview 6 tu: 103, Female, Aged 51, Diagnosed thirty years ago, recruited from epilepsy patient support group

This highlights that health status although taken into account when disclosing is on occasions qualified: the participants specifically states her condition is: “controlled”.

Many felt that having epilepsy led to unfair discrimination in the workplace and cited examples of previous experiences:

That’s the whole bit of getting a job: telling them I’ve got epilepsy. I just get turned down every time.

Interview 19 tu: 56 Female, Aged 21, diagnosed seven years ago, recruited from epilepsy patient support group

Some had their employment terminated and this they felt was due to disclosure of their condition:

(When) I got diagnosed (with epilepsy) ... I was in hospital for a month. Then I took the note to my employer and I was sacked on the spot!

Interview 30 tu: 15 Female, Aged 28, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

Others, particularly those newly diagnosed chose not to disclose as they feared being treated differently by others as a consequence of the disclosure:

They’ve said: “Tell your employer” ... I don’t really want them to know ... to be like “Oh John can’t do that job because he’s diabetic!” ... I don’t wanna be treated any differently to anyone else.

Interview 23 tu: 90: Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetic clinic

However as the following quote illustrates non-disclosure appeared to place a burden upon the individual:

I felt that if I never told them about my epilepsy I could have got somewhere ... I never told them ... but I felt that I was being deceitful because I thought: “Well what if I do have a fit? What are they going to do? I’m not going to be covered by the insurance!” ... So I was never really successful ... I never stayed in the job for long.

Interview 34, tu: 46 Female, Aged 31, Diagnosed twenty years ago, recruited from epilepsy nurse specialist clinic

5.19 Discussion of the Role of Disclosure in the Workplace

This section has identified the issues around disclosure in the context of the workplace. Decisions around disclosure within this setting appear to be complex despite the existence of legislation on disclosure in the workplace (Disability Discrimination Act, 1995).

Some felt that they were successful in getting offered the job because they had not disclosed their condition to the employer. Conversely, those who choose not to disclose their condition, felt burdened by this and some left their employment in advance for fear of their condition being disclosed. This finding concurs with the literature arguing that the process of “passing” as “normal” can lead to stress and embarrassment if the condition suddenly becomes visible, thus leading to “discreditation” (Goffman, 1963).

It also concurs with research which suggests that the workplace is a “high risk” setting for disclosure (Lowton, 2004).

Issues of health status appeared to mediate decisions around disclosure of their condition although these were not straightforward. Across both conditions participants felt that the heterogeneity of the condition was not taken into account by employers. Thus disclosers often expressed frustration at employers’ responses to the disclosure. Underlying these feelings were unmet expectations by the disclosers as many were seeking a more positive response from employers and for their condition to be taken into account in their ability to do the job. This concurs with Beatty’s (2004) findings who describes this form of disclosure in the workplace as “instrumental disclosure” the purpose of which is to influence the actions and responses of others towards the individual with the condition.

A process of “covering” was identified as some participants disclosed their condition but noted that it was “controlled” (Goffman, 1963). Issues of health and safety emerged as some disclosed as participants felt they had no choice but to disclose due to their condition. Overall, most participants did disclose the condition in the workplace to their line manager. This type of disclosure has been described in the literature as “partial self-disclosure” for example telling their line manager that they do have an illness (Munir et al 2005). In the current study younger participants found that disclosing to the line manager the implications of the condition and potential limitations that it placed upon their ability to do the job difficult. Munir et al (2005) has described this form of disclosure as: “full self-disclosure.”

The findings illustrate a process of learning about disclosure over time. Participants took previous experiences of disclosure into account when making decisions around

disclosure. Previous perceived negative reactions to disclosure led to the avoidance of disclosure unless absolutely necessary. Many participants associated the process of disclosure of their condition as reaffirming issues of difference and stigma.

This has raised issues around the lack of advice and support for those having to disclose. For many the intention of the disclosure, described in the literature as, “workplace adjustment:” a process of taking the condition into account was not met by their employers (Disability Discrimination Act, 1995). This led many to express disappointment that their employers did not react as they desired and they linked the negative responses to the disclosure to the perceptions that the employers did not fully understand the full implications of having epilepsy or type 1 diabetes and the associated adjustments required in the workplace. This has implications for the process of self-care in the context of the workplace.

In summary, the following issues were considered when making decisions around disclosure or non-disclosure of their condition: past experience of disclosure, health status and identity. Such issues were also highlighted in a study of cystic fibrosis in the workplace (Lowton, 2004). In the next section I present findings to illustrate the process of: “learning about disclosure” over time.

5.20 Section Four: Learning about Disclosure: Disclosure and the Role of Time

5.21 Introduction

This section sets out comparative data from participants recruited from the patient support group setting and nurse specialists clinics to illustrate the process of “learning about disclosure” over time. Firstly I set out findings from the patient support group participants. It examines the role of time and disclosure, illustrating

that feelings about disclosure are not necessarily fixed but dynamic and subject to change over time. I illustrate how experiences of stigma are taken into account presenting data on epilepsy, stigma and disclosure. A second role for disclosure is identified in this context: participants recruited from the patient support groups adopted anticipatory strategic disclosure, (redressing myths about the condition to others in advance), the role of which is to avoid stigma around the condition.

In the second part of this section I set out comparative data from the nurse specialist clinic participants and illustrate a process of learning about disclosure leading to the adoption of non-disclosure in this context.

5.22 Patient Support Group Findings: Disclosure and The Role of Time

There appears to be a link between the role of time, accepting the condition and attitudes towards disclosure. Those who were members of the patient support groups tended to cite feelings of acceptance of the condition. The data highlighted that feelings about disclosure are not necessarily static, but dynamic and subject to change.

Time appears to play a significant role in terms of individual perceptions of disclosure and subsequent decision making. Some cited how over time their attitude had changed from being reluctant to disclose to acceptance of the condition and a greater openness:

(Now) I'm involved in running a group ... When I was younger ... I didn't like to show, or tell anybody I'd got it ... Now I'm that bit older, it's ... something I'm accepting.

Interview 15 tu 194, Female, Aged 48, Diagnosed thirty-two years ago,
recruited from epilepsy patient support group

Similar findings were identified across both conditions.

The following quotes illustrate the profound effect that difficulties around disclosure may have on the subsequent management of the condition and therefore potentially on health status. A member of a patient support group reflects on this:

I was supposed to be testing my sugar levels all the time and I just didn't ... I wanted to be the same as my friends. I didn't want to have to keep saying to my friends: "*Oh I need to go and eat something. Oh I need to go and test my blood sugar levels*" ... while my friends are all footloose and fancy free ... doing things spontaneously!

Interview 16 tu: 61, Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group

However, such feelings about disclosure changed over time:

I'm a lot more comfortable at telling and I just think that comes with age anyway. It doesn't bother me that I'm diabetic anymore. My lifestyle's changed as well you know so I'm more in control of my diabetes.

Interview 16 tu:373, Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group

You were embarrassed by it! You were different from everybody else in those early days I suppose.

Interview 4 tu: 74, Male, Aged 71, Diagnosed fifty-eight years ago, recruited from Diabetes Patient Support group

Over time this participant became more open, about the condition disclosing in the context of a social group as the following quotation illustrates:

About six or seven years ago, I just thought that it was something that needed to be said ... I just believed that I should tell them all there was sort of to know about me I'd been a member for maybe 12 years since then so that I knew everybody well I just sort of felt that they should know who was the person standing out front.

Interview 4 tu:181, Male, Aged 71, Diagnosed fifty-eight years ago, recruited from Diabetes Patient Support group

Others highlighted that not disclosing in the workplace had led to difficulties, particularly for those who were not "in control" of their condition. The following quote illustrates not disclosing to her employer in advance led to feelings of regret:

Obviously it's come out, which probably made it worse ... I just sort of collapsed on the floor ... with antiques lying around ... ceramics and paintings ... I had two weeks notice and had to leave.

Interview 15 tu: 91 Female, Aged 48, Diagnosed thirty-two years ago, recruited from epilepsy patient support group

Another interviewee reflected back that in future she would disclose her condition to her employer, thus highlighting that feelings about disclosure may change over time:

If I apply for another job I'm telling them up front I've got it ... to be fair to them really ... 'Cos it's not very good ... if somebody collapses and you think: "Oh my God! What's happening?!"

Interview 15 tu: 141 Female, Aged 48, diagnosed thirty-two years ago, recruited from epilepsy patient support group

5.23 Discussion of Patient Support Group Findings: Disclosure and the Role of Time

Time appears to have played an important role in decision making in terms of how participants viewed disclosure and subsequently adopted strategies around it. A number of participants highlighted that over time they found it easier to disclose. Others stated that over time there was an increase in the knowledge and the experience of the condition which gave them confidence to disclose. This suggests that time may influence decisions and attitudes towards disclosure thus views on disclosure are not static. Processes of adapting to living with type 1 diabetes or epilepsy were identified in the interviews (Paterson et al, 1998, Dovey-Pearce et al, 2007, Scambler and Hopkins, 1986). Indeed, literature on long-term health conditions has cited the important role of capturing changes over time regarding feelings about the condition (Charmaz, 2000). Issues of control of the condition were raised by participants. However some participants felt their condition had become more controlled over time, and equated this with changes in lifestyle. Evidence for this finding is supported in the literature on diabetes which describes how the process of controlling one's condition is dynamic and linked to changes in lifestyle, referring to a process of "learning to balance" the condition in one's life (Paterson et al, 1998).

Members of patient support groups reported adopting strategies of disclosure in order to avoid stigma around the condition thus highlighting that “learning about disclosure” is a key process which evolves over time. The relationship between stigma and disclosure, for those living with epilepsy is now discussed.

5.24 Patient Support Group Findings: Epilepsy, Stigma and Disclosure

The data illustrated that participants recruited from the patient support groups felt that not only can having an acute episode be dangerous to themselves and others and require a need for others to help them, they also felt socially judged. How others beyond friends or family perceived the symptoms appeared to play a key role in how people felt about having the condition. Participants raised concerns that sometimes people mistake the symptoms of their condition for example, shaking or slurring words to be as a consequence of drugs or being drunk. This led them to feel they were being unfairly judged by onlookers.

One participant described how others ignored her when she had an epileptic seizure in a busy city train station:

I remember having a seizure on (place) railway station ... Luckily I had somebody with me ... He told me afterwards people were quite literally stepping over my body pretending that I just wasn't there! ... They were frightened of it and they would assume you know, drink, drugs.

Interview 3 tu: 131, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group

Many participants cited such negative reactions as experiences of being stigmatised. They felt that there was a stigma around the condition itself, in particular when they

had an acute episode. Therefore not only did they have to cope with the physical, biomedical management of the condition but also the stigma, that is the social judgement of the condition manifested through others' reactions:

There's a stigma attached to it because you can't see it obviously and you just fall on the floor ... People don't know how to cope with it.

Interview 15 tu:260, Female, Aged 48, Diagnosed thirty-two years ago, recruited from epilepsy patient support group

Others felt that while these attitudes stemmed from historical prejudice, there was little doubt that such negative attitudes and connotations of the condition epilepsy, still existed in the present day. Participants believed that the frightening and powerful image of someone having a seizure contributed to this:

In the past (people) with epilepsy were thought to be possessed. They were also thought to be mad! ... I think that's part of where it comes from ... People do think you are going to fall down, ... have a major seizure and thrash around and froth and they're scared!

Interview 6, tu: 132, Female, Aged 51, Diagnosed thirty years ago, recruited from epilepsy patient support group

The following quote illustrates how a co-worker responded to the disclosure of epilepsy:

She said: "Oh but you don't look epileptic!" and I said: "Well how am I supposed to look?" and she sort of shrugged her shoulders and said "Well I don't know, I thought you might fall down and froth a bit!"

Interview 6 tu: 346 Female, Aged 51, diagnosed thirty years ago, recruited from epilepsy patient support group

Participants therefore reflected that others had strong mental images of what someone having an epileptic seizure might “look like.”

5.25 Discussion of Patient Support Group Findings: Epilepsy, Stigma and Disclosure

The data suggests that epilepsy has long been associated with negative historical beliefs. Evidence for this finding is supported in the literature on socio-cultural understanding of epilepsy (Eisenberg, 1998). Thus perceived stigma becomes a barrier to disclosure since perceptual images of the condition can lead to others socially judging them, thus resulting in stigma.

Many participants feared then that by disclosing they would in turn be stigmatised and in the interviews there were numerous specific examples of this. Indeed in this respect disclosure was perceived as something “risky” and potentially “discrediting” to their identity (Goffman, 1963). Furthermore existing studies have identified what is termed “felt stigma” that is perceived stigma and “enacted” stigma which is actual experience of stigma (Scambler and Hopkins, 1986).

Participants from the patient support group sample provided access to those who had lived with the condition for a relatively longer time (than those recruited from the nurse specialist clinics). The data illustrated that reactions to disclosure when taken into account, led some to adopt the strategy of disclosing to others in advance. This illustrated that these participants had “learned about disclosure” to avoid

misconceptions of their behaviour and redress myths associated with the condition as I go on to discuss.

5.26 Patient Support Group Findings: The Role of Strategic Disclosure:

Redressing Myths about the Condition in Advance

The data illustrated a second role for disclosure: by disclosing in advance: participants sought to redress myths about the condition “preventive telling” to avoid perceived stigma, as the following quote illustrates:

If you're with someone and they're having a seizure, they think: “They're on drugs or drinking.” Better to tell people that you've got it.

Interview 19 tu: 150, Female, Aged 21, Diagnosed seven years ago, recruited from epilepsy patient support group

In this case it could be argued that the intention of disclosure was to protect themselves from the misplaced judgment of others.

Older people who were members of the patient support groups appeared particularly keen to avoid such stigma and often employed this strategy of disclosing to others in advance, an additional rationale being to gain necessary medical support:

If you see somebody having a hypo (hypoglycaemic episode) ... eventually they just collapse on the floor. You think “Oh he's drunk!” It's the automatic reaction! There's a big difference between what a drunk needs at that moment and what somebody with type 1 diabetes needs ... So ... it became more important to me to tell people.

Interview 14: tu: 164, Male, Aged 72, Diagnosed nineteen years ago, recruited from diabetes patient support group

Therefore, it was not only about stigma it was also for reasons of safety; that those around them knew about their condition, because they relied on outside help in the event of an acute episode. This was found across both conditions:

In case anything happens while you're in their presence ... Tell them and explain to them. Tell them what to do if I do go into one. 'Cos ... they don't know whether to lie you on the floor or on your side ... It's just a case of sitting you down and waiting till I come out of it.

Interview 18, tu:165, Female, Aged 49, Diagnosed thirty-four years ago, recruited from epilepsy patient support group

5.27 Discussion of the Patient Support Group Findings: The Role of Strategic Disclosure

In this context the role of disclosure was to redress myths around the condition in advance. Schneider and Conrad (1980) refer to this as “preventive telling”, the purpose of which is to avoid perceived stigma. “Learning about disclosure” emerged as a key issue in terms of developing strategies over time based upon previous responses. Those who had lived with the condition for a long time, particularly attendees at patient support groups appeared to develop strategies to manage the process of disclosure, in order to minimise the potential for stigma. Other studies have found that disclosure can be typically planned in order to minimise negative reactions from others (Charmaz, 1991, Schneider and Conrad, 1980, Troster,1997).

The findings of this study suggest that participants made “strategic” decisions regarding to whom to disclose. Decision making around disclosure appeared to be linked to assessment of the risk of being stigmatised as a consequence of disclosure.

This finding reflects earlier work which highlights the link between stigma and decision making around disclosure in order to avoid “discreditation” (Goffman, 1963).

In part two of this section I now present comparative data from the clinical nurse specialist clinic participants and highlight how similarly the process of “learning about disclosure” emerged in this setting. The challenges around disclosure, the rationale for non-disclosure and participants’ adoption of concealment of their condition are presented. The third role of disclosure is identified in this context to be: non-disclosure as a means to avoid stigma.

5.28 Clinical Nurse Specialist Clinic Findings: Challenges of Disclosure

Participants described a process of learning about disclosure over time. In particular the challenges they faced around the timing of disclosure. Previous negative reactions to disclosure played a key role in their perceptions and strategies they adopted concerning disclosure.

5.29 Timing of Disclosure

Younger participants, particularly those who were newly diagnosed expressed apprehension at the prospect of disclosing their condition to potential partners. In the following quotation, the young woman recently diagnosed with epilepsy reflects on this:

One of the girls at uni has epilepsy as well. She says that she really struggled to tell a long-term boyfriend ... Trying to tell him all about her epilepsy was she found difficult ... I haven’t been seeing anybody ... I suppose that would be quite difficult trying to share that with somebody.

Interview 1 tu: 181, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group

Similar dilemmas emerged with regard to the timing of disclosure to potential friends:

Once you get to know somebody then you tell them ... There's no point telling every Tom, Dick and Harry your problems unless you are actually gonna be friends with them and then you're gonna know for a long time.

Interview 26 tu: 240, Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Participants expressed concerns around "finding the right moment" to tell.

This appeared to be dependent on how well they knew the individual:

It's sort of finding like the right moment as well. I always think if I turned round and said "Hi my name's Emma blah, I'm diabetic." That's sort of defining myself as it (diabetic) ... Whereas it's just something that happens to be there.

Interview 35 tu 62: Female, Aged 22, Diagnosed nineteen years ago, recruited from young adult diabetic clinic

It's also hard to drop into the conversation ... Say for example ... I'm talking about football to someone I've just met, to then turn round to them and say "Oh yeah, by the way, I've got epilepsy." They take a step back and sort of like then they're careful.

Interview 31, tu:75, Male, Aged 32, Diagnosed twenty-one years ago, recruited from epilepsy nurse specialist clinic

For those newly diagnosed it was an important decision because the disclosure underlined feelings of “difference” and potentially jeopardised social acceptance:

You don't want it to change how people feel about you. You want to tell them 'cos it's important to you but you don't want them to feel differently about you or to feel sorry for you. I don't really like telling people just because it then makes you different and you're not! It's really hard to explain.

Interview 27 tu: 53 Female, Aged 19, Diagnosed six months ago, recruited from young adult diabetes clinic

I'll tell someone once I sort of know them well enough to sort of have a bit of faith in them. So that I know that ... they wouldn't sort of react in a negative way. I wait until I'm sure that they're sort of able to handle as much as I can handle it.

Interview 23 tu:79, Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetic clinic

The above quotations illustrated that individuals took others' reactions into account when making decisions around the appropriate time to disclose.

Participants across both conditions highlighted that decisions to disclose or not emerged frequently in the context of seeking travel insurance. Many cited how they could only gain medical insurance from specialist companies thus bringing their condition to the forefront:

I don't think about it a great deal ... Trying to get travel insurance and things

like that, that's the only time it ever really becomes a problem ... The only people you can really get insurance off of is from the Diabetes UK people ... Sometimes I fib about that ... 'cos if I break an arm, I'm always fairly confident that nothing diabetes related is gonna happen if I'm away.

Interview 35, tu 93: Female, Aged 22, Diagnosed nineteen years ago, recruited from young adult diabetic clinic

Some therefore chose not to disclose their condition to travel insurance companies as they felt it was unlikely that the condition itself would lead to complications whilst on holiday. The following quotation highlights difficulties encountered around misconceptions concerning medication for those living with epilepsy:

Some epilepsy drugs that I've been on are classed as an antidepressant ... They've (travel insurance companies) come back to me and said: "How long have you been depressed for?" ... when I said to them: "It wasn't for depression. It was medication for me epilepsy." ... So then I've had trouble and I've just not had medical insurance at all. They're not listening to you ... It's just so frustrating! 'Cos I need the medical insurance! And it's like when I go on holiday I have the same problem again. I have to pay more and I think why? I'm fine! It's not like I have an ailment where I've got a limited short life span! It's not like that at all.

Interview 34, tu: 115 Female, Aged 31, Diagnosed twenty years ago, recruited from epilepsy nurse specialist clinic

The ongoing, enduring nature of the condition makes disclosure a difficult process to negotiate for many, not only to partners but to "outsiders" such as in the context of

disclosure to seek travel insurance. Other studies have highlighted the difficulties encountered around disclosing a long-term health condition to potential partners, due to fears of a negative reaction (Lowton, 2004)

I now go on to present data concerning participants perceived responses to disclosure which were often deemed to be negative. Reactions are often linked to issues of visibility and images of what someone with the condition might “look like.” Participants felt such reactions illustrated a lack of understanding regarding the heterogeneity of both conditions. Such reactions were reportedly the rationale for their subsequent adoption of the strategy of deliberately choosing not to disclose their condition.

5.30 The Rationale for Non-disclosure: Perceived Negative Reactions

Disclosure did not always lead to a perceived positive response from employers. Typically participants felt this was due to a lack of understanding around the potential difficulties encountered living with diabetes. Some reported feelings of not simply fear of the consequences of neglecting self-care, but also guilt as sometimes their condition required additional time away from work to attend hospital appointments:

I feel guilty for having to ask for time off, but if I don't go (to the hospital) then my diabetes goes out of control ... I end up having time off being sick anyway ... but you say to somebody nowadays: “I've got diabetes” and they just go: “ok!” because they don't understand ... Then you say: “I need the time off for the hospital and you go to the eye hospital ...“But why?!” They (employers) expect you to have diabetes and it's all fine and normal and that's it!

Interview 26 tu: 85 Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Others felt that disappointing responses from employers were due to a lack of understanding around the implications of living with the long-term condition. As one respondent recalls:

There were a number of times where I'd had a full-blown seizure and I would phone in work and say: "Actually I'm sorry, I'm not well enough to come in." ... She'd (the manager) phone in a couple of hours and say: "Oh can you come in now?" She didn't have an awareness that actually I'd feel pretty lousy for the rest of the day.

Interview 33 tu:39 Female, Aged 28, Diagnosed 18 months ago, recruited from epilepsy nurse specialist clinic

Everybody's got an illness who works but I suppose with epilepsy they're scared 'cos they don't know what's going to happen!

Interview 30 tu 38 Female, Aged 28, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

Participants recruited reflected upon perceived reactions when they did choose to disclose their condition to others. The quotations provide valuable insights into the process of disclosure and the reactions of others' to disclosure.

Mental images of the condition could be perceived as negative markers by some attendees of nurse specialist clinics as the following quotation illustrates:

I feel that once you say you're an epileptic – it's about what their opinion and perspective is about epilepsy. They haven't got a clue about what a fit is

really. They think it's aggressive, they think you're a loony, ... you're mad, you're crazy, you're gonna have outbursts!

Interview 34 tu: 53 Female, Aged 31, Diagnosed twenty years ago, recruited from epilepsy nurse specialist clinic

Difficulties were experienced in disclosing due to others' reactions which did not take into account the heterogeneity of the conditions:

I'm not keen on telling people about my epilepsy as there are many types of epilepsy. Due to the different types all having the same name, to an uneducated person they tend to tar us all with the same brush.

Interview 31, Male, Aged 32, Diagnosed twenty one years ago, recruited from epilepsy nurse specialist clinic (added in by letter)

Many described "being asked the same questions" to be a typical response to disclosure:

They always ask me the same questions: "*Do you have to take injections?*" and "*Does it hurt?*" That kind of drove me mad being asked those two questions constantly for a few years of my life.

Interview 25, tu:16, Male, Aged 19, Diagnosed fourteen years ago, recruited from young adult diabetic clinic

This response caused frustration and led many younger participants to avoid the process of disclosure where possible because they perceived it as burdensome.

A further complication of disclosure for those living with diabetes is that there are two types: type 1 and type 2. Some participants highlighted that there appears to be

greater public understanding of diabetes type 2, as opposed to type 1 diabetes. This led to frustration for those disclosing as one participant emphasises:

When you tell them they'll say stuff like: "Oh you can't eat sugar then?" or "You have to eat sugar?" or some people think there two types: one where you don't have enough sugar, and one where you have too much sugar and like: "Which one do you have?" I'm like: "It doesn't work like that!"

Interview 29 tu: 64, Female, Aged 17, Diagnosed three years ago, recruited from young adult diabetes clinic

There appears to be a link between what others know about the condition and how they respond to the disclosure. In some instances the discloser felt that they were being unfairly judged for having a "self-inflicted" condition:

A lot of people associate it with being quite overweight and being unhealthy ... Completely the opposite to what I was, and still am ... I guess there's some stereotypes.

Interview 23 tu: 40, Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetic clinic

This raises issues of information needs, as the response of others was perceived to be linked to their understanding of the condition. Put simply, when others knew little it made the process more difficult for the discloser:

If you just had one person that actually knew what diabetes was it would be so much simpler to tell people! ... You wouldn't have to tell em what it's all about. You wouldn't have to explain why you have injections? Why you do

blood tests? Why you land in hospital? They'd just know it's one of those things that needs to be done!

Interview 26 tu: 147, Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Some felt that the general lack of information on epilepsy and lack of "high profile" role models made disclosure more difficult:

With epilepsy there's just such a lack of information in the public arena ... You never hear of famous people with epilepsy!

Interview 33 tu:89, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

Younger participants, discussed how they had been advised to tell others for insurance purposes. However, many cited that this was not a simple act:

All I've been told is: "You have to let them know, you have to let them know!" Not why? "Just tell them! It's easy!" ... It's been hard telling them!

Interview 34, tu: 110 Female, Aged 31, Diagnosed twenty years ago, recruited from epilepsy nurse specialist clinic

Some living with epilepsy feared that they would be stigmatised for having disclosed the condition:

I just want people to take me for who I am ... 'Cos it feels like I've got a stamp on me head that says: "*I've got epilepsy!*"

Interview 31, tu: 115, Aged 32, Diagnosed twenty-one years ago, recruited from epilepsy nurse specialist clinic

5.31 Discussion of Clinical Nurse Specialist Clinic Findings: Challenges around Disclosure

The data presented above has illustrated that previously perceived negative reactions appear to play a role in perceptions of the role of disclosure and strategies around disclosure. Those to whom they disclosed did not understand the implications of having the condition were for the discloser or for them. With reference to employers, participants felt they often did not understand the medical implications of living with the condition for the discloser this impacted on the practical application of self-care such as the need to attend hospital appointments or periods of recovery following epileptic seizures.

Participants found that disclosure may lead to negative consequences such as repeatedly being asking the “same questions,” and feelings of stigmatisation such as being treated differently, which is in line with the work of Goffman, (1963). They highlighted that there appeared to be a significant gap in information with many discussing the necessity for raised public awareness of the conditions.

Previously perceived negative reactions to disclosure led some to avoid the process altogether as I go on to illustrate.

5.32 Clinical Nurse Specialist Clinic Findings: The Role of Non-disclosure: Avoiding Stigma

5.33 The Process and Role of Non-disclosure (Type 1 diabetes participants)

This section presents findings which illustrate that some chose to conceal the process of medical management of their condition, in order to protect themselves from stigma, particularly those living with type 1 diabetes whose process of management

such as injecting insulin was perceived as “visible.” The process of visibly injecting appeared to represent a form of unwelcome disclosure and as such was to be hidden as the following quotation indicates:

I go to the toilet. I don't do it (inject insulin) in front of anyone else! ... If they don't know what you're actually doing - they might think you're a druggie!

Interview 26 tu:126 Female, Aged 21, diagnosed eleven years ago, recruited from young adult diabetic clinic

I think it's quite a taboo thing isn't it like needles?! Everybody associates it with the spread of diseases! ... I'd never sit on a bench and just do it (inject), in public.

Interview 23 tu: 86, Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetic clinic

Fear of social stigma led to a process of concealment which in turn affected self-care:

It's even worse when you go out clubbing for the night as well 'cos that's one of the places I wouldn't take my injection with me 'cos the drug dealing and that kind of stuff that you expect in the night club.

Interview 26 tu:138 Female, Aged 21, diagnosed eleven years ago, recruited from young adult diabetic clinic

As the following example in the workplace illustrates for some this link of maintaining a “healthy identity” was related to concealing ways of managing the condition, for example non-disclosure meant not allowing others to see them injecting their insulin:

I've kept it quiet at work, just done my injections at the loo at lunch.

Interview 23 tu: 91: Male, Aged 21, diagnosed four months ago, recruited from young adult diabetic clinic

Whilst many did disclose their condition to their employers, many younger participants chose to hide the process of managing the condition. This had a negative impact upon her health status as the following quotes illustrate: they didn't want to be seen as "different:"

I just didn't want to be seen to be different ... Having to say: "Look I need to eat, I can't come to a lunchtime meeting" ... I would try and hide it under the carpet and just get on with it quietly myself ... I was having to rearrange my life around my work ... and not be doing things that I should have been doing with my diabetes like having regular meals and stuff.

Interview 16 tu: 197 Female, Aged 38, Diagnosed twenty years ago, recruited from diabetes patient support group

In this context concealment appears to play a role of social management for example protecting oneself from stigma.

Some younger participants preferred their family members disclosing on their behalf as they found it a difficult process at the time of diagnosis:

I think I got my mum to tell them by phone. I didn't know what to say.

Interview 29 tu: 64 Female, Aged 17, Diagnosed three years ago, recruited from young adult diabetes clinic

As the following quotation from a young woman illustrates, some chose to avoid the process of disclosure altogether:

I only let my mum do it (disclose) ... Bad reactions ... It also upsets me quite a bit ... 'Cos I know all the things that are wrong with me.

Interview 26 tu: 277, Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Thus for some, disclosure represents an ongoing burden to be avoided: reflecting the emotional impact of living with the condition, and the perceived negative responses of others, leading many to state such reactions to be the rationale for their subsequent non-disclosure of the condition.

5.34 Discussion of Clinical Nurse Specialist Clinic Findings: The Process and the Role of Non-Disclosure

The data presented above illustrates that the process of managing the condition had not only biomedical connotations but social connotations. Many younger participants living with type 1 diabetes described the process of injecting insulin as having profound social connotations such as negative links to illicit drug use. Therefore injecting became not only an act of medical management but a potentially “discrediting” form of disclosure to others (Goffman, 1963). This process of deliberate concealment is referred to as “passing” the purpose of which is to become part of the “normal” group and not be treated differently (Goffman, 1963).

Others chose to deliberately avoid verbally disclosing their condition to others and asked their parents to do so. Again the process of disclosure was to be avoided because it appeared to compound feelings of difference. Protecting their identity as “normal” appears to be the key rationale for this behaviour. This linked to difficulties of accepting the condition and fear of the reactions of others, such as

stigma, based upon misconceptions or myths. Such feelings are significant because they have implications for managing the condition which may lead to the deterioration of health status and in particular for those living with type 1 diabetes. Evidence for this finding is found in other studies on the management of type 1 diabetes, which suggest that difficulties accepting the condition and feelings of difference tend to affect the management of the condition (Paterson et al, 1998). The data identified issues around non-disclosure of one's health condition and similar findings are highlighted in other studies (Goffman, 1963, Charmaz, 2002, Sandelowski, 2004). Goffman (1963) argues that not disclosing is a strategy by which to manage or avoid issues of stigma.

I now go on to discuss commonalities and differences identified in the data from patient support group participants and nurse specialist clinic participants with regard to: "learning about disclosure" disclosure and the role of time.

5.35 Discussion of patient support group and nurse specialist clinic findings

Learning about Disclosure: Disclosure and the Role of Time

The study findings illustrate differences across the participants recruited from the patient support group and nurse specialist clinics in relation to their views on disclosure. For example those recruited from the patient support groups recounted how many had changed over time from not disclosing their conditions towards adopting the strategy of disclosing their condition to others in advance. Participants were particularly keen to avoid stigma where possible and had adopted this strategy based on previous negative responses to unanticipated disclosure. Thus they used strategic disclosure to redress myths about the condition to others in advance, and so avoid perceived stigma and gain medical support where appropriate. Such feelings

appeared to reflect a greater acceptance of living with the condition moving from the personal perception of disclosure as being “my problem” towards it being others’ problem: “their problem.” This is further discussed in the discussion and conclusions chapter (Chapter six).

Conversely those recruited from the nurse specialist clinics whilst still “learning about disclosure” tended to conceal their condition based on perceived negative reactions. Disclosure was for many younger participants a difficult process leading to compounding feelings of difference and stigma and so to be avoided where possible. They did not typically disclose their condition to others where possible. Such differences in the strategies around disclosure do illustrate that those living with long-term conditions are not heterogeneous and strategies for disclosure are not fixed by dynamic and subject to change over time.

In the next section I go on to present findings which participants across both recruitment settings raised on issues of information.

5.36 Section Five The Role of Information and Disclosure

This section presents findings from the study on the role of information and disclosure and sources of information. This includes the need for additional information on the conditions at the point of diagnosis, the role of patient support groups in the provision of information, the role of the internet in the provision of information, the role of clinical nurse specialist clinics in the provision of information. Findings are presented from participants recruited from the clinical nurse specialist clinics setting out their views on patient support groups and the provision of information via the clinics.

It illustrates the perception of a lack of information at the point of diagnosis and the gap in information on disclosure: this led some to seek information from patient support groups.

The following quotes illustrate how participants when diagnosed frequently had little pre-existing knowledge of the conditions:

I didn't know anything about epilepsy when I found out I had it. It was quite a shock really.

Interview 1 tu:39, Female, Aged 18, Diagnosed one year ago, recruited from epilepsy patient support group

Others cited that they had no idea what the implications of having the condition would be as the following quotation illustrates:

I didn't really know much about it ... How it was going to affect me?

Interview 23, tu:8, Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetic clinic

Another issue raised by participants was they felt following diagnosis they did not receive the necessary support from clinicians:

I remember being quite shocked the day I was diagnosed ... It was very much like: "Oh well here's your tablets, you've got epilepsy, come back and see me in six months and have these tests in the meantime" and that was it! I mean whilst I didn't think like ... "Oh my God it's like cancer!" or really severe but ... I did think well this is quite a life changing condition!

Interview 33, tu:106, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

It appears that one of the reasons participants sought information was a dissatisfaction with that provided by healthcare professionals particularly at the point of diagnosis. The following participant living with type 1 diabetes reflected that this was and still remains an ongoing issue:

I mean there is a major problem with education of newly diagnosed diabetics ... I mean apart from being shown how to draw up insulin and inject it that was all I was told! ... I would have preferred to have sat down with somebody who knew all about it who would tell me exactly what it was, why diabetes happens? 'Cos I hadn't a clue!

Interview 14, tu: 140, Male, Aged 72, Diagnosed nineteen years ago, recruited from diabetes patient support group

Those living with epilepsy frequently highlighted difficulty in locating sources of information about the condition in comparison to other long-term conditions:

There's a real lack of information ... If I go into a bookshop ... there will be reams of books on diabetes or various other conditions ... On epilepsy you'll be lucky if you find one book!

Interview 33, tu:73, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

The perceived lack of information led some to seek out patient support groups to gather further information as I go on to discuss. It is highlighted that not all participants felt that the group setting was relevant to them.

5.37 Patient Support Group Findings: The Role of Patient Support Groups

Those who were members of a patient support group explained that the purpose of their attending was to gather views and knowledge from those who also had the condition. The belief seemed to be that only those living with a long-term condition could fully ‘understand’ the nature of it. The role of the patient support group involves more than gaining information.

As the following quotation illustrates, groups can give people a sense of how to manage their conditions in ways that receiving medical information can not:

You’ve been given the clinical information but know very little else about it. You’re frightened it’s going to put so many restrictions on your lifestyle ... You realize by talking to other people who’ve lived with it for years that ... it’s not going to be a restriction ... just a different way of doing things ... That ... takes a big load off other people’s shoulders and ... realizing as well that they’re not all alone.

Interview 3, tu: 304, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group

Other members commonly highlighted that they shared experiences with others and gained comfort in the knowledge that others were facing similar issues including feelings of stigma, as the following quotes illustrates:

It’s helped me come to terms with some of it...Some of the things that used to happen to me I used to think I must be the only one! ... When you get talking in a group you realize it’s happening to other people as well. That kinda helps. You know you’re not the freak you thought you were!”

Interview 21 tu: 181, Male, Aged 56, Diagnosed twelve years ago, recruited from epilepsy patient support group

I don't know many other diabetics because they keep themselves to themselves ... You know we're all in the same boat, let's all talk about it! ... They're all there because they want to share any experiences.

Interview 13, tu: 176, Female, Aged 61, Diagnosed twenty-nine years ago, recruited from diabetes patient support group

The group setting thus provided an opportunity to meet with their peers which was particularly beneficial to some in reducing feelings of social isolation. Those living with diabetes also expressed the benefits they felt when sharing their experiences of living with the condition as they did not often have the opportunity to discuss such issues.

However attending the group itself was not necessarily a straightforward process. The following quote illustrates that amongst those attending patient support groups a level of acceptance of the condition exists. One woman reflected that attending the meeting is in itself a form of disclosure and this some may find difficult:

A lot of people wouldn't even come forward and step over the pathway to come into the group. As soon as they walk in you know they've got epilepsy ... I think they're scared that you're "announcing yourself" as epileptic.

Interview 15 tu:328, Female, Aged 48, Diagnosed thirty-two years ago, recruited from Epilepsy Patient Support Group

I now go on to discuss data which illustrates that some felt the group settings were not appropriate for all those living with a long-term condition.

Indeed, some of those who attended a patient support group commented that they were aware that it was mainly older people who attended. There was a commonly held view by older participants that younger people living with long-term conditions may not wish to attend since it may emphasise the notion of being “different” to others. This was something that many group members had experienced when they were younger as the following quote illustrates:

There weren't any youngsters there (at the meeting), none at all ... They want to get on with life –and you feel it's an old fogies complaint ... You perhaps still feel and share the embarrassment that I did in those early days, that you're different!

Interview 4, tu: 441, Male, Aged 71, Diagnosed fifty-eight years ago, recruited from diabetes patient support group

Group leaders were aware that few younger people attended and were actively seeking ways to address this:

I think young people are the ones that we really need to make contact with ... Explain to them how to disclose it and why it's better to let other people understand.

Interview 3, tu: 494, Female, Aged 47, Diagnosed forty years ago, recruited from epilepsy patient support group

Others cited difficulties reaching out to younger people in terms of how to contact them, they were aware the format of the group meetings may not appeal to them:

It seems old fashioned to them people sitting around drinking cups of tea just having a discussion. I think they like things to be hip and trendy and when

they see a group of over 50's sitting around they feel ... they're back in the school situation again ... My idea is to somehow ask some of these people, but the medical people won't give you the names of the people that are involved.

Interview 17, tu:50, Aged, 67, Male, Diagnosed thirteen years ago, recruited from diabetes patient support group

Thus younger people living with long-term conditions may require groups or information sources tailored to their specific needs which are likely to be different to those of older people living with the same conditions.

5.38 Patient Support Group Findings: The Role of the Internet

Group attendees speculated that now younger people need not attend patient support groups to seek information because it can be sourced via the internet as the following quotes illustrates:

Today they'll look on the internet ... They can be there reading all about it and the drugs ... It doesn't mean that they have to go out then, or even join these groups!

Interview 15 tu: 336, Female, Aged 48, Diagnosed thirty-two years ago, recruited from epilepsy patient support group

There's a lot more help. You have the internet which you can go on and trawl through.

Interview 13, tu: 233, Female, Aged 61, Diagnosed twenty-nine years ago, recruited from diabetes patient support group

However in this study younger participants did not cite the internet as their primary source of information concerning the condition as the following newly diagnosed diabetic describes:

I've been on the (patient support organization) website a couple of times ...
I've got a really good book which I look at quite a lot. It just tells me everything!

Interview 27 tu:125, Female, Aged 19, Diagnosed six months ago, recruited from young adult diabetes clinic

Participants preferred to use it to as an additional source of information on specific issues such as health insurance as the following quote illustrates:

I'm going off to America to go to university out there ... and at the moment we're in the process of looking for health insurance and we wanted to find out as much information as we could so we went on the Diabetes UK website.

Interview 24, tu:38 Male, Aged 18, Diagnosed seven years ago, recruited from young adult diabetic clinic.

Further exploration of reasons why younger people did not attend patient support groups is now presented by examining the views of the nurse specialist clinic interviewees.

5.39 Clinical Nurse Specialist Clinic Findings: Views on Patient Support Groups

Those participants who were recruited from the clinical nurse specialist clinics were not currently attendees at patient support groups. Some had attended them in the past, but had opted not to return. There were two main reasons given for non-

attendance at the groups. Firstly, younger participants highlighted the age gap, so whilst they were also living with the same long-term condition (type 1 diabetes or epilepsy) participants cited that this was all they shared in common with those attending. Secondly, they cited that they did not feel the need to attend a group at that point in time.

The following quote comes from a young woman living with epilepsy highlighting the relevance of the age gap:

I did go to a local support group. I was the youngest by about thirty years ... I didn't necessarily feel "Oh I'll go back again." I just found they couldn't necessarily relate to the issues that I had.

Interview 33, tu: 47, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

Others stated that they simply had not felt the need to talk to others in the same situation as one newly diagnosed diabetic illustrates:

I haven't really got anyone to talk to about it - because I don't know anyone (with type 1 diabetes) ... It doesn't ... bother me at all.

Interview 23 tu: 48, Male, Aged 21, Diagnosed four months ago, recruited from young adult diabetes clinic

Participants also highlighted the heterogeneity of those living with the condition, sensing that members of the group may not all share the same experiences:

Ok I could talk about it, so could somebody else, but we're not all gonna be the same ... I don't wanna know what other people have!

Interview 34, tu: 90, Female, Aged 31, Diagnosed twenty years ago, recruited from epilepsy nurse specialist clinic

I now go on to present data which illustrates participants' perceptions of the role of nurses as providers of information on medication issues and disclosure.

5.40 Clinical Nurse Specialist Clinic Findings: Information Needs and Disclosure

This section presents findings on the nurse specialist clinics in terms of the role of disclosure and emerging information needs.

The following quotations illustrate how participants felt that the nurse specialist clinics offered a valuable setting in which to discuss queries about their condition:

I go about every sort of four to six months ... It's good just to kind of touch base ... I prefer to do that than just go to my GP (general practitioner) and discuss it with them ... I feel that at the clinic they've got a more in depth knowledge of my particular needs and situation.

Interview 25, tu:29, Male, Aged 19, Diagnosed fourteen years ago, recruited from young adult diabetic clinic

They obviously know what the condition is and how you suffer it and really they know the ins and outs don't they? So it's easier.

Interview 30, tu:64, Female, Aged 28, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

Also nurses offered a much welcome source of contact regarding issues of medication, as some felt they did not gain much information from the neurologist when diagnosed:

I had quite a few questions I wanted to ask about epilepsy ... medication and things like that ... I have found her (the nurse) a lot more supportive than a consultant ... When I was diagnosed with epilepsy the first neurologist I saw he was very sort of matter of fact about it like sort of: “Well we think it’s epilepsy and we’ll start you on this medication.” and that was it! Like it was nothing!

Interview 33, tu:13, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

The following quotation illustrates that participants found that the nurses also offered a source of ongoing social support and information to help them come to terms with living with epilepsy:

She (the nurse) puts your mind really at rest because I was thinking: “Well I’m going nuts! You know I’m gonna be in straight jacket and a padded cell soon!” She puts you totally at ease ... Any queries we’ve got no matter what they are we can phone the nurse to have a chat with her. She’s brilliant like that! I thought I was the only person in the world ... and she made me feel like: “Well I’ve got two hundred and forty patients (with epilepsy) so what the hell are you worrying about?” It does help.

Interview 32, tu: 42, Male, Aged 52, Diagnosed eight years ago, recruited from epilepsy nurse specialist clinic

Due to the difficulties some had encountered in disclosing to others, participants suggested that being advised on disclosure by medical professionals, at the point of diagnosis would be valuable:

When you first get told you're a diabetic that would be the time to tell you how to approach somebody about telling them you've got diabetes ... You think: "Well how do I tell somebody? ... For me it's a big thing!" but for them it's nothing because they don't have to deal with it! I do!

Interview 26 tu: 275, Female, Aged 21, Diagnosed eleven years ago, recruited from young adult diabetic clinic

Some sought greater guidance from health care professionals:

It would be useful if they did say to people: "Well actually this is how you could broach it." ... They could say: "Well actually here's some leaflets specially designed ... for relatives or friends, or ... some guides that you can give to employers."

Interview 33, tu: 107, Female, Aged 28, Diagnosed eighteen months ago, recruited from epilepsy nurse specialist clinic

A similar point was raised by one young man attending the epilepsy nurse specialist clinic who stated simply:

I wish I could just hand 'em a piece of paper that explains it all!

Interview 31, tu: 141, Male, Aged 32, Diagnosed twenty-one years ago, recruited from epilepsy nurse specialist clinic

The burden of disclosure would then be removed from the discloser and the necessity of having to reveal personal details.

5.41 Discussion of The Role of Information and Disclosure

Issues emerged for those newly diagnosed in particular with the condition in terms of

seeking information. Others have argued that people living with epilepsy need more information at the point of diagnosis (Prinjha et al, 2005) and a randomized controlled trial illustrated the benefits of the provision of information to those newly diagnosed with epilepsy via nurse specialists (Ridsdale et al, 2000).

Nurses offered a much needed source of information regarding medication issues and an ongoing source of support for participants across both conditions attending the clinics. However, more information on methods of disclosing to others was raised as a key issue, particularly for those newly diagnosed. Many highlighted that nurses would be well placed to offer this information.

Being a member of a patient support group appears to alleviate feelings of isolation and feelings of burden through the process of talking to others with the same condition. The data has highlighted that many participants chose to join patient support groups where they felt accepted and free to disclose within a safe environment. This section identified that younger interviewees from the nurse specialist clinic did not typically feel comfortable attending patient support groups. In contrast, participants recruited from the patient support groups who had lived with the condition for longer had changed their mind about the need to be with others in the same situation. Those who were recruited from the nurse specialist clinics were not regular attendees at patient support groups. Thus group settings are not appropriate for all living with a long-term condition. However they did cite information needs, around the process of disclosure. Attendees highlighted that nurses provided valuable ongoing support regarding medication issues as well as social support. The benefits of nurse specialists in epilepsy and diabetes as well as other conditions have been reported elsewhere (New et al, 2003, Ridsdale et al,

2000, Daly and Carnwell, 2003). Participants also felt that nurses are well placed to offer specific information needs particularly for those newly diagnosed. A point illustrated in a study of epilepsy nurse specialists (Ridsdale et al, 2000). The question of gaining information and support from medical professionals about how to go about disclosing one's medical condition emerged. The nurses as a point of contact therefore played a dual role of offering both medical and social support and reduced feelings of isolation of living with the condition. Having information in the form of health education leaflets was felt to be vital in that they could serve to alleviate the perceived burden of disclosure.

I now go on to set out the conclusions to the study findings.

5.42 Summary and Conclusions

In conclusion the decision to disclose is not straightforward as there are a number of mediating issues to be taken into account aside from stigma as has been the prime focus of previous studies (Goffman, 1963, Schneider and Conrad, 1980, Troster, 1997).

This study has provided insight into six key elements from which a conceptual framework of disclosure has been developed. This framework is set out and discussed in detail in the following chapter (chapter six).

The six key elements are:

Firstly, the findings having provided insight into **the nature of disclosure**, illustrating that participants viewed health status as personal and so disclosure has to play a functional role. Secondly, the findings have provided greater insight into **the process of disclosure**, illustrating that it may occur in a broad range of ways, not

only directly (verbally) but indirectly (visibly through acute episodes, injecting, dietary restrictions, “objects” associated with the management of the condition).

This study has also provided insight into the **process of non-disclosure**, the means by which participants actively concealed their condition such as concealing the biomedical aspects of managing the condition. Thirdly, the study revealed that **the context of disclosure** is an important issue which participants raised when considering to whom to disclose: three settings were identified: friends and family, partners and the workplace. **Fourthly**, this study has identified **mediators of disclosure**, illustrating a range of factors taken into account when disclosing: personal, previous experiences of disclosure, fear of stigma, medical control, acceptance of the condition, planned/unplanned, temporality visibility, context, denial. **Fifthly**, this study has provided insight into **the role of disclosure in managing a long-term condition**.

This study identified three predominant roles for disclosure illustrating that disclosure is a key concept in the lives of those living with long-term conditions: (1) **access to Self-care and Social Support: enabling participants to manage their condition medically in terms of self-care and gaining social support**. An important finding of the current study is that perceptions of disclosure are not necessarily “fixed” but subject to change over time, as participants “learned about disclosure”. For example the current study identified a shift from participants recruited from the patient support group who previously had adopted the strategy of (2) **non disclosure: concealment of the condition to protect one’s identity from stigma**) towards choosing to disclose to others in advance (3) **strategic disclosure: redressing myths about the condition in advance to avoid perceived stigma**.

Finally this study has provided insight into the role of disclosure in relation to **Living with a long-term condition**, illustrating that learning about disclosure is a key element of living with a long-term condition the overarching challenges of living with a long-term condition; enduring, managing the medical, managing the social elements of the condition such as identity, living with limitations, managing disclosure “who needs to know”, “learning about disclosure” over time moving from personal perception of disclosure as “my problem” towards it being others’ problem “their problem.”

The next chapter presents an in-depth discussion of the study findings taking into account the broader literature and policy and practice implications. The process of disclosure and non-disclosure, mediating issues around disclosure, and the role of disclosure in the lives of those living with epilepsy or type 1 diabetes are discussed. The three roles identified are set out in the discussion. The conceptual framework of disclosure is further discussed in the following chapter (Chapter six).

6.0 Chapter Six: Discussion and Conclusions

6.1 Introduction

Part One of this chapter, **discussion of the study findings**, discusses the study findings in relation to the literature and broader policy and health care agenda. It sets out the nature of disclosure; mediating issues around disclosure; the role of non-disclosure; three roles of disclosure; the process of learning about disclosure; disclosure in the context of the workplace; the role of information, and the conceptual framework of the role of disclosure.

Part Two of this chapter, **study reflections, implications and conclusions**, sets out the lessons learned from the process of conducting the study and reflections on the process of adopting the methodology constructivist grounded theory (Charmaz, 2006). It also presents the implications of the study findings for health care practice; policy and education, and future research. Finally, the summary and conclusions of the thesis are presented.

6.2 Part One: Discussion Of The Study Findings

6.3 Introduction

This section discusses the study findings in relation to the existing literature concerning the nature of disclosure.

6.4 The Nature of Disclosure

The study findings suggest that for many people disclosure of a health condition involves the divulgence to others of what is considered very personal information. This finding is supported by other studies which have also argued that disclosure of one's health status is regarded as highly personal (Charmaz, 1991, Beatty, 2004).

Similar findings have emerged within the discipline of psychology illustrating that disclosure is a process which reveals something personal: of the “self” (Jourard 1971, Derlerga 1979, Rosenfield 2000).

However, I found that not only does disclosure of having epilepsy or type 1 diabetes constitute divulging personal details, as others have argued, this study further illustrates that specifically due to the personal nature of disclosure and notions of personal and public boundaries there had to be a clear reason for disclosing, therefore it must play a specific role for the individual. In contrast, existing studies have tended to focus on the role of disclosure in relation to management of stigma (Goffman, 1963, Scambler and Hopkins, 1980, Troster, 1997, Green and Sobo, 2000). Yet, this study illustrates that disclosure plays a much broader role. I go on to later discuss the diverse roles which disclosure plays as identified in this study. I would argue in this study that the nature of disclosure is a personal matter and so the context of disclosure is deemed extremely important to participants. Therefore, indiscriminate disclosure was considered inappropriate, a point also made by Pennebaker (1990) whose work emphasises the problems of disclosing to the ‘wrong person’. In the next section I go on to discuss the study findings in relation to the existing literature regarding what is disclosure and the diverse nature by which disclosure may occur.

6.5 What is Disclosure? The Process of Disclosure

In this section firstly I discuss how disclosure occurs in the form of self-care, secondly I discuss how the process of self-care itself often becomes a trigger for disclosure, and thirdly I discuss how disclosure is therefore a process which is difficult to control.

6.6 Visibility and Self-Care

This study found that the process of self-care itself constituted forms of disclosure. For example, people living with type 1 diabetes injected insulin, or took medication in the case of participants living with epilepsy. Also attending a patient support group; managing dietary restrictions; or wearing a medical alert bracelet constituted a form of disclosure. This finding has extended current research concerning the visibility of a long-term condition by illustrating that it does not only include the visible symptoms of the condition as others have argued (Joachim and Acorn 2000, 2003). The necessity of maintaining daily treatment regimes against a backdrop of feelings that disclosure is highly personal raised a number of dilemmas for participants, notably the fear of bringing personal issues into the public domain. This was particularly the case for younger participants who were “learning about disclosure” through others’ reactions. This study’s extension of what constitutes “visibility” of a long-term condition is a key point because it broadens understanding of how disclosure occurs and thus greater insight into potential difficulties concerning managing decisions around the timing of disclosure. For example existing research has argued that disclosure decisions are made in terms of the physical symptoms of visibility or invisibility of a long-term health condition (Joachim and Acorn 2000, 2003).

The findings identified that “triggers” or “opportunities for disclosure” frequently emerged in the lives of those living with epilepsy or diabetes and decisions had to be made about how to respond which I now go on to discuss.

6.7 Self-Care: Triggers for Disclosure

Triggers for disclosure were often linked to the process of self-care or were manifested in others' "questions". For example, those living with epilepsy cited that being asked routine innocuous questions such as: "do you Drive?" offered an opportunity to disclose because many were not permitted to drive due to having the condition. Similarly, opportunities for disclosure emerged for those living with type 1 diabetes when responding to questions from others which linked into the self-care of their condition, such as, being offered cake, and having to refuse and explain that this was because they had type 1 diabetes, or in the case of university students, responding to questions as to why they had a fridge which stored their insulin in their university room. These examples of opportunities for disclosure extends current research on unplanned "spontaneous disclosure" by illustrating it occurs during everyday life as well as after having received particularly bad news about the condition. In her study of people living with long-term conditions Charmaz (1991) defined spontaneous disclosing as follows: "*Full expression of raw feelings, open exposure of self, and minimal or no control over how, when, where, what, and whom to tell. People spontaneously disclose when they receive startlingly bad news or perceive dramatic changes*" (p.119). The current study showed spontaneous disclosure occurred in a much broader range of situations. The range of potential ways in which disclosure may occur as identified by the participants, highlights that it is not always possible to plan disclosure in advance which I now go on to discuss.

6.8 Control over Disclosure

As stated earlier this study revealed that unplanned disclosure did not only occur through having an acute episode such as an acute hypoglaeacemic episode, or

epileptic seizure. In contrast other studies have argued that it is possible to control disclosure by making “strategic decisions” based upon the potential visibility of the condition and so decisions are therefore linked to perceptions of “medical control” and stigma as a result of “visibility” (Goffman, 1963, Schneider and Conrad, 1980, 1981, Charmaz, 1991, Joachim and Acorn, 2000). Furthermore, Goffman (1963) refers to, “the discredited and the discreditable” suggesting that disclosure decisions are primarily linked to the visibility of the condition and subsequent stigma. He argues there is therefore a decision to be made concerning disclosing information to others or not: *“To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where”*(Goffman, 1963, p.57).

Yet this study has identified a diversity of opportunities for disclosure, thus illustrating that adopting anticipatory strategies concerning when to disclose may be difficult to employ. However, research in the field of epilepsy has argued that stigma may be avoided by adopting the concept of “preventive telling” which constitutes: *“purposeful mention of their disease”* (Troster, 1997, p1228). Furthermore, Charmaz (1991) has also argued that those living with long-term conditions may employ strategies of: “protective disclosing:” the purpose of which is: *“to control how, what, when, and who people tell about their illness”* (p.119) this therefore also suggests that disclosure is possible to plan.

Other studies of those with “invisible” symptoms have argued that as a consequence, individuals have a choice whether or not to disclose because they appear “normal” to others (Joachim and Acorn, 2003). However, such strategies do not take into account that disclosure may occur through ways of managing the condition as

identified in the current study. The data illustrated that the process of disclosure and therefore the role of disclosure is broader than Goffman's (1963) term "information management" suggests. This is a key finding of the current study as many studies on disclosure have subsequently employed this term (Schneider and Conrad, 1980, Admi, 1995, Green and Sobo, 2000, Troster, 1997, Joachim and Acorn, 2000). For example, Schneider and Conrad (1980) refer to the link of "managing information" to controlling the stigma associated with the condition epilepsy.

Whilst stigma did emerge as a significant factor in the mediating of decisions to disclose or not disclose, this study identified that participants took a broader range of issues into account which I go on to discuss in the next section.

6.9 Mediating Issues around Disclosure

This section presents a discussion of the range of issues which emerged as important in decision making concerning disclosure which I have termed: "mediating issues". These include: the challenges of living with a long-term condition, health status, identity and disclosure. I then go on to discuss the relationship between disclosure, stigma and self-care.

6.10 Challenges of Living with Long-term Conditions

Being diagnosed with epilepsy or diabetes does not simply have medical implications but also important social implications such as stigma (Troster, 1997, Eisenberg, 2007, Gabe et al, 2004, Tak-Ying Shiu et al 2003). This was supported by the current study, where not only did participants have to manage the new status as a "person with diabetes" or "a person with epilepsy" and the biomedical regimes, they also had to manage the social implications of the conditions, including dealing

with stigma.

Participants across both conditions highlighted the challenges of living with a long-term condition not only in terms of the “medical implications” of the condition but also the social implications as Bury et al (2005) have argued. Participants revealed that, the moment of being diagnosed represented an emotional impact which had a subsequent negative effect upon their identity. Those newly diagnosed with diabetes described feeling “overwhelmed by the disease” supporting Paterson’s (2001) findings. For example, the interviews with younger participants revealed that the prospect of facing an ongoing process of daily management was perceived to be a burden. This also supports the work of Bury (1982) who has referred to this as “biographical disruption” and Charmaz (1983) who has referred to it as “loss of self.”

The data suggest that those who are younger find the process of disclosure difficult, as they cited problems in coping with the symptoms of the condition and the enduring suffering due to feelings of difference to others, and all of this in addition to the negative reactions of those to whom they disclosed. The responses of others to the disclosure of the condition played a key role in terms of not only their views on disclosure but in turn upon their perceptions of living with the condition and thus their identity. The current study builds upon existing work on identity because it illustrates that the process of self-care appears to play a potentially burdensome role on the person’s identity. For example, tensions between managing the condition and the ongoing enduring nature of having diabetes while seeking to have a “normal” life were highlighted in the data and support Paterson et al’s (1998) work which refers to the process of “learning to balance.” There is sometimes considerable tension

between the medical discourse of seeking to control one's blood sugar and an individual's goal of having a balanced life (Paterson, et al 1998). Many participants found the unpredictability of the condition difficult to come to terms with and again this appeared to play a role in decision making around the timing of disclosure. Issues of acceptance and denial also played a key role in coming to terms with being diagnosed with a long-term condition and are perceived as important when complying with their treatment regimes or not. This finding supports the work of (Telford et al, 2006) who has argued that when those living with long-term conditions do not adhere to treatment regimes they may be criticised by health care professionals as being "in denial." In contrast they argue the need for health professionals to take into account: "*the wider social context of people's lives as well as the medical aspects*" (p458). This underlines the importance of taking psychosocial issues into account in the lives of those living with long-term conditions as difficulties in accepting the condition appear to play a role not only in terms of concordance to treatment regimes, but furthermore in terms of challenges around disclosing to others (Markinker and Shaw, 2003, Medicines Partnership, 2008). This finding builds upon the work of Telford et al (2006) by illustrating that disclosure issues are another aspect to take into account when considering concordance to treatment regimes (Markinker and Shaw, 2003, Medicines Partnership, 2008). I now go on to discuss the relationship between health status, identity and disclosure.

6.11 Health Status, Identity and Disclosure

Disclosure had profound implications for participants' identity because it potentially led to what others have referred to as a "double stigma": not only are they revealing

they have a long-term condition, they are reliant on others' perceptions of the condition which may be positive or negative (Green and Sobo, 2000). Others' responses were often deemed to be negative which in turn reinforced, "being epileptic" or "being diabetic" as a negative identity. This finding supports psychological literature which has argued that disclosure is strongly linked to identity issues because it represents a: "*verbal message about the self*" (Derlega and Grzelak, 1979, p60).

The ongoing nature of both conditions was identified in the data as was the suffering which many endured. Difficulties around controlling the condition tended to affect how participants perceived the condition. Those whose condition is less controlled found that it had a greater impact upon their daily life. Younger participants described the ongoing process of daily management to be a burden that affected not only themselves, but also their families and partners. A similar point was found in Dovey-Pearce et al's (2007) study on young people with diabetes. It is clear that those living with a long-term condition must not only cope with the biomedical diagnosis but with the social implications and potential changes in family and relationship dynamics and it takes time to learn how to cope with these changes. I now go on to discuss the relationship between disclosure, stigma and self-care.

6.12 Disclosure, Stigma and Self-Care: What is the link?

A link between disclosure, stigma, self-care and subsequent potential negative effects upon health status was identified. Many perceived the process of self-care as a means by which they risked being "discredited" (Goffman, 1963). This had implications for practical self-care issues. For example, those living with type 1 diabetes highlighted the difficulties they faced around the process of injecting insulin

due to others' reactions. Negative associations around injecting any form of drugs led, they felt, to some people judging them and possibly branding them as "illicit drug users." Such references are more frequently found in studies of HIV/AIDS than diabetes (Green and Sobo, 2000). This finding suggests that current understanding of what constitutes a stigmatised long-term condition is arguably broader than may be assumed since this study has identified that the person living with the condition may become stigmatised through the process of managing the condition itself. The current study argues that the concealment of the self-care processes of a condition, subsequently impacts on the individual's health status. In this study, disclosure for many younger participants was perceived as an additional burden, due to perceived negative responses such as being stigmatised. These findings provide additional insight into the role of disclosure, and concordance, as patients may choose not to follow medical advice from health professionals because it conflicts with their desire to keep their condition private. This supports the work of Kyngas and Hentinen (1995) who found that younger people with diabetes have difficulties complying with their treatment regime because of their fear of stigma. This has also been identified in a small study of people with diabetes in Hong Kong (Tak-Ying Shiu et al, 2003). In this study participants did not wish to disclose because they felt that they would then only be known by "the condition", rather than as the person who also happens to have a long-term condition. Participants were concerned that others may treat them differently, or even be fearful of them.

The findings provide insight into the issues of stigma raised by those living with type 1 diabetes since there is relatively little research on the link between type 1 diabetes and stigma, compared to epilepsy which is strongly associated with stigma

(Schneider and Conrad, 1980, Scambler and Hopkins, 1986, Troster, 1997, Eisenberg, 2007). Although stigma appears to be a key element which may mediate decisions to disclose, this focus on particular “stigmatised” groups has limited the generalisability of the findings of such studies. Disclosure as a concept appears to be of relevance across a broader spectrum of long-term conditions. In this study, simply having a long-term condition led many to feel “different” to others, as Goffman, (1963) and Gabe et al, (2004) have argued. However, questions of stigma appeared to affect in particular younger people; a distinction which is not always recognized in other studies (Goffman, 1963, Joachim and Acorn, 2000).

6.13 Learning about Disclosure: Disclosure and the Role of Time

Findings concerning responses to the disclosure illustrated that participants drew upon previous experiences of disclosure and had adopted strategies of disclosure or concealment accordingly: a process I have referred to as “learning about disclosure.” Existing studies in the field of disclosure research typically refer to a lack of certainty concerning others response to the disclosure, describing it as “a double edged sword:” whilst it may result in support, it comes at the cost of disclosure which may lead to stigma and discrimination (Williams and Healy 2001, Pennebaker, 1990, Fesko, 2001).

I now go on to discuss one of the three roles of disclosure identified in this study: the role of non-disclosure, the purpose of which was to avoid being stigmatised and which was typically adopted by younger participants recruited from the nurse specialist clinics.

6.14 Clinical Nurse Specialist Clinic Findings: The Role of Non-disclosure:

Avoiding Stigma

This section presents a discussion of the role of non-disclosure: avoiding stigma. I then go on to discuss the process by which participants concealed their condition: the process of non-disclosure and finally the rationale for non-disclosure.

Overall, it was striking that younger participants often chose not to disclose in order to maintain “normality” and avoid being stigmatized. Those recruited from the nurse specialist clinics were typically younger and tended to adopt strategies of non-disclosure through concealment of their condition. The concepts of concealment of long-term conditions have been identified in other studies (Goffman 1963, Schneider and Conrad, 1980, Charmaz 2002, Sandelowski et al, 2004). This study extends this work by illustrating that such strategies are not necessarily “fixed” but rather appear to be dynamic and subject to change over time. I now go on to discuss the process of non-disclosure: the means by which participants attempted to hide their condition.

6.15 The Process of Non-disclosure

For those who anticipated unwanted or negative reactions to disclosure, the findings have illustrated the means by which they sought to conceal their condition. For example, some participants living with type 1 diabetes described the process of concealing their condition by injecting their insulin in a place where others could not observe such as the public toilets in a restaurant. Others described how they chose not to carry their insulin needles with them on a social evening to a nightclub for fear of a bag search when they felt they risked being unfairly labelled as an illegal drug user. Some living with epilepsy described how they “took a gamble” by not telling others that they had the condition as they did not wish to be excluded from

participating in certain activities which others may judge to be “too risky” for them. This process of hiding something discreditable has been referred to by Goffman (1963) as “passing”, the intention of which is to remain part of the “normal” group. This appears to be linked to living with a condition which is unpredictable and weighing up the consequences of non-disclosure to be overall more beneficial than choosing to disclose. In the current study some participants did disclose but explained that their epilepsy was “controlled.” Goffman, (1963) has referred to this process of not concealing the condition completely but attempting to minimise its importance as “covering”.

I now go on to discuss participants rationale for choosing to conceal their condition, illustrating that such decisions stemmed from prior perceived negative responses to disclosure.

6.16 The Rationale for Non-disclosure

Participants in the current study revealed that for those who had experienced negative or unwanted reactions to disclosure, the role of non-disclosure constituted an important tool in the management of a long-term condition, a point also made by Charmaz (2002).

Participants in this study recounted that epilepsy has long been associated with negative historical beliefs and such perceived stigma associated with epilepsy was a barrier to disclosure. This finding extends existing research on stigma and epilepsy as it illustrates stigma was not only based upon negative historical beliefs but also upon others visual images of what epilepsy “looks like” (Eisenberg, 2007, Scambler, 1989).

The study findings highlighted that a common response to disclosure was that others had strong “visual” images of what people with either epilepsy or diabetes might “look like”. For example a diabetic would be overweight or an epileptic would “froth at the mouth.” Sometimes this led others to question the validity of their disclosure as they stated: “you don’t look like an epileptic.” This finding taps into a broader discussion on the stereotyping of certain illnesses in terms of what someone with the condition “looks like” (Peters, 2008). This illustrates that such difficulties are not only confined to conditions such as epilepsy but other long-term conditions.

The current study also found that inaccurate public perceptions of the causes of diabetes emerged as a key element in decisions to disclose or not disclose. Participants in this study felt that type 2 diabetes has a higher public profile than type 1 diabetes. When they disclosed their condition they felt that responses were based on the perceptions of type 2 diabetes as being linked to an unhealthy lifestyle and so having the condition was deemed to be “their fault.”

Participants across both conditions sought to explain that having the condition was not their “fault”, a process also identified in a study of those living with lung cancer (Ziebland et al, 2004). The perceptions of the lack of information amongst the general public on both conditions resulting in negative reactions, led to the discloser having not only to disclose their condition, but also having to dispel “myths” around the conditions. This point has been raised in other studies on epilepsy (Beatty, 2004). For example in the current study they cited that upon disclosing a frequent response was being asked “the same questions.” Such perceived negative reactions led many to avoid the process of disclosure altogether, particularly younger people as they felt not only did they firstly have to disclose the condition but secondly they

then had to go on to respond to questions about the condition and “educate” others as to the implications of living with the condition. For the participants such reactions constituted a “double burden” because the condition was long-term and therefore such negative reactions to disclosure were potentially ongoing and to be avoided where possible.

The lack of public campaigns about epilepsy and the lack of high profile role models with the condition was raised by participants in this study. This supports existing work which argues that there is a link between public disclosure and public understanding of the condition and stigma because despite many people living with the condition, epilepsy in particular does not have high profile and is often “a hidden condition” (The All Party Parliamentary Group on Epilepsy, 2007). This study found that participants discussed the need for more public education because in their view it could assist both the discloser and those to whom they disclose thus reducing the burden. This supports the need for a programme of education in schools and the workplace on Epilepsy as suggested by The All Party Parliamentary Group on Epilepsy Report (2007). As stated earlier the high profile given to type 2 diabetes conversely led to a lack of understanding of the heterogeneity of the condition which impacted on participants decisions to disclose type 1 diabetes.

Disclosure to others and receiving a perceived negative response has a potentially negative impact upon participants’ emotional health. This finding contrasts with studies which have argued that not disclosing illness to others may have a negative impact on the individual with the illness. For example, psychological studies by Pennebaker et al (1986, 1988,1990) have argued for the beneficial elements of disclosure and this does not take into account that negative reactions to disclosure

are equally possible and may include a negative impact upon health, such as stigma, discrimination and “feeling judged.” Charmaz (1983) has referred to the impact of living with a long-term condition as constituting “loss of self.” In this study I am building upon this concept by arguing that the act of disclosure itself may contribute to “loss of self” because negative responses have a strong impact upon issues of identity in the lives of those with a long-term condition. Studies on non-disclosure of long-term conditions in the literature have predominantly focused on potentially transferable long-term conditions such as HIV (Sandelowski et al, 2004, Green and Sobo, 2000). Whilst this is helpful it has left a gap in understanding in terms of perceptions of disclosure of non-transferrable conditions such as epilepsy and diabetes. The debates around non-disclosure are typically linked to moral and legal debates linked to the health implications of non-disclosure for “others” rather than the impact of others on the non-discloser (Edward Rutledge, 2007, Marks et al, 1991, Smeon and Crosby, 2004, Green and Sobo, 2000). The impact of non-disclosure could have implications for the non-discloser’s health status in the event of an acute episode: others may then not know what is wrong with on the individual or how to help. An additional difficulty identified in this study was that due to not disclosing their condition some people had a limited source of social support.

Having discussed reasons for non-disclosure or “who doesn’t need to know”, I go on to discuss the process and rationale by which participants identified “who does need to know?” and the role of disclosure in this context.

6.17 The Challenge of Disclosure: “Who Needs to Know?” and Why?

6.18 The Role of Disclosure: Access to Self-care and Social Support

In this section I discuss the challenge of disclosure: “who needs to know?” I discuss disclosure of long-term conditions to friends and family or partners and the intended role of disclosure in this context. I go on to discuss the second role for disclosure identified in the current study (across both recruitment settings and conditions), the purpose of which was to access to Self-care and Social Support.

In this study it became clear that participants did make decisions about to whom to disclose. They frequently referred to the process of disclosing to those who ‘need to know’ about their condition. Typically decisions concerning “who needs to know?” are characterized by disclosure having a “role” and illustrates an anticipatory form of disclosure.

Verbal disclosure is a key process which enables participants to manage their condition medically in terms of self-care and in gaining social support. For example, the data suggest that those living with epilepsy experienced difficulties around the unpredictability of the condition. Existing studies which have explored the social aspects of epilepsy have described how an unpredictable condition which requires an explanation is associated with fear (Trostle, 1998). This suggests in this context that the role of disclosure is concerned with minimising fear and a sense of burden in others (Charmaz, 1991).

6.19 Who needs to know?

The concept of “who needs to know?” also emerged as a particularly important question for those living with type 1 diabetes because those around them often

played a key role in assisting with the management of the condition. Family members and partners typically performed the role of “rescuers” in the event of a hypoglycaemic event and acted as “back up” to the person with diabetes by looking out for potentially dangerous signs of the condition. This confirms Paterson, et al’s (1998) findings of the importance of “allies”. Other studies also suggest that the role of disclosure may be to garner support from others and that having a condition affects not only the person but those around them (Charmaz, 1991, Williams and Healy, 2001). Participants felt that when others knew about their condition, they would be able to “help them” thus reducing the psychosocial impact of managing the condition themselves. Social support may play a positive role in one’s physical and emotional health (Wang et al, 2005). It seemed important that they were not “alone” with the condition and the majority of participants stated that their friends and family knew about their condition. This was reflected in the current study and indeed the majority of participants stated that they felt “protected” by their friends or family. There was a link between those whom they saw frequently and those who knew about their condition. In this context, disclosure appears to play a “dual role” not only for the person “to whom they disclose”, but also for the discloser. Firstly, because disclosing reassured the discloser that others “would know what to do” in the event of an acute episode and secondly, because those to whom they disclose were generally grateful that they had been told stating that they would rather know in advance. The findings concur with studies in the field of psychology which state that responses to disclosure are more likely to be beneficial if they assume a positive response (Pennebaker, 1990).

There also appeared to be a clear distinction between disclosing to friends and family and people outside of this circle who were deemed to be more “risky.” This supports other studies which have linked “who needs to know?” to issues of risk. For example, Lowton’s (2004) study of disclosure of cystic fibrosis which has linked the setting of disclosure to varying levels of “risk.” Risk she claims is linked to levels of intimacy such as how well they know the person and also to an assessment of the potential implications of non-disclosure including “low risk situation,” “medium risk situation” and “high risk situation” (Lowton, 2004). Furthermore, Green and Sobo (2000) identified the term “who needs to know?” in a study of disclosure of HIV/AIDS to be linked to perceptions of the intimacy and goal of the relationship. The findings of the current study suggest that the term “who needs to know?” might be transferrable to other long-term conditions.

6.20 Disclosure to Partners

Younger participants raised the issue concerning the challenge of disclosing their condition to their partners during the initial stages of the relationship. In this setting fears were expressed around how a potential partner would react to the disclosure. Many feared a negative reaction and felt that the timing of the disclosure was crucial. This illustrates the key role which partners play in the management of a long-term condition and how the condition can become “disruptive” (Bury, 1982). Earlier work in the field of psychology suggests liking someone makes one more likely to disclose to them (Jourard, 1971).

In the next section I discuss the findings from the patient support group participants and illustrate how perceptions of disclosure may change over time as they appear to

be linked not only to perceptions of identity of living with the condition but also perceptions of the medical management of the condition.

6.21 Learning about Disclosure and the Role of Time

6.22 Patient Support Group Findings

In this section I discuss the process of “learning about disclosure” over time illustrating how over time shifting identities can lead to shifting views on disclosure. Finally I discuss the patient support group findings illustrating how over time they had changed from no disclosure towards adopting strategic disclosure. This is the third role of disclosure identified in the current study the aim of which is to disclose in advance to others and so redress myths about the condition in advance.

The study findings suggest that time plays a key role in disclosure and thus “learning about disclosure” is an important process. Views on disclosure appear to mirror the varying changes in both medical and social perceptions of the condition. Learning about disclosure appears to be part of the process of adapting to and living with a long-term condition: the process of adaptation or life transitions over time.

This finding is supported in the work of Charmaz (1983) who refers to the role of time and living with a long-term condition, thus describing the changing nature of the condition. As both conditions under study are long-term, decisions around disclosure are also long-term and therefore enduring. Disclosing is as Charmaz (1991) suggests, an ongoing, indeterminate process. However, this study found that participants adopted strategies of disclosure were not necessarily “fixed” but diverse, situation specific and subject to change over time. The data identified that feelings may change over time as participants recounted a process of adjustment to living

with the condition (Sharpe et al 2006, Paterson, et al 1998) and further supported by Paterson (2001) who discusses the “shifting perspective model of chronic illness”.

6.23 Shifting Identities, Shifting Views on Disclosure

The data illustrate that changes in the identity in the lives of those living with either epilepsy or type 1 diabetes are linked to their views on whether to disclose their condition to others or not. Studies have argued that long-term conditions do pose challenges to the identity of those living with long-term conditions which are typically deemed to be negative (Charmaz, 1983, Bury, 1982, Schneider and Conrad, 1980, 1981). In contrast this study suggests that a shift may occur from such negative perceptions of the condition towards a process of adaptation which is in turn linked to their likelihood to disclose or not disclose. Studies within a sociological framework have argued that when living with a long-term condition changes in the perception of one’s identity may occur as: “*the person learns new definitions of self and often relinquishes old ones*” (Charmaz, 1983, p170). For example, I found that older participants had often changed their views on disclosure and were reportedly more open about their condition, compared to when they were younger (Paterson, 2001). This change appears to be linked to shifting identities which in turn impact upon their views on disclosure (Paterson, 2001).

Studies on young people living with diabetes have identified that perceptions and experiences of living with diabetes may change over time (Rasmussen et al, 2007, Dovey-Pearce et al, 2007). For example Rasmussen et al (2007) refers to: “life transitions” in the lives of those living with diabetes and how the: “*changing social and emotional conditions during life transitions have a major impact on their diabetes management*” (p18). Furthermore Paterson et al (1998) have referred to the

process of: “*adapting to and managing diabetes*” referring to the process of “learning how to manage diabetes.” Changes in the process of managing their condition are they argue not fixed but rather dynamic and subject to change (Paterson et al, 1998, Thorne and Paterson, 1998).

Those who were older tended to have expressed a sense of having adapted to or come to terms with the condition. Paterson (2001) describes this as “wellness in the foreground” which facilitates a focus on things outside the illness (in other words their identity is not solely defined by the condition itself) compared to “illness in the foreground” which represents a focus on the condition itself. This model of chronic conditions illustrates how perceptions and attitudes towards the condition may “shift” over time (Paterson, 2001).

In this thesis changing perceptions of risk appeared to be linked to the participant’s identity with regard to coming to terms with having a long-term condition and having negotiated disclosure over a period of time. Other studies have also noted the transient and changing nature of what they refer to as the “risk assessment” associated with disclosure (Green and Sobo, 2000). This perception of the changing nature of risk regarding disclosure was identified as participants reflected that they had negotiated reactions to disclosure over many years and “no longer cared” what others thought of them. Thus they had learned “ways of managing the risks associated with disclosure” In some cases the way of managing this “risk” was to choose not to disclose to others. As participants learnt about their condition, they appeared to be simultaneously learning about disclosure. This focus upon disclosure as an additional process to take into account builds upon work on diabetes which has

argued that those living with diabetes tend to: “*manage their diabetes by adapting to it rather than by coping with it*” (Kelleher, 1988, p153).

Whilst studies have referred to the process of adapting to or learning about their condition over time, the role of disclosure in this process is largely overlooked. However, in this study difficulties brought issues of disclosure to the forefront. This finding is supported by the work of (Paterson, 2001) whose meta-study of qualitative research on long-term conditions led to the development of the shifting perspectives model of chronic illness this is defined as: “*an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their “world”*” (p23). Disclosure sometimes led to additional feelings of “burden” or “suffering” and thus I argue may contribute to placing “illness in the foreground”.

Studies of epilepsy have also identified a process of adaptation to the condition over time. For example, Schneider and Conrad (1980) in their study of disclosure of epilepsy has referred to the process of “learning to be discreditable” as based upon others negative reactions to epilepsy. Scambler and Hopkin’s (1986) study of epilepsy have referred to a process of “coming to terms with stigma.” Glaser and Strauss (1967) referred to living with a long-term condition as an “illness trajectory” whereby the person goes through a number of different stages as the condition improves or gets worse. Abram (1972) has referred to the psychology of chronic conditions as involving the need to adapt to: “*long standing conflicts, adjustments, and psychosocial situations to which he must adapt*” (p659). Therefore the current study which has identified the process of learning about disclosure builds upon existing work in the field of long-term conditions. The findings in this thesis have illustrated that learning about disclosure and specifically how to “manage” disclosure

appears to be a key part of living with a long-term condition. Therefore disclosure taps into key concepts of living with a long-term condition identified in previous studies (Goffman, 1963, Charmaz, 1983,1991, Joachim and Acorn, 2000, Bury et al, 2005). These include stigma, self-care, invisibility, visibility as well as identifying information needs and it plays a key role in the process of learning to adapt to living with a long-term condition.

In the next section I discuss the patient support group findings to illustrate the role of strategic disclosure: redressing myths about the condition in advance.

6.24 Discussion of Patient Support Group Findings: The Role of Strategic

Disclosure: Redressing Myths about the Condition in Advance

In this section I discuss a third role of disclosure identified in the current study: redressing myths about the condition in advance. This is a strategy that aims to disclose the condition in advance, in order to avoid perceived stigma and manage risks. This study builds existing work on the concept of anticipatory “preventive telling” (Schneider and Conrad, 1980, Troster, 1997) through illustrating that such strategies are not necessarily fixed but may be subject to change over time. This finding was particularly striking in the patient support group sample. This study identified that those recruited from the patient support groups (across both conditions) who tended to be older and had lived with the condition for a longer period of time had also experienced stigma, but had adopted strategies of telling others in advance in an attempt to negate issues of stigma. The role of the support groups in helping participants cope with stigma is further discussed in the following section of this chapter. Within this context, once more the role of disclosing to others in advance was adopted in order to manage risks.

In the next section I discuss how participants sought out information about their condition, with particular reference to the role of the patient support groups and nurse clinics in the provision of information. I also go on to discuss information needs for those newly diagnosed and the timing of provision of information on disclosure.

6.25 Disclosure and the Role of Information

6.26 Sources of Information: The Internet

Patient support group attendees were aware that younger people living with the condition did not typically attend the groups. They reflected that the internet and the information which it contains on health conditions may be sufficient and thus explain why they did not attend. This study did not find that younger participants used the internet as a key source of gaining information or as a means to discuss their condition with others despite studies that suggest that some young people use internet discussion groups regarding diabetes (Davison et al 2000, Zrebiec and Jacobson, 2001, Rasmussen et al 2007).

Younger participants recruited from the nurse specialist clinics emphasised that they did not wish to become members of patient support groups: some had attended in the past and found that the groups did not meet their needs. They did raise similar issues to older participants including stigma and learning about the practical daily management of their condition. Many younger participants cited that they did not feel the need to be with others with the same condition: they preferred to manage the condition by themselves. It has been argued that the process of attending a patient support group may lead to an unwanted focus upon the illness: as in order to take part in group discussions, a focus upon the illness is required. This process is a

further example of “shifting from wellness to illness in the foreground” (Paterson, 2001). This may explain why younger people do not wish to attend the groups as many did not see or wish their condition to be “in the foreground” (Paterson, 2001).

However, an alternative explanation may lie in the study findings that not all participants from nurse specialist clinics were even aware of the patient support groups in their area. A similar issue was raised by Krizek et al (1999) in a study of patient support groups for those living with cancer.

6.27 Sources of Information: Nurse Specialist Clinics

Participants from the nurse specialist clinics highlighted that nurses provided valuable ongoing support regarding medication issues as well as social support. Current evidence suggests specialist nurse clinics play a beneficial role in the management of diabetes (New et al, 2003), and information on epilepsy (Ridsdale et al, 2000). Furthermore, the benefits of nurse specialists provision of information in comparison to general practitioners has been reported elsewhere (Daly and Carnwell, 2003). It was however striking in the current study that interviewees reported that nurses did not routinely offer advice on disclosure. Participants did gain some information on the issues of disclosure in the workplace, in terms of legislative issues but other social settings were not discussed.

The timing of provision of information may be important as those who are newly diagnosed may have different needs to those who have lived with the condition for longer. This may relate to issues around acceptance of the condition. It may therefore be useful to divide information to meet the needs of those newly diagnosed and those at a later stage (Breau and Norman, 2005). From a practical perspective, nurses are well placed to offer advice regarding information needs for clinic

attendees, not only in terms of the medical management issues in their lives but also in terms of the social implications of being diagnosed with a long-term condition. Other studies have identified the benefits of nurse specialists in the provision of information to those newly diagnosed with epilepsy (Ridsdale et al, 2000). Many participants suggested the development of health education leaflets to assist them in the process of disclosing may prove beneficial as it would remove the burden of continually having to explain the condition in detail to others on an ongoing basis. The implications of the findings for health care professionals are discussed later in this chapter.

One of the key findings for those who attended patient support groups was the view that the group represented a “safe place” where others could “understand” their difficulties in a way that no one else could. Many of the participants from the support group sample reported that they had experienced stigma and were aware there was a strong perception of stigma associated in particular with epilepsy. This has been identified in other studies on epilepsy (Schneider and Conrad, 1980, Jacoby, 1994, Eisenberg, 2007). The patient group performed the role of gaining social support and acceptance as well as learning more about medical management. This finding concurs with literature on social support which argues that those with living with similar conditions may be able to offer one another social support (Davison et al, 2000). A similar finding emerged in a study of cancer and patient support groups (Taylor et al, 1986).

In the next section I discuss the key findings of disclosure in the workplace setting.

6.28 Discussion of Key Findings on Disclosure in the Workplace

Participants reported that the workplace was perceived as a particularly difficult context in which to disclose and supports other research which has referred to the work place as a: “high risk situation” (Lowton, 2004). Previous studies have identified stigma associated with epilepsy in the workplace (Jacoby, 1994). This study has provided insight into the rationale for disclosure and the rationale for non-disclosure in the workplace, an area which has been neglected (Munir et al, 2005).

“Learning about disclosure” emerged as a key process in terms of decision making in the context of the workplace. Previous experiences of disclosure in the workplace were employed to make decisions as to whether and in what way the condition should be disclosed, a finding which supports the work of Lowton (2004) concerning cystic fibrosis. In this study participants reported regrets over not disclosing in the workplace and reflected on times when having an unanticipated diabetic or epileptic episode became the form of disclosure. Participants stated that in the future they would ideally disclose to their employers and co-workers in advance in order to minimise the shock to others of such acute episodes. This changing view of disclosure decisions again illustrates the important process of “learning about disclosure” in terms of personal strategies to adopt in the future. Conversely, other participants in this study believed that they had been discriminated against in the past because of their condition and would choose not to disclose in the future. These findings suggest such strategies around disclosure or non-disclosure are not “fixed” but rather dynamic and subject to change based on what Green and Sobo (2004) term “risk landscapes.”

Health is typically considered to be a personal matter and this perception contributed to difficulties around the process of disclosure. This finding is supported in the work of psychological studies which have argued that disclosure is fundamentally a personal issue (Jourard, 1971), including in the workplace (Beatty, 2004). This supports research which highlights that those living with epilepsy are more likely to be unemployed (The All Party Parliamentary Group on Epilepsy, 2007). Indeed it has been argued that those living with long-term conditions are less likely to be in full time employment (Department of Health, 2008).

Most participants in this study did disclose their condition in the workplace to their line manager. However they often expressed frustration that their employer or co-workers did not understand the implications of the condition on their working lives. This finding suggests that there may be different levels of disclosure and raises the question as to who is responsible for disclosure, in terms of what employers “need to know.” For example in this study I found that participants often did not wish to “educate” others about the condition yet felt co-workers and employers should know more. This frustration appeared to be compounded by the ongoing nature of disclosure for those moving jobs who found such negative responses to be an ongoing burden. Munir et al (2005) has referred to the process of telling their line manager that they do have a long-term condition to be: “partial self disclosure”. The study also identifies a second type of disclosure described as “full self disclosure” (Munir et al, 2005). This refers to the process of the employee disclosing to the line manager in terms of explaining the implications of the condition and potential limitations of the condition upon their ability to do the job. In the current study the data illustrates that younger participants found “full self-disclosure” difficult and

were often frustrated at employers' responses. Those disclosing often did not see it as their role to go into detail as to the implications of the condition. This raises the point that there may be different perceptions of the role of disclosure for the employee, when compared to the employer.

For example, some felt unable to disclose that they would not be able to attend lunchtime meetings due to the need to eat at particular times and thus missed key meals. Some younger participants cited that they had effectively struggled to daily manage their type 1 diabetes and difficulties around disclosure had played a part in this. They were now living with serious side effect such as kidney disease and eye damage due to difficulties they had faced in managing their condition (Department of Health, 2007b). Participants reported frustration at how the need to self-care for example insulin injections pushed the personal matter of health into a public domain when many wanted to retain the choice over disclosure.

In summary this study identified a range of issues which were taken into account when making decisions around disclosure in the workplace. These included current health status, identity and the condition, perceived reactions of staff, safety, and perceptions of legislative issues. Similarities were found to Fesko's (2001) study of disclosure of HIV in the workplace in which a range of factors were considered to play a role in whether to disclose or not. These include: current and predicted future health status; personal acceptance of the illness; culture of the work environment; consideration of risk factors such as discrimination; stigma; ability to cope with potential negative impact of disclosure, need to maintain privacy, and consequences of non-disclosure which may be negative and thus lead to a lack of support.

The study findings illustrate that what constitutes visibility and invisibility in a long-term condition is a complex question as they are not fixed. Yet Vickers (1997) argues that decisions around disclosure in the workplace are particularly difficult primarily for those living with “invisible” long-term conditions. Health status and perceptions of the severity of the condition were taken into account such as the likelihood of the condition becoming “visible.” Yet in this study such decisions were less clear but some participants chose to adopt the strategy of not disclosing and thus risking unplanned disclosure during an acute episode. This was considered a risk worth taking by some as it avoided perceived negative reactions to the disclosure such as being treated differently, and enabled participants to maintain a “healthy”, “normal” identity.

Thus in the current study, non-disclosure appears to be linked not only to risk assessment but also to minimising the impact on their identity, in particular how to avoid stigma (Williams and Healy, 2001). Some felt they had no choice but to disclose however this is not an easy decision and public misconceptions concerning the stigmatization of epilepsy and type 1 diabetes played a role in this study. In this study participants stated they feared people would treat them differently following disclosure and draw upon such misconceptions of epilepsy. This finding is supported by studies which have identified that co-workers do fear working with someone with epilepsy (Jacoby et al, 2004).

Currently, studies on disclosure in the workplace are set in an North American context, which has different employment laws (Dyck, and Jongbloed, 2000, Fesko, 2001, Beatty, 2004). They have also tended to focus on potentially transferable conditions such as HIV/AIDS (Fesko, 2001). This study has found that stigma is a

key concern for those living with type 1 diabetes as well as those conditions which are historically associated with stigma. The implications of the study findings for employers are presented later in this chapter.

In the next section I discuss the development of the theoretical conceptual framework of the role of disclosure.

6.29 Development of Conceptual Framework

Drawing upon the interviews I developed a conceptual framework of the role of disclosure to others (figure 4). Disclosure was found to be a dynamic process linked to a number of mediating issues.

The conceptual framework of disclosure has six elements:

1. **Nature:** the essence of disclosure, (what?).
2. **Process:** the manner in which disclosure occurs, (how?).
3. **Context** in which disclosure occurs, (where?).
4. **Mediators** of disclosure.
5. **Role** of disclosure, (why?)
6. **Living with a long-term condition.**

These six elements set out are now discussed:

1. **The Nature of Disclosure:** health status is personal and so disclosure has to play a functional role
2. **The Process of Disclosure:** disclosure may occur in diverse ways;
 - directly (verbally)

- indirectly (visibly through acute episodes, injecting, dietary restrictions, “objects” associated with the management of the condition).
- 3. The Process of Non-disclosure:** the means by which participants actively concealed their condition such as:
- concealing the biomedical aspects of managing the condition
- 4. The Context of Disclosure:** three settings were identified:
- friends and family
 - partners
 - workplace
- 5. The Mediators of Disclosure:** illustrating a range of factors taken into account when disclosing: personal, previous experiences of disclosure, fear of stigma, medical control, acceptance of the condition, planned/unplanned, temporality visibility, context, denial.
- 6. The Role of Disclosure:** identifying three predominant roles of disclosure:
- i. Access to Self-care and Social Support:**
 - enabling participants to manage their condition medically in terms of self-care and gaining social support.
 - ii. Strategic Disclosure:**
 - redressing myths about the condition in advance to avoid perceived stigma.
 - iii. Non-disclosure:**

- concealment of the condition to protect one's identity from stigma.

7. Living with a long-term condition: the overarching challenges of living with a long-term condition; enduring, managing the medical, managing the social elements of the condition such as identity, living with limitations, managing disclosure: “who needs to know”, “learning about disclosure” over time: moving from personal perception of disclosure as “my problem” towards it being others’ problem: “their problem.”

Figure 4 Conceptual Framework of the Role of Disclosure in Managing a Long-term Condition

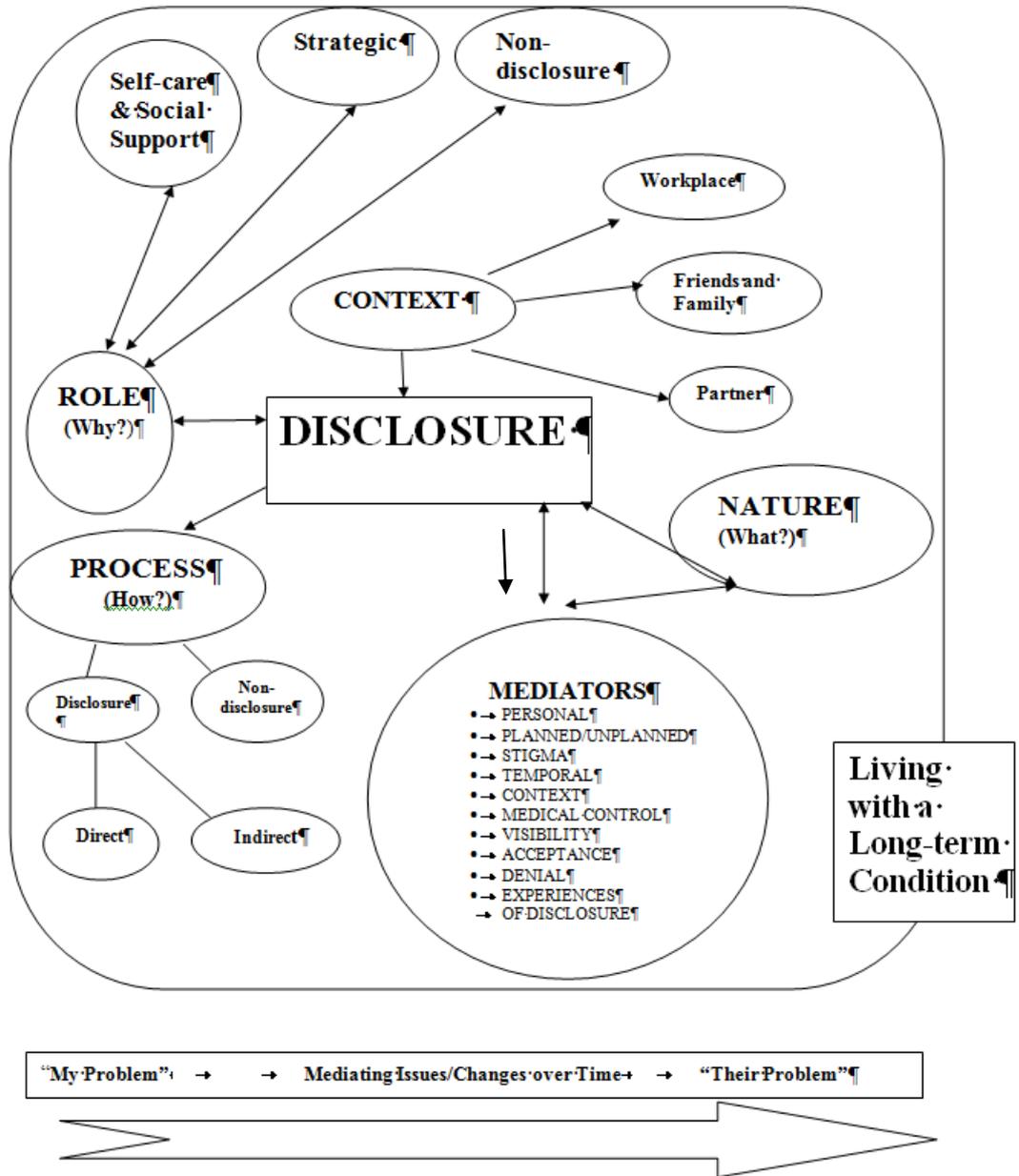
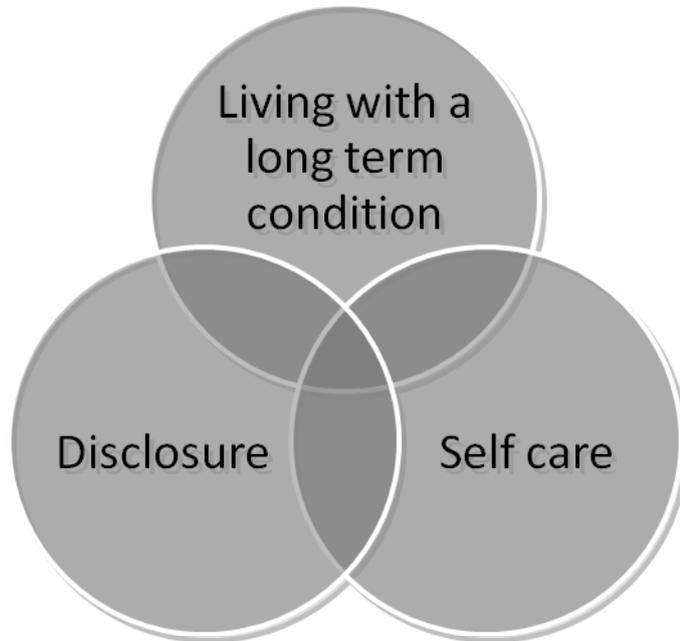


Figure 5 The Role of Disclosure in Self-care and Living with a Long-term Condition



The figure above illustrates how disclosure plays a role in the process of self-care and how this overlaps into living with a long-term condition.

Disclosure plays a key role in management of a long-term condition in several ways:

- through gaining access to self-care and social support
- non-disclosure is used to protect the individual's identity from anticipated stigma and so in itself forms a self-care strategy
- fear of reactions to disclosure inhibits self-care regimes leading to concealment and possible negative impact on the individuals' health status

The role of disclosure is currently absent from governmental policy documents on self-care (Department of Health 2008, 2005a,b, 2001a). However learning about disclosure plays an integral part of the lives of those living with a long-term condition: to manage the process of self-care. Thus as Bury et al (2005) notes it is

important to take the psychosocial elements of living with a long-term condition into account such as dilemmas around disclosure, alongside policy strategies on self-care which simply tell individuals “what to do” (Department of Health, 2008, 2005a,b,2001a).

In the next section of this chapter (part two) I go on to discuss the process of evaluating the findings of this research study.

6.30 Part Two: Study Reflections, Implications And Conclusions

6.31 Introduction

In the second part of this chapter I set out: the criteria for evaluating the current study, the lessons learned from the process of conducting the study, reflections on the strengths and limitations of adopting the methodology constructivist grounded theory and the implications of the study findings for health care practice, policy and education, employers and future research are presented. Finally, the summary and conclusions of the study are presented.

6.32 Evaluating the Research

In this study I have drawn on the specific criteria identified by Charmaz (2006) which are: originality, resonance and usefulness to assess the value of this constructivist grounded theory study. Firstly I consider the “credibility” of the study (Charmaz, 2006).

6.33 Credibility

According to Charmaz (2006), credibility is concerned with whether the results are plausible in terms of the data presented, the analysis, the evidence presented for

claims made and the breadth of data gathered. Credibility of a study is crucial not only in terms of the data gathered but to the entire research process.

Charmaz (2006) presents six criteria with which to judge whether a study is credible.

1. Does the research present intimate familiarity with the setting or topic?
2. Are the range, number and depth of the data gathered sufficient?
3. Were categories systematically compared?
4. Do the categories cover a range of empirical settings?
5. Does the data gathered link rationally to the data analysis and subsequent arguments which emerge?
6. Has sufficient evidence been provided in the study to enable a detached reader to concur with the findings of the study?

I now go on to discuss how the current study fits each criterion.

The data meets these criteria in the following way:

1. The research presents intimate familiarity with the topic through a presentation of a multi-disciplinary literature review of disclosure, the presentation of new insights into disclosure and a range of discussion and implications of the study taking the existing literature on disclosure into account and comparing this to the new empirical findings in this study.
2. The sample group consisted of a range of participants living with the condition, diverse in terms of age, length of time since diagnosis and severity of condition (health status) resulting in a broad range of perspectives on disclosure. Therefore, I was also able to tap into both

retrospective views of disclosure and prospective anticipated difficulties concerning disclosure.

Thirty-five in-depth qualitative interviews were conducted with participants recruited from patient support groups, and nurse specialist clinics. To facilitate depth to the data I conducted the interviews in a location which suited the participants, typically these took place in their homes. These interviews lasted on average around one hour and so facilitated a relatively lengthy interview with sufficient time to explore areas of relevance to the participants' covering a broad range of topics. In order to gauge the depth of the data gathered, the preliminary findings were discussed on an ongoing basis with colleagues to discuss the emerging categories.

3. The process of constant comparison was employed to compare different categories. For example strategies of disclosure and means of disclosing were compared as described in depth in the methods chapter.
4. In the current study participants were recruited from two key settings: either patient support groups, or nurse specialist clinics. However, experiences of disclosure emerged in the course of the interviews that had occurred in a range of empirical settings including: school, the workplace, friends and family, partners, and spouses providing experiences from a range of settings thus meeting the criteria.
5. In this study the emerging data was considered against existing literature on disclosure and long-term conditions. Turning to the literature enabled me to draw upon key concepts within the field of long-term conditions research and build upon existing studies. The logical links between the data and

subsequent analysis were further ensured by ongoing discussion with colleagues about the data and emerging categories.

6. The findings were discussed regularly in an ongoing way with colleagues until it was felt sufficient evidence had been provided. Preliminary work on the study was also presented to colleagues as well as at two international research conferences. This provided a useful forum in which to discuss others views of the findings of this study.

I now move onto the second criteria identified by Charmaz (2006) the “originality” of the study.

6.34 Originality

Charmaz (2006) presents four questions as criteria by which to judge the “originality” of the study. These are:

1. Do the categories present fresh insights?
2. Is there: “*a new conceptual rendering of the data?*” (p182)
3. What is: “*the social and theoretical relevance of this work?*” (p182)
4. To what extent will the grounded theory: “*challenge, extend, or refine current ideas, concepts and practices?*” (p182).

I now go on to discuss how the current study fits each criterion.

1. In this study I have presented “fresh insights” into the process, and role of disclosure: the process of disclosure may occur in diverse ways, not only verbally, but indirectly through the management of the condition, three roles for disclosure were identified which are: (1) access to self-care and social

support, (2) non-disclosure (concealment) of the condition to protect one's identity from stigma. (3) redressing myths about the condition in advance: "preventive telling" to avoid perceived stigma, illustrating that disclosure plays a key role not only the medical management of the condition but also in the social management of the condition. These findings build upon existing work which is relatively limited in this field. A key finding is that views on disclosure are dynamic and subject to change over time thus extending existing work in this area. The implications of the study are further set out later in this chapter.

2. Charmaz (2006) argues originality should be measured in terms of whether the data presents: "*a new conceptual rendering of the data*" (p182). This is represented in this study in the new conceptual framework (figure 4) of the role of disclosure in managing a long-term condition. The framework sets out the process of disclosure, nature of disclosure, and range of mediating issues. This provides clarification of the role of disclosure in the lives of those living with type 1 diabetes and epilepsy, illustrating that disclosure is of relevance to a broad set of those living with long-term conditions. This study's clarification of the relevance of disclosure may facilitate further fruitful exploration in the context of other long-term conditions in the future.
3. The social and theoretical relevance of this work are reflected in the implications of the findings for health care practice, employers, and future research and are set out in further detail in later in this chapter.

4. Finally I set out in detail how my grounded theory will: “*challenge, extend, or refine current ideas, concepts, and practices?*” (Charmaz, 2006, p182).

The view that self-care is a straightforward process as set out in policy documents that 70-80% of those living with a long-term condition may self care (Department of Health, 2005a) is challenged by the findings of this study which illustrates that despite the integral role of disclosure in the lives of those living with a long-term condition in terms of self-care and gaining social support many participants faced difficulties when disclosing. The findings that disclosure is a key element also extends current understanding of the challenges of living with a long-term condition, illustrating that disclosure is an important concept in this field. Therefore issues of disclosure are not only relevant to those conditions which might be termed stigmatised but broader conditions.

I now go on to consider the “resonance” of the study taking the criteria recommended by Charmaz (2006) into account.

6.35 Resonance

Charmaz (2006) presents four questions for consideration and how the current study fits each criteria is discussed.

These are:

1. To what extent do the categories present: “*the fullness of the studied experience?*”(Charmaz, 2006, p.182).
2. Have you: “*revealed...taken for granted meanings?*” (p182).

3. To what extent have links been made between: *“larger collectivities or institutions and individual lives, when the data so indicate?”* (p183).
4. *“Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?”* (p183)

I now go on to discuss how the current study fits each criterion.

1. There were two elements to the process of examining: *“the fullness of the studied experience”*. Firstly, by the end of the period of data collection no new issues regarding disclosure were being raised in the interviews. This is termed “theoretical saturation” (Charmaz, 2006). Secondly, member checking was also used to assess the resonance of the study and the “fullness of the studied experience.” The purpose of member checking is twofold: to gain feedback from the participants regarding the data collected and to enable participants to have access to amend the data (Sandelowski, 1993). In the current study I employed two key ways of member checking.
 - a) At the end of each interview I summarized verbally the key issues which the participant had raised to check that my understanding of their perspective was accurate. Interviewees were invited to amend or add to the summary.
 - b) Participants were given the option to review the transcripts, to remove or add anything as they wished. Six of the thirty-five participants requested a copy of the transcript and these were posted to them. Two added further comments. One specifically asked if I would delete a section of the interview which he regretted disclosing and the other articulated that she must have been extremely nervous in the interview and reflected that

the content of conversations can appear very differently when typed up and presented for review. Four participants enclosed a positive note to say they were happy with the contents of the transcripts and wished me well for the study.

2. In this study I identified a range of views on disclosure. The *“taken for granted”* meanings identified were: that disclosure is not generally seen as an issue when it actually is, and may become the source of difficulties in their lives. In particular its key role in terms of the process of the self-care regimes in their daily lives and its overlap into both their social, private and working lives. The role of time was identified in this study to be a mediator of views on disclosure.
3. Links were made between: *“larger collectivities or institutions and individual lives”*. In this study disclosure was identified as being of relevance in the lives of those living with long-term conditions in a broad range of settings. These included issues of disclosure and self-care in the workplace as well as personal relationships with spouses, friends and family. The study identified the *“need to tell”* personal information about their health in the public and potentially risky setting of the workplace.
4. The extent to which the analysis *“offer them deeper insights about their lives and worlds”* was achieved through the process of reflecting back upon the key issues participants raised in the interviews to the participants. Furthermore, some participants initially felt that they had little to say on disclosure but following the interview reflected that disclosure had in fact been of relevance to them. Opportunities to provide feedback to

participants were also built into the study design in the form of a summary of the key findings to individual participants on completion of the study, and feedback to support groups. Some participants raised the point that a health education leaflet on how to disclose would be particularly helpful and the need for greater publicity campaigns on long-term conditions thus illustrating the study tapped into their concerns.

I now go on to consider the “usefulness” of the study taking Charmaz (2006) criteria into account.

6.36 Usefulness

Charmaz (2006) offers four questions to consider whether the study has “usefulness.” These are:

1. The extent to which the analyses may be applied in people’s “everyday worlds”?
2. Does the study’s theoretical categories capture: “generic processes?” Have these generic processes have been analysed for: “tacit implications?”
3. Does the analysis identify the need for additional research in other: “substantive areas?”
4. How do the study findings build upon existing knowledge?

I now go on to discuss how the current study fits each criterion.

1. This study has identified that disclosure might be applied to peoples “*everyday*” situations because it plays a key role not only in the medical management of their condition, but also in the social management of their identity. Evidence from the study may be used to provide information for

support groups, clinics and professional staff. Further work may be conducted to assess its utility.

2. The study findings captured “*generic processes*” as follows: “learning about disclosure” as a key temporal element in the lives of the participants was identified across both epilepsy and type 1 conditions. Charmaz (2006) goes on to question whether these generic processes have been analysed for “tacit implications?” In this study I examined the process of “learning about disclosure” and identified that the “tacit implications” of this process are that disclosure plays a key but often hidden role in the lives of those with living with type 1 diabetes or epilepsy in terms of both the social and medical management of their condition and identity.
3. The analysis identified “*the need for further research in other substantive areas*” as follows. The potential for further research has been identified in this study in terms of raising awareness of the role of disclosure in terms of the link to self-care of the condition and also in terms of the broad range of ways in which disclosure itself may occur. Research might be conducted on other long-term conditions, and examine the concept of disclosure further in relation to the role of time. Examples of other substantive areas include: further research in the field of sociology of health and illness on the role of disclosure in individuals lives and further research in the field of psychology on the role of disclosure in relation to health conditions.
4. This study has “*built upon existing knowledge*” by illustrating that disclosure is a key process in the lives of those living with epilepsy and type 1 diabetes. The study has identified three key roles for disclosure a) the role

of disclosure as access to self-care and social support, b) the importance of strategic disclosure applied in redressing myths about the condition in advance to avoid perceived stigma, (c) non-disclosure also plays a role as others choose not to disclose at all, in order to protect one's identity from stigma. Disclosure has been identified as a dynamic process subject to change over time. The implications of the study are set out later in this chapter in detail.

In the next section I go on to discuss the “lessons learned” from the process of conducting the study in terms of the potential limitations identified in the study.

6.37 Lessons Learned from the Process of Conducting the Study

In this section I consider the lessons learned from the process of conducting the study namely: the limitations of the study, reflections on the application of constructivist grounded theory and consideration of ethical issues.

The study raised a number of issues regarding gaining access to study sites once ethical approval was secured. In particular this raises issues of gaining access to study sites via clinicians, a time consuming and potentially sensitive process. The process of seeking access to the study sites was frequently blocked by clinicians, thus illustrating the degree of medical control. These issues raise the question as to who is the “gate keeper” to patient access within the nurse specialist clinics and illustrate the nature of power relations in the workplace. I reflected that being a PhD student at an external institution possibly did not merit the study a key priority in the context of their busy work lives. In summary, these issues of access illustrated the busy nature of clinical work and the potential difficulties of seeking to conduct a study in a clinical context without some form of prior “link.”

I now go on to discuss some of the potential limitations identified in the study.

Firstly I discuss the sample group.

6.38 Limitations of the Study

6.39 Sampling Issues

Limitations emerged in terms of practicalities in adopting theoretical sampling, in particular recruiting those with specific viewpoints on disclosure to the study because I had effectively no control over who would choose to participate in the study. Whilst participants were given the opportunity to recount their views of disclosure, when following up issues raised in interviews such as feelings of stigmatisation I sometimes felt I may be imposing others views upon them, such as questioning: “have you ever felt different to others?” and thus not giving each participant a fresh voice.

The sample group was recruited to the study by varied means. In the epilepsy clinic it was the nurse and in some cases the consultant selected who was to be invited to participate. Therefore, those included in the study may be atypical of the range of people living with the conditions. I found during the course of this study that recruitment from the clinics was slower than anticipated and when I proposed offering a gift voucher the nurses felt that it would be an appropriate token in appreciation of participants’ time. However I reflected that this incentive may have been the primary reason for participation rather than the genuine desire to take part in the study.

It could be argued that those who choose to participate in a research study about a topic such as disclosure of long-term conditions may not be typical of all people

living with the condition. For example, overall more perceptions of disclosure were negative than positive, and it may be because those who did not perceive any difficulties around disclosure chose not to participate. In this way then, positive experiences of disclosing to others may be under-represented in the current study. Due to the voluntary nature of the groups those attending the patient support groups may not be seen as “typical” of the broad range of people living with the condition. However they were selected upon the basis that they would have a particular perspective on disclosure and this proved to be the case as they did mention the benefits of peer disclosure. The sample from the patient support groups tended to be older and female but this was counterbalanced by recruitment in terms of both gender and age through the nurse specialist clinics.

I now reflect upon the strengths and potential limitations in the application of the methodology constructivist grounded theory to this study (Charmaz, 2006).

6.40 Reflections on the Process of Adopting the Methodology Constructivist Grounded Theory

Firstly I discuss the strengths of using this approach.

6.41 The Strengths of Constructivist Grounded Theory

I reflect upon six key aspects of this approach:

- the role of the researcher
- ethical issues for the participant and the researcher
- the process of coding
- an emergent approach

- theoretical sampling
- the timing of the literature review

6.42 The Role of the Researcher

Charmaz (2006) argues that the techniques themselves are neutral: the researchers' role is key. To clarify, constructivist grounded theory is defined as follows: "*Constructivism means seeking meanings – both respondents' meanings and researchers' meanings*" (Charmaz, 2000, p524). Therefore, a key tenet of constructivist grounded theory is that researchers' must adopt a reflexive approach to consider their contribution to the emergent theory (Charmaz, 2006).

My contribution to theory is set out. In this study I was able to consider my role in the process of gathering the data in terms of coding, interview questions and analysis and I now go on to reflect upon this process. I also reflected that sometimes the unexpected emerged during the course of the interviews as Charmaz (1991) notes. This was the case in the current study, raising the question of the researcher's role in managing this as I go on to discuss.

Before conducting the study I had little prior knowledge of type 1 diabetes or of epilepsy. I did not know of anyone in my personal life with either condition. This meant that as I was interviewing participants I was simultaneously learning about the conditions and was thus able to build up knowledge on issues which were important to my participants and allow data to emerge without preconceptions which might be unhelpful or steer my data analysis in specific directions. This allowed me to be open in my approach and gain fresh insight into the areas. During the process of conducting this study I did become more emotionally involved in the research as

events in my personal life began to raise questions around disclosure and certainly throughout the research process I developed a greater understanding of disclosure on a personal level. It could be argued that this is not surprising given that disclosure is perceived from a psychological perspective as a deeply personal, potentially emotive topic (Jourard, 1971, Rosenfield, 2000). Charmaz (2006) argues that as researchers: “...we construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices” (p10). Furthermore Strauss (1987) notes that researchers may become involved in their research, not only intellectually, but emotionally, describing this process as being “*in the work*” (p10). When absent from work due to illness, I noted that I was required to state the medical reasons for this. This form was kept in a communal folder and open to the scrutiny of others. Furthermore, the question of disclosure again emerged in my professional life when seeking to gain access to the nurse specialist diabetic clinics I was required to complete a medical form citing previous and current medical conditions and was informed that dependent upon my responses, I may be contacted by an occupational health advisor. This led me to consider that disclosure of sensitive health topics might be problematic. When I began a course of psychoanalytic counselling, once more, the question and implications of disclosing to others arose again, such as to whom I should disclose and why, and how would others react? Thus the unexpected aspects of grounded theory emerged for me in as much as I had commenced the project with limited knowledge of disclosure and by the end of the project, had learned directly through my own unanticipated personal experiences. Other studies have emerged from academics’ personal experiences and interest in the area. It is worth noting that Glaser and Strauss’s (1967) original grounded theory study on death and dying in hospital emerged from their personal

experiences of the subject and this demonstrates that our professional and personal lives are frequently intertwined as Charmaz (2006) has argued: “*your journey through grounded theory may transform you*” (p185).

The researcher’s role in the study raises the question of ethical issues and these are now discussed.

6.43 Ethical Issues Raised in the Study

The ethical implications of the study not only for the participant, but also the researcher are increasingly considered in terms of the emotional impact of conducting research on potentially sensitive topics (Commissioned Enquiry Risk to Well-being of Researchers in Qualitative Research, 2007, Lalor et al 2006, Craig et al, 2000, Lees, 1993).

6.44 Ethical Issues for the Participants

Some participants were distressed during the interviews and that raised the question as to my role as a researcher in managing this. In particular, many of the epilepsy clinical nurse specialist attendees were unaware that they could access local groups for support and so appeared to be somewhat isolated. In one of the interviews the participant was tearful during the interview, but assured me when asked, that she wanted to continue with the interview. I deemed that she appeared quite isolated and provided her with a contact number for a local support group co-ordinator whilst underlining that it was entirely her choice to do so.

6.45 Ethical Issues for the Researcher

In this study I was frequently surprised at the sensitive nature of some of the content of the interviews and on occasions during my fieldwork this left me feeling fatigued

and drained emotionally. As noted earlier Charmaz (1991) does state that the unexpected may emerge during the process of interviews and so I was prepared for this to a certain extent. I debriefed interviews with my supervisor which I had found difficult or emotionally draining and found this to be a valuable process that enabled me to maintain a professional approach as suggested by Bowling, (1997). Other studies have identified the emotional impact of conducting qualitative interviews on researchers (Lalor et al, 2006). I reflected that I was not trained as a counsellor but rather my role was to listen and to enable participants to tell their story (Charmaz, 2006, Bowling, 1997).

For those participants newly diagnosed, participating in the research interview may have been a cathartic experience. Three of the younger participants asked me specifically what others had said in the interviews. I reflected that the purpose of this was to gauge whether or not they shared similar experiences to those of their own age. To minimise undue concern and without going into specific details I told them that their accounts were comparable to others. Others noted it was liberating to have someone to talk to and described it as “too good an opportunity to miss.”

Some of the issues for participants which emerged in the course of the interviews included, feeling unfairly judged for having developed a condition, perceived to be a result of their own behaviour, some described how the reactions of others to their condition led them to feelings of depression and notions that life was not worth living. Others voiced extreme difficulties around coming to terms with the condition and its subsequent management. Where appropriate I did offer additional information on local patient support groups but emphasised that making contact was entirely a personal choice.

I now go on to reflect on the process of coding the data in this study.

6.46 The Process of Coding

Upon reflection a number of negative aspects of disclosing to others emerged in the interviews alongside positive responses. Using the grounded theory qualitative approach facilitated an understanding of such views changing over time, a process which would not have been easily captured on a questionnaire. For example, it captured a number of changes over time and both retrospective and prospective views on disclosure such as reflecting back on previous experiences and for younger newly diagnosed participants' anticipatory reflections on potential difficulties around disclosure. Constructivist grounded theory is particularly well suited to the exploration of long-term conditions because it is a flexible approach allowing one to follow up key issues which emerge in the data such as capturing participants views of changes over time (Charmaz, 1990, 2000, 2006).

More specifically adopting constructivist grounded theory was particularly beneficial in the current study because it offers greater flexibility in coding procedures compared to other grounded theory approaches (Glaser and Strauss, 1967, Glaser, Strauss and Corbin 1990). A key approach which Charmaz (2007) recommends is "*learning to tolerate ambiguity*" (p28) to facilitate emergence. Using this approach I was able to examine the data in terms of "action" to facilitate insight into the social process of disclosure in addition to exploring the data for thematic issues, this led to the identification of the process of "learning about disclosure". I found this fresh approach helpful because I was seeking insight into the area of disclosure which lacked definition.

6.47 An Emergent Approach

Upon reflection, a narrative approach was a possible alternative to grounded theory to have researched and analysed the data collected (Clandinin and Connelly, 2000).

The narrative approach encourages participants to recount stories about their lives.

Conducting unstructured interviews within a narrative approach may have also identified emergent themes that could have focused on learning to live with a long term condition and how telling people about chronic illness is part of this. This approach would have been particularly well suited to exploring the temporal, chronological findings which emerged in the data with regard to aspects of disclosure, in particular “learning to disclose” as well as the temporal aspects of living with a long term condition which emerged in the interviews. The narrative approach also encourages a collaborative narrative by combining the participants perspective and the researcher’s. As Clandinin and Connelly (2000) note: *“Research... is a collaborative document, a mutually constructed story out of the lives of both researcher and participant”*(p12). Thus the researchers life stories are taken into account as well as the participants. This would have also been a particularly helpful approach to take given my personal experiences of disclosure.

In considering: “what is truth?” it is argued within the constructivist paradigm that truth is “antifoundational” (Lincoln and Guba, 2000). They describe antifoundational as follows: *“the term used to denote a refusal to adopt any permanent, unvarying (or “foundational”) standards by which truth can be universally known”* (p177). In my personal correspondence with Charmaz (2007) it was confirmed that there is no single end product which is “arbitrarily preordained.” In other words what emerges from the study is itself a “construction” developed by

the researcher. I felt it was particularly important to adopt a strategy which did not force me to adopt a preconceived endpoint to ensure that the findings reflected the participants' perspective and thus a flexible approach was for me pertinent. Many of the studies conducted on disclosure were specifically based in the workplace. This study provides perspective and broader insight into the decision making process around disclosure or non-disclosure in the lives of those living with type 1 diabetes or epilepsy.

In particular the methodology highlighted the key role which others play in making sense of one's health condition: it is through interaction with others that one makes sense of things (Blumer, 1969). For example participants felt stigmatised or conversely felt supported directly through others' reactions. The negative reactions of others led many to avoid disclosure altogether. Disclosure fundamentally involves others and thus adopting a constructivist approach which considers the role of others was essential. I now go on to reflect on the role of theoretical sampling in this study.

6.48 Theoretical Sampling

Charmaz (2006) defines the role of theoretical sampling as follows: "*to elaborate and refine the categories constituting your theory*" (p96). The sample includes a range of participants in terms of how long they have been living with the condition. This has resulted in a sample with older participants mainly reflecting back upon their experiences of disclosure and younger participants reflecting on their current experiences of disclosure and prospective views on disclosure. This adds range and rich depth to the study as it includes a range of perspectives. It also taps into how views of the conditions and attitudes towards disclosure of the condition changed

over time. I now go on to discuss the literature review conducted in this study, taking the debates surrounding its timing into account.

6.49 The Timing of the Literature Review

There is considerable debate in the field of grounded theory methodology regarding the timing and the role of the literature review in grounded theory (Glaser and Strauss 1967, Glaser 1978, Charmaz, 2006). It has been argued that in order to avoid what has been termed “received theory” (Glaser and Strauss 1967, Glaser 1978), the literature review should be delayed until data analysis has been completed so that the researcher remains open to fresh insights and is not swayed by existing literature. In the development of this study a literature review was required to set out a clear rationale for conducting the study. Conducting the literature review after the data has been analysed can serve a key role in terms of clarifying and building upon the data analysis (Charmaz, 2006). This process facilitates the process of critiquing existing work in relation to the grounded theory which emerges. In this study I initially completed the literature review to set out the broad parameters of the study and then sought new literature for example, in the area of concordance and young people, to compare the data against existing work. This played a key role in clarifying the study’s contribution to the field of disclosure.

I now go on to discuss some limitations of the methodology.

6.50 The Limitations of Constructivist Grounded Theory

Charmaz's (2000) extensive critique of Glaser's (1978) grounded theory approach as "positivist" appears contradictory since she recommends adopting his criteria for what constitutes a good grounded theory as: "*useful for thinking about how your constructed theory renders the data*"(p182). As stated earlier, Charmaz (2006) presents constructivist grounded theory to be a flexible approach whose methods can be adopted relatively easily in contrast to the rigid approach grounded in positivism. Indeed, Charmaz (2006) argues that one can use the procedures set out by Glaser and Strauss (1967) and later modified by Glaser (1978) and then Strauss and Corbin (1990) because these are themselves "neutral": "*Techniques themselves are neutral – the researchers role is key: We may think our codes capture the empirical reality. Yet it is our view: we choose the words that constitute our codes*" (p9). However, Charmaz's argument (2006) that the researcher plays an integral role in the study in terms of the data analysis raises the question of pre-existing knowledge the researcher has. This does however suggest that differences in terms of the data analysis are likely to occur among experienced researchers rather than those who may be new to the field. For example, Charmaz herself has conducted research on long-term conditions for many years which are arguably difficult to exclude (see Charmaz, 1983,1990,1991,2000,2002).

Charmaz (2006) argues that constructivist grounded theory is an innovative approach which promises new things for the future: "*...we look back into the history of grounded theory in the twentieth century and look forward into its yet unrealised potential for the twenty-first century*" (p1). However there is little detail in her book as to how to achieve this and it seems to be largely based upon the rhetoric rather

than the process of how to achieve such: “unrealised potential.” She sees grounded theory methods as: “*a set of principles and practices, not as prescriptions or packages*” (p9).

It might be argued that her argument of flexibility in the approach of grounded theory is not consistent with her approach to the assessment of the emergent grounded theory which is more prescriptive as I go on to discuss.

This study has provided additional insights into the methodology in the following way. Charmaz (2006) states: “*analytic directions arise from how researchers interact with and interpret their comparisons and emerging analyses rather than from prescription*” (p178). This study found however that “external prescriptions” do exist and do play a role in terms of “analytic directions” in the following ways:

- External prescriptions exist in the form of limitations in terms of accessing “ideal” sources of theoretical sampling: pragmatic issues of both access to the study sites and the timeframe of data collection in the field
- the process of gaining access to specific sites through clinicians form additional “external prescriptions” as they can play a key role in the recruitment and sampling process
- the role and timing of adopting the literature review links into the discussion of “external prescriptions”

Issues around the role of the literature review do however further illustrate the limitations of a constructivist approach. Whilst it is true that it is the researcher who codes the data, and therefore influences the “*analytic directions*”. Charmaz (2006) also encourages the researcher to consider the literature to define the parameters of

the study. Therefore the researcher does not live in a knowledge vacuum and inevitably must draw upon “external prescriptions” in the development and construction of the grounded theory.

In the next section I go on to discuss the implications of the study findings which are relevant to a number of audiences.

6.51 The Implications of the Study Findings

6.52 Introduction

This section presents the implications across three areas:

- **Health Care Practice**
- **Policy and Education**
- **Future Research**

6.53 Health care Practice

6.54 Clinical Nurse Specialists

An increased awareness of the issues around disclosure and how these can affect individuals’ self-care regimes has implications for health care practice and in particular clinical nurse specialists. As key providers of care for those living with long-term conditions, nurses are arguably well placed to offer support to clinic attendees regarding issues around disclosure.

The implications for practice are that specialist nurses might provide an information leaflet to patients identifying how disclosure can be an issues and how it can be related to the medical management of their condition. Specific support and education for newly diagnosed patients and their families on methods of negotiating

disclosure including its role in their medication regimes. In addition, incorporating a discussion on disclosure when providing education on how to manage their condition.

I go on to present the implications of the study for policy and education.

6.55 Policy

The study findings build upon the policy work which sets out to support those living with long-term conditions to self-care and the development of patient-centred services by illustrating that learning about disclosure is a key element of living with and managing a long-term condition. There have been a prolific number of policy documents concerning long-term conditions however the role of disclosure is currently absent and should be included in future policy documents on long-term conditions. There is an additional need for policy documents to be tailored to specific long-term conditions rather than generically as is currently the case. Policy documents should take into account the dynamic nature of living with a long-term condition as ways of managing disclosure may change over time in relation to mediating issues such as the heterogeneity of the symptoms, severity and ability to cope with living with the condition into account particularly in relation to supporting individuals self-care strategies. Policy might support health care professionals in the delivery of education programmes which might include the topic of disclosure, delivering a programme of education in schools and the workplace on the implications of living with long-term conditions including epilepsy or type 1 diabetes in particular with emphasis on the heterogeneity of the conditions. The current study raised the difficulties which those living with epilepsy faced in terms

of gaining support and information for their condition and there is a need for epilepsy to have a higher policy profile than present.

The development of health education leaflets for the patient living with the condition on disclosure strategies and those around them such as friends, family and employers.

It is argued that ongoing education on long-term conditions might play a key role in terms of educating the general public and thus making the process and responses to disclosure less burdensome. I now go on to present the implications of the study findings for patient support groups.

6.56 Patient Support Groups

The study findings raised a number of important implications for patient support groups are as follows:

- innovative ways of supporting those who are younger by targeting their specific needs
- raised awareness of patient support groups by offering contact details through primary and secondary clinics
- Advice and guidance on disclosure

The implications of the study for the workplace are set out in the following section.

6.57 Employers

Decisions around disclosure in the workplace were particularly challenging for participants. Many experienced discrimination and were fearful of the consequences of disclosing their condition to employers and co-workers.

The study findings have important implications for employers. Disclosure of health was deemed to be a highly personal matter for employees and so advice on employers' responsibilities in supporting employees living with long-term conditions in the workplace would be beneficial drawing on these study findings which suggest a need for:

- Raised awareness of the heterogeneous symptoms and experiences of living with such conditions and their impact on the individual's role in the workplace
- Raised awareness of continuing discrimination in the workplace (despite legislation)
- Raised awareness of the psychosocial impact of discrimination and stigma
- Raised awareness, advice and support in terms of the practical implications of managing long-term conditions within the workplace: workplace adjustments linked to self-care.

6.58 Employees

- Advice on disclosure to employers and work colleagues
- Guidance on how the condition may impact on their role in the workplace

This appears to be particularly relevant as the number of people living with long-term conditions who wish to continue in employment may rise in line with the increased percentage of the population living with such conditions. I now set out the implications of the study findings for future research.

6.59 Future Research

The implications for future research are as follows:

- Taking the role of disclosure in the management of long-term conditions into account in health care research
- Views of partners, carers and family on disclosure should be taken into account to facilitate greater insight into the role of disclosure.
- An exploration of ethnic communities perspectives on the role of disclosure
- An exploration of gender differences on disclosure
- Using a longitudinal research design to further explore perceptions of the nature and role of disclosure over time
- Constructivist grounded theory is a methodology which can successfully explore long-term conditions and disclosure
- Exploratory work on disclosure in the workplace taking employers views into account

I now turn to the summary and conclusions of this thesis.

6.60 Summary and Conclusions

In conclusion, this study has provided clarification as to what constitutes disclosure and consequently broadened understanding of the role of disclosure in the lives of those living with either epilepsy or type 1 diabetes. The rationale for this study stemmed from the paucity of research in the area of the role of disclosure of long-term conditions in health care research. This study adds to the field of research in

several different ways: providing insight into the nature of disclosure, process, and role in the lives of those living with type 1 diabetes or epilepsy.

The conceptual framework and findings in this study extend current definitions of disclosure (as set out on p50) in the following ways. Firstly, the findings support Charmaz's (1991) definition which suggests disclosure is an ongoing process throughout the lives of those living with a long term condition. Furthermore this study also identified the process of "protective disclosure" which Charmaz (1991) notes sets out to manage to whom disclosure occurs and when. Schneider and Conrad's (1980) "preventive disclosure" which seeks to disclose to others to minimise potential distress of having an acute episode was also identified in this study.

However in contrast to this previous work this study extends and develops conceptually understandings in the area of disclosure by strongly identifying the temporal aspects of disclosure. Participants described how many changed their strategies of disclosure from concealing their condition towards disclosing to others in advance. This study identified the process of "learning about disclosure" to be a dynamic process subject to change over time. In contrast previous definitions of disclosure have suggested "fixed" strategies of disclosure (Charmaz, 1991, Schneider and Conrad, 1980, Beatty, 2004, Joachim and Acorn, 2003, Munir et al 2005).

The conceptual framework (figure four) and findings extend and develop conceptually understandings in this area in three key ways. Firstly, by illustrating that disclosure may occur in a diverse number of ways not only verbally but indirectly such as through visual aspects. This study extends understandings in this

area by illustrating that disclosure is not a straightforward process and may occur in broader ways than current definitions suggest (Dyck and Jongbloed, 2000, Williams and Healy, 2001, Munir et al, 2005). Furthermore this study has raised the point that individuals living with a long term condition did consider “who needs to know?” about their condition across contexts such as the workplace, family and friends. In contrast previous work has focussed on disclosure primarily in the context of the workplace (Beatty 2004, Munir et al, 2005, Dyck and Jongbloed, 2000). Secondly, the framework identified that there are a number of key mediators taken into account when deciding to tell or not to tell. These are not included in current definitions of disclosure (Charmaz, 1991, Beatty, 2004, Troster, 1997, Dyck and Jongbloed, 2000, Joachim and Acorn, 2003). Finally this study identified a key role of disclosure to gain: “access to self-care and social support”: enabling participants to manage their condition medically in terms of self-care and gaining social support. Therefore this study has identified that disclosure plays a key role in the lives of those living with a long term condition, aside from the management of stigma thus building upon other work in this area (Schneider and Conrad, 1980, Charmaz, 1991, Troster, 1997).

The study identified that disclosure of a long-term condition was itself deemed to be a highly personal process and therefore only to be divulged for a reason within appropriate settings and context. This study has provided additional insight into the process of disclosure illustrating that it may occur in a number of different ways. For example, opportunities for disclosure emerged indirectly through the process of self-care of the condition through questions posed to participants such as, “do you drive?” for those living with epilepsy and: “why do you have a fridge in your room?” for those with diabetes. Disclosure also emerged through self-care: the process of

medically managing their condition. Thus the potential opportunities for disclosure are broader than previously assumed.

Outwith the context of friends and family disclosure was deemed to be more “risky” particularly when linked to the fear of being stigmatised by others. In this context the role of disclosure was to gain access to social support and medical support where required. Disclosure therefore presented participants with the challenge of managing their condition medically whilst seeking to maintain control over the personal and private nature of their condition. The question of disclosure was therefore identified as an additional challenge to be managed in the lives of those living with long-term conditions as it had both profound social and medical implications.

This study identified that decisions around disclosure were not straightforward and a number of mediating issues around disclosure were identified. These included the enduring nature of the condition; issues of the visibility of the condition as linked to perceptions of medical “controllability” of the condition, and coping with the potential unpredictability of the condition. Across both groups and conditions, participants appeared to be “learning about disclosure” over time. Issues of temporality emerged in the data suggesting that strategies around disclosure or non-disclosure may change over time. For example participants recruited from the patient support group setting who tended to be older and to have lived with the condition for a longer period of time described a process of changing from seeking to avoid disclosure altogether where possible, described in the literature as “passing” (Goffman, 1963) to disclosing to others in advance as a means of redressing potential myths about the condition: “preventive disclosure” (Schneider and Conrad, 1980). This study extends the concept of “preventive disclosure” by illustrating that it is

subject to change over time.

In contrast those recruited from the nurse specialist clinics identified their ongoing frustrations with reactions to disclosure leading many to choose to avoid disclosure where possible. Such negative reactions were perceived to be a consequence of a lack of understanding concerning the heterogeneity of the conditions and potential limitations on their daily lives. In this group disclosure was identified to be an additional burden to be avoided.

Differences in information sources emerged across the settings and provided insight as to why younger participants tended not to seek out patient support groups. Overall this study has identified that the role of disclosure is not only linked to the need for others to: “know what to do” in the event of a potential acute episode as Schneider and Conrad (1980) have argued. Disclosure plays a broader role in the lives of those living with either epilepsy or diabetes in terms of the medical management of their condition and the social management of their condition. The study identified three different and diverse roles of disclosure:

- Firstly, disclosure is a key process which enables participants to manage their condition medically in terms of self-care and gaining social support.
- Secondly, the role of disclosure appears to be applied in redressing myths about the condition in advance.
- Thirdly, non-disclosure also plays a role as others choose not to disclose at all, in order to protect one’s identity from stigma.

A number of common issues were identified across both conditions. The nature of disclosure was deemed to be highly personal as a consequence it must have a

“functional” role which is influenced by context and the passage of time. This study also identified that disclosure may occur in a broad range of ways: verbally, visibly as a result of an acute episode, visibly when linked to the self-care of the condition. Triggers for disclosure illustrated that it is not always possible to control the timing of disclosure.

This thesis has identified that disclosure is a key yet often overlooked concept in health care research and deserves further empirical attention. Learning about disclosure is an integral part of living with a long-term condition. In the context of the rise in the proportion of those living with a long-term condition and the implications for health services, the government has focussed upon supporting self-care as a means of addressing this. The link between disclosure as it impacts on self-care has been strongly identified in this study. Therefore, the role of disclosure in managing a long-term condition must be taken into account in future policy work as well as future research to explore this further. Living with a long-term condition is an increasingly important part of many people’s lives. Part of this includes learning about disclosure and this study highlights that this is an area which those living with long-term conditions require additional support with managing which in turn will improve individuals’ experiences of living with such conditions.

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APPENDICES

APPENDIX 1

Literature Review Search Strategy

APPENDIX 1

Literature Review Search Strategy

Search Strategy (1982-2008)

The following electronic databases were searched: **SOCIOLOGICAL ABSTRACTS, MEDLINE, EMBASE, CINAHL, PsycINFO, BRITISH NURSING INDEX, AMED, INDEX TO THESES and DISSERTATION ABSTRACTS**

The following search terms were used: Self-disclosure, Truth-Disclosure, disclos\$, prejudice, decision-Making, work-place, chronic-disease, Chronic illness\$ or long-term illness\$, long-term condition, coping, self adj care, self-care# work or workplace, employment, managing, coping, interpersonal-communication, invisible, visible, stigma, views of illness, carers, patients, sick role, social support, complex condition, patient experiences, Epilepsy, type 1 diabetes

APPENDIX 2a

Request Form to Take Part in Research Interview

REQUEST FORM TO TAKE PART IN RESEARCH INTERVIEW

Please tick the appropriate response and post in the pre-paid envelope. Thank you.

-
- I am willing to take part in an interview about my experiences of telling others that I have a long term health condition

Please contact me to arrange an interview

NAME

TELEPHONE NUMBER

BEST TIME TO CALL

- I am not willing to participate in an interview

THANK YOU FOR YOUR TIME

APPENDIX 2b

Personal Data Collection Sheet

Personal Data Collection Sheet

Oxfordshire Research Ethics Committee "A" (O6/Q1604/79)

Please can you give us the following information to help us to plan the study

1. Please can you tell us your age?

2. Are you female/ male? Please circle one.

3. Can you tell us your occupation or job?

4. Please tell us about your marital status? Please tick one option.

Single	
Married	
Divorced	
Cohabiting	
Other (please tell us)	

Please return this slip in the prepaid envelope. Thank you.

APPENDIX 3a

Invitation Letter (Patient Support Group)

RCN Institute
Whichford House
Building 1400, Parkway Court,
Oxford Business Park,
Cowley
Oxford OX4 2JY

Lorna Henderson Postgraduate
Research student

Telephone (01865) 787105/787113
P.mail:loma.henderson@rcn.org.uk

Invitation Letter (Patient Support Group)

Study title: Patients' experiences of telling others that they have a long term health condition

Dear Patient,

I am a postgraduate research student registered at the Royal College of Nursing Institute, Oxford. I am contacting you because you have attended your patient support group. I am undertaking a study of patients' views and experiences of telling others that they have a long term condition e.g. friends, family, employers or other people.

Whilst many people are living with a long term condition it is currently unclear how and why patients choose to tell others about their condition and how others react to the news. I am keen to hear your views. The findings of the research will be used to help understanding of what it's like to tell others about a long term illness.

An information sheet is enclosed which explains the study in further detail. If you would like to participate please return the slip in the pre-paid envelope and I will contact you to arrange an interview at a time and place that suits you. It would be very helpful for the study if you could return the slip within the next **two weeks**. If you require any additional information please do not hesitate to contact me. This study has been approved by the Oxford Research Ethics Committee "A" reference number **(06/Q1604/79)**.

Yours sincerely,

Lorna Henderson

APPENDIX 3b

Invitation Letter(nurse specialist clinic)

APPENDIX 3b

RCN Institute
Whichford House
Building 1400, Parkway Court,
Oxford Business Park,
Cowley
Oxford OX4 2JY

Lorna Henderson Postgraduate
Research student

Telephone (01865) 787105/787113
Email:lorna.henderson@rcn.org.uk

Invitation Letter (nurse specialist clinic)

Study title: Patients' experiences of telling others that they have a long term health condition

Dear Patient,

I am a postgraduate research student registered at the Royal College of Nursing Institute, Oxford. I am contacting you because you are due to attend a nurse specialist clinic at the (Hospital name). I am undertaking a study of patients' views and experiences of telling others that they have a long term condition e.g. friends, family, employers or other people.

Whilst many people are living with a long term condition it is currently unclear how and why patients choose to tell others about their condition and how others react to the news. I am keen to hear your views. The findings of the research will be used to help understanding of what it's like to tell others about a long term illness.

An information sheet is enclosed which explains the study in further detail. If you would like to participate please return the slip in the pre-paid envelope and I will contact you to arrange an interview at a time and place that suits you. **To recompense you for your time in taking part in the interview we would like to offer participants a £15 voucher for the record shop HMV.** It would be very helpful for the study if you could return the slip within the next **two weeks**. If you require any additional information please do not hesitate to contact me. This study has been approved by the Oxford Research Ethics Committee "A" reference number **(06/Q1604/79)**. Yours sincerely, Lorna Henderson

APPENDIX 4a

Patient Information Sheet (Patient Support Group)

Patient Information Sheet (Patient Support Group)

Study Title: Patients' experiences of telling others that they have a long term health condition

Oxfordshire Research Ethics Committee "A" (O6/Q1604/79)

You are being invited to take part in a research study. Before you decide whether you would like to participate, we would like to explain why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. The information sheet tells you the purpose of this study and what will happen to you if you take part. Please contact me if anything is unclear or if you would like more information. Take your time in deciding whether or not you wish to take part. The research is being conducted by the Royal College of Nursing Institute, Oxford.

(1) What is the purpose of the study?

I am a postgraduate research student registered at the Royal College of Nursing Institute, Oxford. The aim of this research is to find out more about patients' experiences of telling others that they have a long term health condition. The purpose of this research is also to understand more about patients' views and experiences of telling others that they have a long term health condition and to find out more about how others have responded to the news. We hope this will help health professionals understand more about what it is like to have a long term health condition.

(2) Why have I been chosen?

You have been sent this information pack because you recently attended your patient support group.

(3) Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep, and you will be asked to sign a consent form. You are still free to withdraw at any time and

without giving a reason. It is possible that some people may find talking about their disclosing their condition to others distressing. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now or in the future. An example of a consent form is included in this pack for you to read. This is just for your information at the moment; please do not complete it yet.

(4) What would happen in the interview?

I would like to interview you at a time and place that suits you in order to find out more about your experiences of telling others that you have a long term health condition. In the interview I will ask you about how you made the decision to tell (or not tell) others about your illness, how you thought others might react to the news, how others did in fact respond to the news of your condition and how you felt about that. The interview will last approximately one hour. We would like to tape record the interview if you are happy for us to do so. After the interview a typist will type it out in full and you will have the opportunity to receive a copy of the transcript and invited to remove or add anything should you wish to do so. Your comments will remain confidential and no information will be passed onto NHS staff. Any information about you will have your name and address removed so that you cannot be recognised from it. A summary of the results of the study will be available and I would be pleased to send you a copy if you would like them. If you have a concern about any aspect of this study please contact the research Lorna Henderson who will do her best to answer any questions. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. Details can be obtained from your local Patient and Advice Liason Service on (01865) 221473, Email: PALSIRgi'orh.nhs.uk. This study was given a favourable ethical opinion for conduct in the NHS by the Oxford Research Ethics Committee "A" reference number **(06/Q1604/79)**.

APPENDIX 4a

Contact details

If you have any questions or concerns about the research, please contact Lorna Henderson on **(01865) 787105/787113** between 9.30am and 5pm Monday to Friday. Thank you for taking the time to read this.

APPENDIX 4b

Patient Information Sheet (nurse specialist clinic)

Patient Information Sheet (nurse specialist clinic)

Study Title: Patients' experiences of telling others that they have a long term health condition

Oxfordshire Research Ethics Committee "A" (O6/Q1604/79)

You are being invited to take part in a research study. Before you decide whether you would like to participate, we would like to explain why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. The information sheet tells you the purpose of this study and what will happen to you if you take part. Please contact me if anything is unclear or if you would like more information. Take your time in deciding whether or not you wish to take part. The research is being conducted by the Royal College of Nursing Institute, Oxford.

(1) What is the purpose of the study?

I am a postgraduate research student registered at the Royal College of Nursing Institute, Oxford. The aim of this research is to find out more about patients' experiences of telling others that they have a long term health condition. The purpose of this research is also to understand more about patients' views and experiences of telling others that they have a long term health condition and to find out more about how others have responded to the news. We hope this will help health professionals understand more about what it is like to have a long term health condition.

(2) Why have I been chosen?

You have been sent this information pack because you are due to attend a nurse specialist clinic at the (Hospital name).

(3) Do I have to take part?

No, it is up to you to decide whether or not to take part, if you do, you will be given this information sheet to keep, and you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. It is possible that some people may find talking about their disclosing their condition to others

distressing. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now or **in** the future. An example of a consent form is included in this pack for you to read. This is just for your information at the moment; please do not complete it yet. **To recompense you for your time in taking part in the interview we would like to offer participants a £15 voucher for the record shop HMV.**

(4) What would happen in the interview?

I would like to interview you at a time and place that suits you in order to find out more about your experiences of telling others that you have a long term health condition. In the interview I will ask you about how you made the decision to tell (or not tell) others about your illness, how you thought others might react to the news, how others did in fact respond to the news of your condition and how you felt about that. The interview will last approximately one hour. We would like to tape record the interview if you are happy for us to do so. After the interview a typist will type it out in **full** and you will have the opportunity to receive a copy of the transcript and invited to remove or add anything should you wish to do so. Your comments will remain confidential and no information will be passed onto NHS staff. Any information about you will have your name and address removed so that you cannot be recognised from it. A summary of the results of the study will be available and I would be pleased to send you a copy if you would like them. If you have a concern about any aspect of this study please contact the research Lorna Henderson who will do her best to answer any questions. If you remain unhappy and wish to complain formally you can do this through the NIS complaints procedure. Details can be obtained from your local Patient and Advice Liason Service on (01865) 221473, Email: PA_LSJKt@forh.nhs.uk. This study was given a favourable ethical opinion for conduct in the NHS by the Oxford Research Ethics Committee "A" reference number **(06/Q1604/79)**.

Contact details: If you have any questions or concerns about the research, please contact Lorna Henderson on **(01865) 787105/787113** between 9.30am and 5pm Monday to Friday. Thank you for taking the time to read this.

APPENDIX 5

Interview Topic Guide

Interview Topic Guide

Interviews with patients will be broadly guided by the following topics - however we want to ensure the latitude for patients to raise issues that are relevant to them, therefore interviews will also be conducted with this aim in mind. The study is exploratory and so the questions are open-ended.

Key questions/topics to be explored -

- Experiences of disclosing illness to others in different contexts
- What is the outcome of telling others about the condition?
- What are the barriers to disclosing illness to others?
- Patients perceptions of the role of disclosure of illness

EXPERIENCES OF TELLING OTHERS ABOUT THEIR

ILLNESS

- **Please could you tell me about your experiences of telling others about your illness?**

(Aim of question to explore patients views and experiences of telling others that they have a condition)

- **Please can you tell me about who you have told about your illness?**

(Aim of question to explore contexts for telling others about their illness e.g. work, friends, family).

CONTEXT OF DISCLOSURE

- **Please can you tell me about how others have responded to you when you told them about your illness?**

(Aim of question to explore others responses to disclosure of illness)

- **Please can you tell me about times when you have not told others about your illness?**

(Exploring patients reasons for not disclosing illness to others)

PROCESS OF DECISION MAKING

- **Please can you tell me about how you made the decision to tell others about your illness?**
(Aim of question to ascertain whether strategic decisions are made).
- Is there anything else you would like to say that we have not yet covered?

Prompts

Could you describe
further? Tell me about?
How does that differ
from? Can you give me
an example of?

Ending question

Is there anything else you would like to add?

End of interview

Thank participant for their time and information. Inform they can receive
summary of the projects findings.

APPENDIX 6

Consent Form

Consent Form

Project title: Patients' experiences of telling others that they have a long term health condition

Oxfordshire Research Ethics Committee "A" (O6/Q1604/79)

Name of Researchers: Lorna Henderson, Postgraduate research student, Royal College of Nursing Institute, Whichford House, Building 1400, Parkway Court, Oxford Business Park, Cowley, Oxford OX4 2JY Telephone: **(01865) 787105/787113**

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that no sections of any of my medical notes will be looked at by the research team.

4. I agree to take part in the above study.

Please turn page to next sheet.

Consent form continued

Use of tape recorders for recording the interviews

So that the interviewer can concentrate on talking to you during the interview, and not on writing down everything you say, we ask if you mind if the interviewer brings a tape recorder to record the conversation. Your name would not be recorded on the tape, and no-one except the researchers and the person typing out the interviews would hear the tape. If you decide you would rather not have the tape recorder used, we are happy to take full notes instead.

It may be possible to use some quotes from the recordings in our final report and publications. These quotes would be used anonymously.

Please initial box

- 5. I am happy for the interview to be tape-recorded []
- 6. I am not happy for the interview to be tape-recorded. []
 I agree that words I say during the interview can be used
 anonymously as quotes in the reporting of the study. []
- 7. I give permission for my personal data to be stored and securely
 processed. []

Name of study participant	Date	Signatures
---------------------------	------	------------

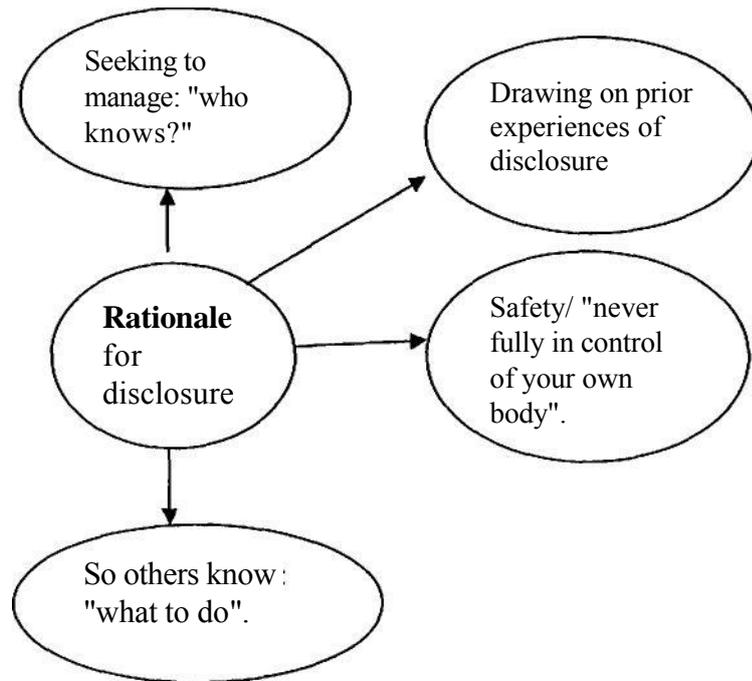
Researcher	Date	Signature
------------	------	-----------

APPENDIX 7

Examples of Visual Diagrams

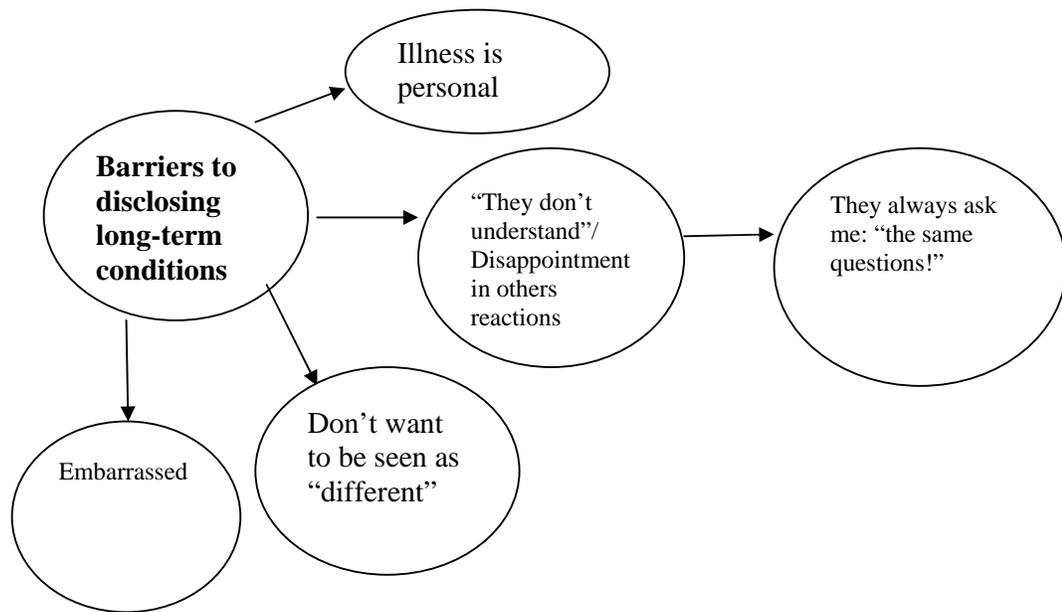
Examples of Visual Diagrams

Diagram exploring: *"the rationale for disclosure and its intention or purpose"*.



APPENDIX 7

Diagram exploring: *“barriers to disclosure”*.



APPENDIX 8

List of Local and National Patient Organisations

LIST OF LOCAL AND NATIONAL PATIENT ORGANISATIONS

LOCAL ORGANISATION:

PATIENT ADVTCE AND LIAISON SERVICE OXFORD: (01865) 221473 Email: PALSR@orh.nhs.uk

Long-term Medical Conditions Alliance 202 Hatton Square 16 Baldwins Gardens London EC IN 7RJ

Tel: 020 7813 3637 Fax: 020 7813 3640

Email: infoajlmca.org.uk **Website:**

www.lmca.org.uk

LIST OF NATIONAL ORGANISATIONS FOR EPILEPSY

The National Society for Epilepsy

Chesham Lane

Chalfont St Peter

Bucks SL9 ORJ

UK

Tel: 01494 601300

Helpline: 01494 601400

Website: <http://www.cpilepsynse.org.uk/>

LIST OF CONTACT ORGANISATIONS FOR DIABETES

Diabetes UK Careline

10 Parkway, London, NW1 7AA

Tel: 0845-120 2960

Email: carelineC^diabetes.org.uk

Website: <http://diabetes.org.uk>