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**Multiple morbidity and moral identity in mid-life: accounts
of chronic illness and the place of the GP consultation in
overall management strategies**

Anne Frances Townsend

**Thesis submitted for the degree of Doctor of Philosophy at
the University of Glasgow**

**MRC Social and Public Health Sciences Unit
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Abstract

This study was conceived against the backdrop of academic and medically based discussions about inappropriate use of General Practice, in the context of an overburdened and under resourced National Health Service. More specifically, in the midst of concerns around 'frequent consulting' there have been calls for a fuller understanding of how people use the GP consultation, and more recently how individuals self-manage. Such dialogue has emphasised the problems brought about by a shift in illness patterning, from acute to chronic conditions, requiring new and complex care solutions. Symptom based consulting behaviour has been well documented and there is an extensive literature on lay perspectives of illness, including dilemmas associated with specific chronic conditions as well as common problems. However, there is a paucity of research which combines an examination of the lived experience of multiple ongoing illnesses, with the consultation process. This thesis explores these interrelated issues.

Twenty-three participants, all aged around 50, were sub-sampled from an existing longitudinal survey which included extensive information about health and social circumstances. All participants had reported at the latest survey contact that they had 4 or more chronic illnesses. Two groups with contrasting GP consulting patterns, 11 categorised as frequent (7 or more GP visits in the last 12 months) and 12 as less frequent consulters (3 or fewer GP visits in the last 12 months) took part in this qualitative study. To gain social variation for comparative purposes, the sample comprised 10 women and 13 men, and 13 home-owners, and 10 home-renters. A 3-stage interview-diary-interview design was used; the interviews conducted at approximately 3 week intervals. The topic guide for the first interview was organised around 3 broad and overlapping sections; the impact of illness on daily life; techniques and resources used to combat illness, and the role of the GP consultation in overall management strategies. The second interview was an opportunity to follow-up themes, or points which had emerged at the first meeting, ask for elaboration of the diary, and explore in more detail issues around experience of the GP consultation. The diary was used as an *aide memoire*, and not analysed as a data source. The accounts were treated as situated narratives; analysis, interpretation and

discussion was informed by a narrative approach and the theory of Bourdieu was applied, using his concepts of *capital*, *field*, *habitus* and *symbolic violence*.

Both the frequent and less frequent consulters prioritised dilemmas around functional ability, reporting attempts to control illness, and resist loss of normal life and familiar selves. Despite our attempt to sample frequent and less frequent users with similar levels of morbidity in the more detailed qualitative interviews the frequent consulters conveyed more severe illness, which limited their lives and challenged their coherent and moral identities. In contrast, the less frequent consulters described less impact, and noted having more resources, and fewer tensions around using techniques to minimise the impact of illness, than the frequent consulters. Cultural, structural and social factors combined to influence health actions; personal troubles were linked to public matters. The accounts revealed how the severity of condition *combined with* social position influenced the place of the GP consultation in overall management strategies. Women and men communicated common problems, but also discussed experiences which were related to their traditional family roles. Housing status was not revealed as significant, in the context of a complex combination of micro and macro influences on experience. In the frequent consulters' accounts the role of the GP was magnified in lives diminished and disrupted by chronic illness, whereas the less frequent consulters' accounts presented a more peripheral role for their GP. Using Bourdieu's central concepts, the GP was conceptualised as a '*dispenser of capital*'. Throughout, all of the participants described the hard work of illness management, and they used the accounts to display their moral competence. The medical encounter was conveyed against a moral backdrop, and this may have had implications for frequency of consulting. Overall, the symbolic and physical burden of chronic illness was highlighted.

These findings have implications for policy and practice, relating to interlocking concepts of 'self-management' and 'concordance'. Whether management strategies are self or professionally led, they carry meaning well beyond the immediate management of physical experience. Self management plans that appreciate the need to maintain 'normal' life and coherent identities are likely to be most effective. Policies, which do not

recognise the hard work that people do, risk undermining rather than supporting individuals' attempts at living with chronic illness. This knowledge can contribute to a concordant relationship based on an understanding that people who experience chronic illness already undertake hard practical and moral work, and often prioritise the management of daily life and the maintenance of familiar moral identities, over and above condition control.

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This thesis is dedicated to 'absent friends': Dad, Jack Townsend (1922-2000); Mum, Bronwen Townsend (1919-2002); and Dave Spencer-Mills (1942-2003).

Declaration

I declare, except where acknowledged, all the work has been undertaken by myself.

Anne Frances Townsend

TABLE OF CONTENTS

Abstract.....	1
Chapter One.....	9
Introduction.....	9
1.1 Aim and structure of the thesis.....	13
Chapter Two.....	18
Literature review.....	18
2.1 Introduction.....	18
2.2 Deciding to consult a GP.....	19
2.2.1 Theoretical models of help-seeking.....	20
2.2.2 Theoretical models of help-seeking: illustrative research.....	23
2.3 Sociological understanding of illness behaviour.....	26
2.3.1 Lay perspectives of illness.....	29
2.3.1.1 Lay management of illness and self-care.....	35
2.3.1.2 The consultation: accounts and observations.....	37
2.3.2 The lived experience of chronic illness.....	42
2.3.2.1 The impact of chronic illness.....	44
2.3.2.2 Managing daily life with chronic illness.....	46
2.4 Illness narratives.....	54
2.5 Summary.....	62
Chapter Three.....	65
Methodology and methods.....	65
3.1 Introduction.....	65
3.2 My philosophical position.....	65
3.3 Interpretivist interviews.....	70
3.3.1 Interviews.....	71
3.3.2 Status of interview accounts.....	72
3.3.2.1 Validity.....	73
3.4 Reviewing the literature.....	78
3.5 Study design.....	80
3.6 Pilot study.....	81
3.7 The main study.....	84
3.7.1 Ethical issues.....	84
3.7.2 Sampling.....	85
3.7.3 Recruitment.....	87
3.7.4 Conducting the interviews.....	94
3.7.5 Diaries in the study.....	95
3.7.6 Post-diary interview.....	95
3.8 Data management.....	96
3.8.1 Collection and storage.....	97
3.8.2 Analysis of the data.....	97
Chapter Four.....	104
The impact of chronic illness: the importance of 'doing'.....	104
4.1 Introduction.....	104
4.2 The impact of chronic illness on daily life.....	104

4.2.1 Functional abilities: <i>'I can't do lots of things...'</i>	105
4.2.2 Talking about control: <i>'hit it on the button'</i> or <i>'like a cat chasing it's tale?'</i>	109
4.2.3 Accounting for change: 'normal' life or disruptive loss?	116
4.2.4 Summary	126
Chapter Five	130
Managing chronic illness	130
5.1 Living with chronic illness	130
5.2 Keeping busy: the importance of 'doing'	130
5.2.1 Paid work	135
5.2.2 Social contact.....	138
5.3. Illness and family life.....	144
5.3.1 Experiencing illness and gender in the family.....	145
5.4. Pacing.....	150
5.5 Alternative therapies and treatments.....	154
5.6 Equipment	158
5.7 Summary	161
Chapter Six	165
Medication matters	165
6.1 Introduction	165
6.2 Regimens and reasons	165
6.2.1 Regular regimen, conditions and 'survival'	166
6.2.2 Flexible regimen, symptom relief, and daily life.....	168
6.3 Tensions around <i>'pills and potions'</i>	175
6.4 The reliability of medication: <i>'keep taking the tablets'</i>	178
6.5 Sourcing the medication.....	182
6.6 Medication and the GP consultation	186
6.7 Moral discourse	189
6.8 Summary	194
Chapter Seven.....	198
Consulting the General Practitioner.....	198
7.1 Introduction	198
7.2 Reasons to consult the GP	198
7.2.1 The last resort	198
7.2.2 Self-treatment	202
7.2.3 Monitoring.....	205
7.2.3.1 GP-monitoring.....	205
7.2.3.2 Self-monitoring.....	206
7.3 Experience of GPs	211
7.3.1 My doctor: <i>'no keen'</i> or <i>'absolutely fabulous'?</i>	211
7.3.2 Being heard.....	213
7.4 The GP, symptoms, and daily life.....	218
7.4.1 The consultation and paid work.....	218
7.4.2 Reasons to consult	220
7.5 Summary	225
Chapter Eight.....	231
Discussion	231

8.1 Introduction	231
8.2 Summary of findings and previous research	232
8.2.1 Chapter Four :The impact of chronic illness	232
8.2.2 Chapter Five: Living with chronic illness	233
8.2.3 Chapter Six: Medication matters	236
8.2.4 Chapter Seven: Consulting the general practitioner.....	237
8.3 Theoretical framework.....	239
8.4 Constructing moral identities through illness narratives and the voice of the habitus..	244
8.4.1 <i>'You just have to grin and bear it'</i>	244
8.4.2 <i>'Illness comes second to your family, you'll know being a mother yourself'</i>	246
8.4.3 <i>'If I didnae have work what would I be?'</i>	249
8.5 <i>'I could sit and talk to my doctor...(he) gets it done':</i> The GP as dispenser of capital..	255
8.6 Policy and practice implications	259
8.7 Conclusions	266
Bibliography	269
Appendices	285
Appendix A Paper: Managing multiple morbidity in mid-life: a qualitative study....	285
Appendix B Analysis.....	290
Appendix C Topic guides	305
Appendix D Field notes.....	306
Appendix E Diary.....	308
Appendix F Diary table	312
Appendix G Letter and information sheet.	317
Appendix H Consent form.....	319
Appendix I Thumbnail sketches of participants.....	320
Appendix J Condition list.....	338
Tables	
Chapter Three	
Table 1	
Number of participants who fulfilled study criteria, numbers contacted and numbers	
Interviewed by consultation, gender and housing status	
.....	90
Table 2	
Characteristics of the participants	
.....	93

Chapter One

Introduction

This study emerged in the midst of widely-voiced concerns around inappropriate use of General Practice, in the context of an overburdened and under resourced National Health Service. Fundamental social developments, such as an ageing population, have seen a shift in the nature of illness from acute to chronic problems. In this context policymakers are stressing the need for a more efficient health service to meet on-going needs. There is also an increasing emphasis on 'self-care' encouraging people with chronic illness to draw on their own resources rather than those of the health service. Whilst there is considerable literature on how people use primary care in response to acute symptoms, and some on the lived experience of chronic illness, there is relatively little on how people live with multiple chronic illness, with an emphasis on the role of the general practitioner in overall management strategies. This thesis addresses these issues.

The research emanated from a series of analyses of survey data from the West of Scotland Twenty-07 study (Hunt et al., 1999; Hunt et al., 2000; Wyke et al., 2003). The Twenty-07 study is a longitudinal, community survey of the social patterning of health amongst three age cohorts, aged around 15, 35, and 55 when first studied in 1987/1988. Participants have completed comprehensive home-based structured interviews on three subsequent contacts in 1990/1991, 1995/1996 and 2000/2003. A wide range of measures of self reported health and health behaviour, of physical development and functioning, and of personal and social circumstances was collected. One analysis examined associations between frequent GP attendance (based on reported number of consultations in the last year in the surgery and at the respondent's home), overall burden of illness, socio-economic circumstances, and social support. This analysis was based on data from the 1995/1996 interviews with the two older cohorts, at that time aged in their early 40s and early 60s (Wyke et al., 2003).

In this quantitative analysis, frequent attendance was significantly associated with having a greater number of serious long term conditions (adjusted odds ratio 1.47, 99% confidence interval 1.09-1.98); higher levels of anxiety (adjusted OR 1.14, 99% CI 1.04-1.25); and lower levels of self-assessed health (adjusted OR 0.67, 99% CI 0.54-0.83).

In other analyses of the Twenty-07 data which examined the associations between a range of measures of ill-health, social circumstances and social support and the number of surgery visits in the previous year, 22% of the variation in surgery visits was attributable to 'burden of illness' (namely number of chronic illnesses, reported experience and severity of these illnesses, and self-assessed well-being) (Hunt et al., 2000). The additional inclusion of indicators of social position and social support together only accounted for an additional 6% of variation. This finding supports other studies that suggest that much of the social variation in consultation is mediated by social inequalities in morbidity. However, despite the wealth of quantitative data on both health and social circumstances that the Twenty-07 study includes, a substantial amount of variation in consulting rates was not attributable to variables included in the model and required an explanation. This suggested the need for further qualitative work, and it was decided that the Twenty-07 study offered an excellent opportunity to purposively sample people with similar (and high) levels of morbidity but contrasting consulting rates for more detailed investigation.

Chronic disease represents a huge burden of ill health world-wide (Cheah, 2001; Lewis & Dixon, 2004). In the United Kingdom it presents a large financial burden to the National Health Service, which has had to shift its focus from acute to chronic care (Von Korff et al., 2002). Discussions have highlighted problems of dual diagnosis. For example, Starfield notes that whilst complex illness combinations are common, and particularly problematic for primary care, little is known about the types of health service that are used by people with co-morbid conditions (Starfield, 2000; Starfield et al., 2003).

The World Health Organisation have also commented that policymakers need to change their priorities from acute care to chronic conditions (Epping-Jordan, 2001), and have

launched a project: 'Innovative Care for Chronic Conditions', which highlights the complex problems which require multi-dimensional solutions. They emphasise the need to look beyond medication and technical advances to solutions that attempt to sustain quality of life in the face of ongoing illness, and call for healthcare systems to move away from a model of *'find it and fix it'* (Epping-Jordan, 2001: 948).

Against this backdrop the Chief Medical Officer for England, Professor Liam Donaldson, has introduced the expert patient programme. Noting that, in England alone, almost 10 million people have a chronic disease, Donaldson observes such individuals provide a potential source of knowledge which could inform health care (Donaldson, 2003). The programme aims to promote a healthcare system which values the experiences of chronically ill patients, and provides a service in which patients are actively involved, and not just recipients of, health care (Shaw & Baker, 2004). Evidence in the United States reveals that such actively involved people make less and better use of formal health care (Shaw & Baker, 2004). These issues are explicitly linked to the UK population's use of the GP, and concerns around frequency of consulting. The government hopes that the expert patient innovation will increase skills, confidence, and motivation of patients allowing them greater control of their disease management (Moscrop, 2001), and that the findings around such innovations in the US will be replicated in the UK.

In support of these government hopes, there is some encouraging evidence in the research literature on self-care. McLaughlin & Zeeberg (1993) investigated self-care and multiple sclerosis. They observed that rather than formal care and self-care being mutually exclusive, they can be regarded as a combination of interconnected resources. They found that practising self-care facilitated independence; it not only relieved the symptoms, but the individuals also felt more in control over daily life. As Dean (1986) suggests 'lay' care should be seen as a crucial part of the health care system.

However, the research literature also details an alternative perspective on the associations between self-care and policy concerns. Sociologically informed, Dean (1986) underlines

the potential economic advantages of what she calls an efficient 'self-care system'. She claims that self-care may be promoted and embraced to reduce demand on formal services rather than for health-care-benefits and in order to enhance well-being. Furthermore, Dean notes the potential emergence of a 'victim blaming' culture whereby, because people are deemed responsible for their own health, the unhealthy can be regarded as culpable. She comments that individuals share neither the same knowledge nor the opportunities to self-manage, and social, cultural and political contingencies need to be examined in a detailed evaluation of self-care (Dean, 1986). Thus, although self-care potentially facilitates independence and empowerment, it has been criticised, as Bolaria notes:

'self-care... obscures the extent to which health and illness depend upon socially determined ways of life, obfuscates the social causes of diseases, shifts responsibility for health and illness back onto the individual, individualises what is essentially a social problem' (Segall & Goldstein, 1989: 160).

These interlinked issues (changing patterns of disease; a need to reconfigure health services to reflect these changes; concerns to enhance quality of life; and concerns over the demands on health care resources) form the social and policy context for this thesis.

On a more personal level, at the time that the opportunity to undertake doctoral studies arose I felt an interest and keen curiosity in how people manage and communicate their chronic illness experiences, whilst attempting to maintain a 'normal' life. This stemmed from my own biography. Over thirty years ago, one typical, lazy Sunday morning, as the familiar aroma of the roast dinner reached my teenage bedroom and into my sleepy consciousness, I heard the anxious voice of my father. My mother had collapsed, the doctor was already in the house, and his tentative diagnosis proved correct. My mother had had a severe stroke. The following day we were told it was 'a bleeder', and 'they' were waiting and hoping for the bleeding to stop. When it did not, 'they' operated as a last resort. As the days passed and we waited, we were afraid that my mother would die; and desperate for her to get better. But neither of these things happened, at least in any way that we could have foreseen. So, I became familiar with debilitating, frustrating, and

ongoing symptoms; uncertainty, anxiety, and fear; and a range of medical professionals, medications and treatments. Illness in all its complexity had swooped upon our normal family life, and was here to stay. What makes this experience special is, of course, that it is mine. But virtually everyone will be touched, to some extent, at some time in their lives, by chronic illness. Thus, this ‘uniquely universal’ experience is one of enduring interest and importance.

1.1 Aim and structure of the thesis

The aim of this thesis is to present an investigation into how people with multiple chronic illness, but contrasting consulting rates, manage their illnesses and make use of the general practitioner consultation in primary care.

I address this aim by examining three key research questions:

1. How do the participants experience the *impact* of multiple chronic illness in their daily lives, and what are the similarities and differences between people with contrasting consulting rates?
2. How do the participants perceive and use resources and strategies in their attempts to *manage* multiple chronic illness in daily life, and what are the similarities and differences between people with contrasting consulting rates?
3. How do the participants perceive and *use the GP consultation* in the context of living with multiple chronic illness, and what are the similarities and differences between people with contrasting consulting rates?

The literature review in **Chapter Two** sets the scene. It outlines dominant models of understanding help-seeking in response to illness, and refers to research on decision making, and consulting behaviour, largely linked to symptom responses. As a result of the shortcomings of this literature, I then shift focus to investigations on lay perceptions of illness, and aspects of the consultation. This work leads me to engage with the more

subjective and common sense view of illness and this forms the thrust of the review. I go on to draw on a number of studies about the experience of specific chronic illnesses, and then address the burgeoning literature on narrative analysis. The narrative turn aims to illuminate aspects of the chronic illness experience by capturing as far as possible an 'insider's view'. In the light of these associated but diverse strands of interest, this chapter illustrates that there is a need to combine such knowledge, and address the subjective experience and role of consulting in the context of managing multiple ongoing illness in daily life.

Chapter Three describes practical and theoretical aspects, and the overall design of the study. I set out my epistemological approach, and discuss the associated methods of data collection. I focus on the interviews as accounts of subjective experience which, through systematic and detailed analysis, offer the opportunity to gain insight into the life-worlds of the participants.

Twenty four participants, purposively sampled from the West of Scotland Twenty-07 study, were selected for interview, twenty three of whom took part in this study. They were selected on the basis of their level of illness and consulting patterns. Given that we knew from existing quantitative analyses that measures of the burden of ill-health were the most important predictors of GP contacts, our aim was to try and 'control' for morbidity by taking people with high levels of morbidity and then to examine variation in GP consultations. Thus, all the participants who took part in this qualitative study had reported high morbidity (4 or more chronic conditions) in the interviews in the 2000-3 sweep of the Twenty-07 study, but half of the participants were 'less frequent consulters' (3 or fewer consultations in the previous year) and half were 'frequent consulters' (7 or more consultations in the previous year). The definitions of frequent and less frequent consultation rates were constructed on the basis of analysis of consulting patterns. This purposive sample allowed an explicit comparison between the two groups, in order to explore influences on consulting behaviour in Primary Care. The sample were all aged around 50 years, and included a balance of males and females, and home owners and renters, to gain an indication of differing socio-economic circumstances. Twenty

participants were interviewed twice at approximately three week intervals and fifteen completed a two-week daily symptom diary as an 'aide memoire' for the second interview.

My analyses included thematic, framework and narrative approaches. Following Riessman (2003), my narrative stance is informed by both Goffman (1969) and Bourdieu (1984), to aid analytic and conceptual clarity. I included the content, context and the form of the accounts, exploring how the participants constructed themselves as moral agents throughout the interview process. I examined the accounts of the unfolding nature of chronic illness, encapsulating the micro and macro features of individuals' life worlds. This enabled an examination of what was spoken, but also how and why participants said what they did. All analyses systematically examined similarities and differences between the less frequent and frequent consulters. In the findings chapters, I have identified the major themes that emerged. To ensure rigour in my analysis I also identified deviant cases, referred to the key use of field-notes; and noted my reflexive approach in the research process.

Chapters Four to Six report the findings of the study. **Chapter Four** explores how the participants described the impact of multiple chronic illness in their daily lives. It addresses both the consequences, and the significance of, illness, namely concerns around *function; control; and loss*, in the context of an expressed desire to maintain normalcy. Whilst some of the participants conveyed minimal impact on their daily lives, others relayed a clear sense of disruption. A moral discourse infused the accounts; the participants were keen to construct themselves as morally competent individuals who faced their illness with a responsible and stoic resolve.

Chapter Five features how the participants discussed their illness management in an ongoing bid to contain symptoms. They described using a range of resources, and adopting a number of strategies, in a broader structural and cultural context, in their attempts to maintain a *normal* life. Some participants conveyed maintaining *normalisation*, others relayed *disruption*. But they all communicated reflexively

managing their morbidity with fortitude and care. As they spoke they continued to construct themselves in positive ways in the face of adversity.

Chapter Six examines the role of medication in the daily lives of the participants. This was not a specific point on the topic guide but emerged as a major theme in the analysis. Broadly, participants talked about medication in two main ways; they voiced an aversion to it, but a basic need for it. They indicated that medication was part of their overall management strategy, and detailed how drug use influenced their GP consultations. Medication was revealed as a crucial, but often unwelcome resource, thus, the analysis revealed complexities and ambivalences which were integral to the medication experience. This indicated an added burden to the overall experience of chronic illness.

Chapter Seven reports how the participants talked about when and why they made GP consultations. All of the participants talked about consulting as a *last resort*. Depending on their experience of *normalisation* of, or *disruption* in, daily life, participants located the GP on a continuum from virtually superfluous as an '*innocent bystander*', to an essential resource. The GP was used as far as he/she could contribute to the participants' ability to maintain a sense of normalcy, to stave off loss, and to help them sustain their ideas of themselves as morally competent. The participants who considered the GP to be essential highlighted her/his central role in offering treatment, advice, and emotional and practical support. Others indicated their doctor had a peripheral role, and explained how they felt she/he was unhelpful for a range of reasons; they reported negative aspects of the GP consultation regarding both medical and more emotional outcomes. For example, barriers to consult included perceptions that the GP would be no medical help, often combined with interactional problems. Often, these were described in terms of a disagreement about symptoms, diagnosis, and associated concerns around not 'being heard by', or 'attended to' by the GP. This brought into theoretical focus the role of the GP in building participants' moral integrity and sense of self.

Chapter Eight discusses the findings more fully in relation to the literature outlined in the review. This chapter extends the analytical points made in each of the findings

chapters, by using the work of Bourdieu, framed in a narrative approach to attempt a sociological understanding of the experience of chronic illness and consulting. This chapter also relates the findings to the policy context. Thus I attempt to relate my empirical findings to existing studies and sociological theory in a bid to develop understanding of how individuals with multiple chronic conditions experience illness and consulting, in daily life.

Chapter Two

Literature review

2.1 Introduction

This study aims to present an investigation into how people with multiple chronic illnesses, but contrasting consulting rates, manage their illness, and make use of the general practitioner consultation in primary care. In this chapter, I attempt to build a coherent narrative through a wide ranging literature review on help-seeking, illness behaviour and the experience of chronic illness.

I will initially identify the theoretical models that have been used to understand health care use. This provides a context for some of the research cited and illustrates the complexities of this area of study. It reveals a need for more in-depth accounts of how individuals experience, perceive and manage illness, and how they use formal health care in their daily lives. This guides me towards literature which resonates more closely with my study; sociological work on illness behaviour. I outline Parsons' conceptualisation of the 'sick role' rooted in structural-functionalism, and the positivist perspective, before engaging with the interpretivist approach; outlining studies on lay experiences of illness, including the doctor/patient relationship. I then detail research about the lived experience of chronic illness, addressing the literature on particular conditions and associated problems, before discussing common dilemmas which have been identified as permeating the chronic illness experience in daily life. This combines theoretical and empirical work, and reveals concepts fundamental to the chronic illness experience, such as 'biographical disruption' and 'narrative re-construction'. This draws me to the burgeoning literature on illness narratives, where the analytic lens focuses on: the temporal; the episodic; and, at its core, action which has a moral purpose. It also allows for an examination of accounts of the unfolding, complex experience of chronic illness anchored in daily life as well as broader cultural and structural contexts.

A theme which emerges from this review is what motivates individuals to take particular action when they do, in the context of their cultural, social and personal biographies. Thus the approach to the extensive and wide-ranging literature I have taken is not systematic in that I have not searched for all literature around a particular question, and carried out an exhaustive review. Instead my reading and my on-going fieldwork and analysis led me to different literatures in a way that I hope is illuminating and illustrative of the main issues examined in this thesis.

2.2 Deciding to consult a GP

Decisions around whether or not to consult a general practitioner are practically, emotionally, and morally contingent. There is a shared assumption, amongst professionals and the general population alike, that 'ideally' individuals astutely assess whether sensations or feelings are worthy of professional advice. However, research around consultation often demonstrates high levels of disagreement between lay and professional opinion on 'appropriate' presentation (Atkinson, 1977). Many serious illnesses remain untreated, whilst reportedly many consultations are for 'trivial' complaints. If individuals consult 'too soon' they risk being seen as inappropriate users of scarce resources; if they delay they may be regarded as irresponsible, inviting illness escalation and the need to draw further on an over-burdened health service. The dominant discourse commonly features patient 'over utilisation' of services with the emphasis on the patient wasting the doctor's time with minor conditions and inappropriate consulting (Rogers et al., 1999; Galvin, 2002) although there has been concern about under utilisation of use by certain groups (DH, 1996)

It is well documented that those who seek care only represent the tip of the iceberg (Kooiker, 1995). Illness in the community does not simply indicate a need for Primary Care use, and general practitioner consultation, as Campbell and Roland observe:

'...the universal experience of symptoms of illness does not translate automatically into demand for care. Only a small proportion of symptoms which people experience are presented to the general practitioner. The large number of symptoms

dealt with, without medical care has been termed "the illness iceberg" or the "symptom iceberg" (Campbell & Roland, 1996: 75).

As far back as the 1950s, evidence revealed that a considerable amount of morbidity is unreported, and that clear differences in consulting exist between social groups (Calnan, 1987; Dunnell & Cartwright, 1972; Koos, 1954; Suchman, 1964; Zborowski, 1952). More recently, research reveals delays in seeking professional help for specific conditions (Clark, 2001; Dracup et al., 1995; Pattenden et al., 2002). As this chapter will illustrate, explanations of consulting behaviour are embedded in the overall illness experience of individuals, informed by both the context of their daily lives, and the broader structural order, and so combine micro and macro factors.

In order to both contextualise the research around consulting behaviour, and organise this section, I draw heavily on the review by Rogers and colleagues in their examination of the use of Primary Care (1999). In so doing, I briefly outline the commonly cited theoretical models used to aid understanding of help seeking in illness and I identify studies which have been informed by these models. Such research reveals a number of factors, and associations between variables, which go some way to explain decisions to seek formal health care.

2.2.1 Theoretical models of help-seeking

A range of theoretical models rooted in specific disciplines have been formulated in an attempt to understand decision-making in health care. Three core models of health care utilisation which are prevalent in the literature are: the Health Belief Model; 'Rational Choice Theory'; and Socio-Behavioural Models. These are ideal types; there has been a blurring of boundaries and degrees of adaptation and flexibility when the models are used in health research (Rogers et al., 1999).

The psychologically based Health Belief Model (Rosenstock, 1966) informs understanding of people's disease preventive behaviour, including use of health services.

The model assumes goal driven action, and has four core components: perceived susceptibility; perceived severity; perceived benefits; and perceived barriers (Radley, 1994). Studies informed by this model include: decisions to consult for monitoring health (Norman, 1993; Orbell & Sheeran, 1993; Sheeran & Orbell, 2000), exploration of preventive health behaviour (Langlie, 1977) and delay in help-seeking (Dracup et al., 1995). Campbell and Roland (1996) applied the model to patients' use of primary care, and concluded that a number of interconnecting physical, psychological and social factors informed help-seeking behaviour. Although useful in identifying the complexities involved in such decision making, research based on this model has been criticised for neglecting the active agent, the lay person's perspective and the social settings in which people live (Blaxter, 2004), and failing to engage fully with structural constraints on individuals (Rogers et al., 1999).

Rational Choice Theory is rooted in health economics. From this perspective, people take purposive action based on informed and rational decisions (Becker, 1992; Coleman, 1986; Frank, 1992). For example, Coleman (1986) claims that people logically consider the advantages and disadvantages of help-seeking as they decide whether or not to contact health professionals. However, like the Health Belief Model, it neglects the subjective experience of illness in daily life. For instance, symptoms may be masked and health professionals avoided in order to fulfil social obligations such as paid employment (Rogers et al., 1999: 66). Moreover, action is not exclusively reasoned. Nee, citing Scheff's work observes: *'emotions are a virtual wellspring of social action'* (Nee, 1994:1088). More specifically, Pescosolido has criticised the application of rational choice theories to health related settings, noting:

'In sum, even when norms, networks, and situations are brought in as additional items on the individual's checklist, social forces remain either restricted to those perceived or acknowledged by the individual or to an enumeration of additional constraints...The critical dynamic relationship among individuals and their networks and the larger structures that form from and shape them are downplayed, even dismissed' (Pescosolido, 1992: 1102).

In a subsequent article based on research into how people gain access to mental health services, Pescosolido and colleagues (1998) illustrate how some help-seeking can be a question of 'muddling through', rather than rational decision making. This reflects the central shortcoming of Rational Choice Theory; it fails to engage with the meanings people apply to their situations in daily life.

In the late 1960s, as a result of an investigation into health care use, Anderson (1995) developed the Socio-Behavioural Model. The model rests on three essential features: predisposing characteristics (which include demographic and social structural factors as well as health beliefs); enabling resources (identified as the family and the community); and the individual's perceived need for care. Over time, Anderson (1995) has revised the model by incorporating more variables, including organisational aspects of the health services. Underpinning investigations into help-seeking, this model moves beyond the individual's perception of symptoms to include more structural factors. However, it fails to explore the lay person's perspective and for example, does not address delayed help-seeking, or active self-care (Kelner & Wellman, 1997).

These models have also been criticised for their focus on a point in time; the decision to consult. Others have argued for a less variable driven model of understanding, and a need to engage with a multi-faceted, complex decision-making *process* (Calnan, 1987; Dingwall, 1976; Freidson, 1970; McKinley, 1972). Social networks have also been the focus of attention in attempting to understand the complexities of help-seeking (Berkman et al., 2000; Bloom et al., 2001; Bott, 1957; Bury, 2001; Cattell, 2001; Charmaz, 2004; Cockerham, 1995; Trotter, 2000; Young, 2004). In response to the limitations of such theoretical models, Rogers and colleagues suggest a more 'social process' approach to health care use. This attends to the:

'interaction of the patient with others, and views motivation and determinants of decision making as subject to the influence of a wide range of factors often beyond an individual's control'
(Rogers et al., 1999: 69).

Unlike the core theoretical models outlined above, this position emphasises the role of social networks and social interaction as influencing the help-seeking process. Ultimately, responses to illness are seen as socially contingent. With this in mind it aims to highlight diversity in the individual's experience, by allowing for a range of social situations. Although useful, this approach still fails to offer a detailed understanding of how people make sense of chronic symptoms in the context of their daily lives, constrained by structural and cultural factors, which combine to influence the perception, availability and use of formal health services.

The three core theoretical models outlined above have drawn on a range of phenomena but have neglected, to varying degrees, subjective experiences of individuals who negotiate and interpret meanings in daily life. Further, they focus on attempts to understand responses to new symptoms, which may, or may not develop into ongoing illnesses, rather than investigate the chronic illness experience. Before addressing a range of sociological literature on illness behaviour and experience, I will refer to research and reviews which have been published in more medically based arenas, much of which is informed by the above frameworks. This evidence illustrates the usefulness of such models, and links concerns around consulting behaviour to frequency, specific symptoms and illnesses, as well as demographic factors. It also reveals a need for a more subjective approach to explore the complexities which such research identifies, but cannot explain.

2.2.2 Theoretical models of help-seeking: illustrative research

In this section I will outline research which examines the utilisation of health services, particularly patterns of general practice use, with an emphasis on pathways to the general practitioner and inequitable uptake. This evidence identifies the notion of the 'frequent consulter' in the context of an over burdened and under resourced National Health Service, whilst demonstrating that these concerns are not limited to the United Kingdom. It reveals the complex process which leads to consultation, and includes research investigating socio-economic and demographic factors including gender; specific illnesses; and types of health services.

The *social patterning* of consulting in the population has been well documented. For example, Campbell and Roland (1996) conducted a literature review of why people consult the doctor. Informed by the Health Belief Model, they investigated the impact of demographic and socio-economic factors on help-seeking. They found that a combination of physical, psychological and social factors impacted on decisions to consult a general practitioner. These included: severity of, and beliefs about, the illness; the course of the illness; the efficacy of self-care; the perceived benefits/costs of care; access to social support and lay networks; and the availability of formal health care. Overall, they concluded that the combination of high morbidity and social disadvantage increased both objective medical need and in turn, consultation rates.

Research in medically related journals has amply documented the phenomenon of the *frequent consulter* (Heywood et al., 1998; Schrire, 1986; Karlsson et al., 1994). It is well recognised that a relatively small proportion of the population account for a large measure of general practitioner consultation time. Such frequent attendance is known to be associated with social characteristics, such as class, ethnicity and gender but importantly, these social structural patterns are largely explained by the burden of ill health (Scaife et al., 2000; Wyke et al., 2003). That is, individuals who are disadvantaged socially have poorer health status than other groups, so have a greater need for health care. Campbell and Roland (1996) reviewed the literature which explores some of the pathways to care and factors associated with low and high rates of consultation. Overall, they concluded that frequent attenders had higher levels of illness, and did not have a higher propensity to consult. Reid and colleagues studied high users of physician services in British Columbia, and also found that they had a high proportion of complex and multiple health needs (Reid et al., 2003).

Other evidence supports these findings (Baez et al., 1998; Jiwa, 2000; Morris et al., 1992; Vedsted et al., 2004; Vedsted & Olesen, 1999). Ward and colleagues (1994) observed that long term high attenders suffered from chronic illness and typically, those who rarely or never consult their general practitioners appear to be healthy. Gill and Sharpe (1999) conducted a systematic review of the literature on frequent consulters. They concluded that such patients had high rates of chronic disease, psychiatric illness

and social difficulties and were likely to suffer from multiple and complex problems. The overwhelming feature of such evidence is the multi-dimensional nature of the health needs of frequent attenders, who suffer from a disproportionate level of illness alongside other social problems. These studies demonstrate a range of interconnecting factors inform decisions to consult general practitioners, and shed light on the complex consultation process. They reveal a need for more detailed investigations, warranting more qualitative exploration, which this thesis undertakes.

Research that has matched particular *types of ill health and consultation patterns* has indicated the need for further investigations (Cornford, 1998; Ridsdale et al., 1994; Ronalds et al., 2002). For example, Andersson and colleagues (1999) addressed the impact of chronic pain on health care seeking and focused on both individual and social factors. They found that chronic pain leads to high levels of general practice utilisation, but ethnicity, age, socio-economic group and depressive feelings were all also associated with decisions to consult.

Kelner and Wellman (1997) used Anderson's Socio-Behavioural Model to explore consumer choice of medical and alternative therapies. They found that interconnecting factors such as age and education, knowledge of, and access to services, and need for care impacted on decisions to seek help. Those with intrusive chronic complaints, who had found traditional medicine wanting, turned to alternative treatments and practitioners. They described people actively selecting particular treatments for specific complaints depending on the anticipated outcome. However, enabling resources such as money, and pre-disposing factors such as education, played a part. Individuals did not choose one type of care *per se*, but whatever suited their needs at any given time. Kelner and Wellman concluded that a range of factors informed the decision to consult, and reasons for using alternative health care could not be explained either by people totally rejecting traditional medicine, or by a reliance on alternative therapies and associated philosophies.

Considerable research has explored consulting in relation to *gender*. Commonly, studies on morbidity have observed that women have higher consulting rates than men (Gijbbers

van Wijk et al., 1999; Verhaak, 1995). However, some evidence suggests this is a somewhat simplistic picture. Verbrugge (1985) found that men and women responded in the same ways once symptoms are experienced and recognised. Wyke and colleagues (1998) found that men and women responded in similar ways to symptoms, whilst Hunt et al., (1999) found that women were more likely to consult for psychological problems, but there was no difference between men and women in levels of consulting in the five most common physical conditions, once the presence and severity of the condition had been taken into account. Overall, the wealth of empirical evidence on gendered patterning of consulting behaviour demonstrates a complex process which affords more detailed exploration.

The theoretical models and the empirical work referred to above are based on what Dingwall (1976) terms an 'outsider' view of the decision-making process, identifying variables, predictors and determinants of consulting behaviour. The 'social process' approach proposed by Rogers and colleagues (1999) moves away from this pattern based explanation of behaviour, and goes some way to offer a more detailed investigation of help-seeking, but does not engage with the complexities of the experience of chronic illness in daily life. I now trace the sociological literature which focuses on behaviours and actions which people undertake as they attempt to manage their illness. Although, as Blaxter has commented, 'illness behaviour' is *'a somewhat outmoded term for this area of sociology'* (Blaxter, 2004: 71), it moves towards the 'insider view' of the lay perspective, and the experience of illness.

2.3 Sociological understanding of illness behaviour

The sociological study of illness behaviour is commonly linked to Talcott Parsons' conceptualisation of the 'sick role' in which he formulated an 'ideal' type patient. Firstly, he defined illness as a *'state of disturbance in the "normal" functioning of the total human individual'* (Parsons, 1967: 431). He then detailed the ways in which individual illness behaviours are guided by the norms and values of the social system and shared assumptions about appropriate behaviour. He identified four aspects of the sick role: first, individuals are released from social obligations; second, people cannot be expected to get

well by "pulling themselves together"; third, there is an assumption that people want to "get well" as soon as possible, and finally:

'...the fourth closely related element is the obligation - in proportion to the severity of the condition, of course - to seek technically competent help, in the most usual case, that of a physician and to cooperate with him in the process of trying to get well' (Parsons 1967: 437, emphasis in the original).

The moral aspect of the 'sick role' is clear. Parsons identified being 'sick' as a deviant condition, hence, individuals are galvanised into appropriate action to return to 'normal', fulfil their roles and 're-enter society'. This typically involves consulting a health professional and adhering to their advice.

A general flaw of Parsons' theory is that it is based on an over socialised view of individuals, assuming a passive patient who complies with an authoritative doctor (Hahn, 2001); and it involves "surrendering oneself to the care of a physician" (Frank, 1995: 5). Further, its cultural bias has been criticised (Frank, 1995; Cockerham, 1995), along with its neglect of chronic illness (Annandale, 1998), and the concept of self care (Young, 2004). Going some way to answer his earlier critics Parsons reconsidered the 'sick role', and accounted for chronic illness, prioritising the active role of the sick person in self-care:

'This topic of the sick person's active participation shades over into another very important one. This concerns the fact that lay people, as a consequence of their education and experience, have a certain amount of knowledge and understanding in matters of illness. At the very minimum, this should concern decisions about when professional help is indicated and when it can safely be dispensed with. Of course the matter of the concern is not only with the decision maker's own state of health or illness but of others close to him, in particular, members of his family. There is a considerable range of situations in which self-care or non-professional care in the household is not only undertaken but not infrequently proves to be adequate' (Parsons, 1975: 271).

So, Parsons builds into his theory of the sick role, the notion of an active moral agent, whose experience and social situation informs his or her actions of self care, and decisions about seeking professional help. However, what Parsons fails to address is how people from a range of social groups interpret symptoms in the context of daily life. He also fails to account for *levels* of bodily dysfunction and incapacity, which impact on individuals' abilities to perform roles to varying degrees (Robinson, 1971). Finally, the sick role by definition is socially constructed, and various people (friends, work colleagues, and particularly family members), are free to offer a range of interpretations of the situation, validating, or not, illness-status claims.

Koos' (1954) research extended sociological knowledge of how people act when they are sick. His work demonstrated cultural influences on health care use, for example, that upper-class persons were more likely than lower-class persons to view themselves as ill. Further, when they had particular symptoms, they would be more likely to consult the doctor. Mechanic and Volkart, informed by both theoretical concerns (Parsons' sick role theory) and empirical evidence, such as Koos' study, coined the phrase 'illness behaviour' in 1960 to:

'...refer to the ways in which given symptoms may be differentially perceived, evaluated, and acted (or not acted upon) by different kinds of persons. Whether by reason of education, religion, class membership, occupational status, or whatever, some persons will make light of symptoms, shrug them off, and avoid seeking medical care; others will respond to the slightest twinges of pain or discomfort by quickly seeking such medical care as available' (Mechanic & Volkart, 1960: 87).

Similarly, Zborowski (1952) observed differences in reactions to pain between ethnic groups. Jewish and Italian patients exhibited emotional responses to pain, whilst "Old Americans" tended to be more stoical. Investigations into cultural and social responses to symptoms developed further in the 1960s. For example, Suchman (1964) explained the relatively low level of service use by disadvantaged and minority groups, as a result of social organisation. He claimed that cultural beliefs, and peripheral social position,

combined to form a socially cohesive group, and members were unlikely to utilise mainstream health resources. Zola's (1966) analysis focused on how responses to symptoms differed between ethnic groups in Boston. He listed 'triggers' which prompted action, and linked them to ethnicity and educational achievement. For instance, he found that alongside symptoms, the occurrence of an interpersonal crisis, or perceived interference with social or personal relations were commonly associated with consulting in Italians. In contrast, the sanctioning of the sufferer's condition by others was most likely to drive those of Irish ethnicity to action.

Dingwall (1976) has aimed fundamental criticisms at this research. He claims that it fails to allow for the active agent, but instead, portrays behaviour as a passive response to external forces. He cites Freidson's (1960) work on the importance of social networks and help-seeking as another example, commenting that the 'actors' '*become reduced to cultural dopes*' (Dingwall, 1976: 42). Rather, Dingwall views illness behaviour and help-seeking as an active social process and stresses the need to understand the interpretive aspects of behaviour, and the meaning of action. Others agree, and have pointed out that an 'insider approach' to illness behaviour provides a more fertile framework on which to base investigations (Calnan, 1987). Conrad (1990) for instance, has noted how 'outsider' approaches enshrined within the concept of 'illness behaviour' have extended the knowledge base of medical sociology, but they fall short of tackling how illness is experienced and managed.

2.3.1 Lay perspectives of illness

In the 1970s and 1980s, the sociological focus on illness shifted from an 'outsider' view to an 'insider' approach. Lay perceptions were increasingly studied in an attempt to understand how individuals made sense of symptoms in the context of their daily lives prior to, or rather than, seeking medical care. As concerns about chronic illness gained resonance, and the critique of *medicalization* gained force (Illich, 1988; Strong, 1979; Turner, 1987) a heightened interest in the patient's perspective emerged (Herzlich, 1973; Kleinman, 1988; Sacks, 1987; West, 1976). The voice of science-based medicine could

no longer claim the monopoly on knowledge, and the experience of illness in the context of daily life was prioritised (Blaxter, 2004; Dingwall, 1976; Fabrega, 1974; Robinson, 1971).

This area of knowledge is based in the interpretivist paradigm, which is concerned with how people perceive and interpret their surroundings and take action based on their common-sense understandings of a shared world. Individual accounts are given credence, in attempts to gain insight into how people apply meaning in their everyday lives, and make sense of the social world. Here I outline research which has prioritised lay accounts in order to investigate how individuals make sense of illness in the context of their daily lives, and how this relates to action that they may (or may not) take.

Dingwall was an early analyst who developed an understanding of illness as *'based on the practical circumstances of everyday social life'* (1976: 61). Fundamental to this approach is the concept of 'normalisation'; this involves the individual interpreting feelings as 'normal', as well as being able to undertake everyday activities. Importantly, following Parsons, Dingwall claimed attaining 'normalisation' is a social process, reaching beyond personal boundaries, to the interpretations, and assessments of others. Dingwall added that when people are able to explain illness by drawing on common sense beliefs, they are less likely to contact health services. The notion that people tend to consult professionals when symptoms cannot be explained is illustrated by studies of 'common sense' theories about the causation of illness (Blaxter, 1983; Blaxter, 2004; Cornwell, 1984; Fitzpatrick et al., 1984; Helman, 1984; Herzlich, 1973; Radley, 1994; Robinson, 1971).

A major strand to emerge in medical sociology was how individuals perceived illness in the context of their 'normal' lives (Calnan, 1987; Herzlich, 1973; Radley & Green, 1987; Williams, 1990). Herzlich's work has been particularly influential. Her respondents conceived of illness as inactivity. She states:

'It is the notion of inactivity which defines most frequently and, most "primitively" the fact of illness. Illness is first and

foremost the condition which obliges the patient to interrupt his normal activity' (Herzlich, 1973: 85).

Herzlich echoes Parsons in elaborating that illness is everything which makes people incapable of carrying on life normally. However, she extended her analysis to examine how individuals discussed their responses to illness, identifying three metaphors to describe such talk:

- *illness as destructive*: involving loss, isolation and incapacity. Herzlich discusses how this sense of loss is due to an inability to function in social roles in, for example, the family and employment. She observed that inactivity was intolerable. The fact that others could function when those with illness could not, made the suffering more acute. She identifies how respondents described a loss of 'social qualities', a loss of energy, a loss of integrity, a loss of self, and of 'life'. Thus, the maintenance of activity was prioritised to stave off such fundamental losses. She adds that in this way, the physical condition, social participation, and the 'self' can be saved when self-concept and identity is threatened. When this is not possible, the individual relapses into passivity and his or her identity cannot be restored.
- *illness as liberator*: a lessening of burdens and a rest from social obligations.
- *illness as occupation*: freedom from responsibility except to fight the disease. Herzlich stresses the need to fight illness and maintain a positive attitude in the face of adversity. Her respondents described the amount of work and determination involved in managing their physical self in their attempts to sustain a 'normal' life, and resist loss.

Herzlich adds that none of the respondents who were ill at the time of the study saw illness as liberating, rather they tended to see it as occupation, and some saw it as destructive. This mirrors Parsons' view of the sick role, in that the person who is ill feels a need to do what they can to ward off the illness, and avoid its consequences. This is particularly relevant for the purposes of this thesis, as the participants have ongoing

illnesses, and thus, according to this model may be more likely to refer to illness in *destructive* terms or as *occupation*. Herzlich makes a fundamental point when she notes how the conceptions of illness have a common thread, the relations of the individual to society. For example, illness as destroyer strips the ill person of status, whilst illness as occupation guarantees him/her status integration; in both cases a sense of identity is integral to the illness experience. Herzlich's respondents described the need to 'fight' the disease, in attempts to avoid a loss of 'self' and of 'normal' life. In attempting to understand how people interpret their illness, Herzlich revealed that the impact of illness extends beyond the consequences of the physical incapacities, to the *significance* of those consequences to individuals.

Equally pertinent to this thesis is Williams' study of older people in Scotland. Williams noted how his findings converged with Herzlich. Ways of coping with illness were conceptualised as: a loss to be endured; to be controlled by normal living; and as a continuous struggle. Williams describes this inability to maintain a 'normal' life as:

'the estrangement from oneself and from normal living which is the other side of the coin from the (Aberdonian) emphasis on moral control over health. In this view the possibility of self-estrangement is recognised from the start, and between controllable and uncontrollable conditions there is a catastrophic turning point when the claim to be normal can no longer be felt to hold' (Williams, 1990: 44).

These studies demonstrate similar concerns; inactivity and loss are inextricably linked and are pivotal to the illness experience. Furthermore, illness is commonly voiced as something to be endured, to be struggled against, and to be controlled. Other research has reiterated these concerns (Blaxter & Paterson, 1982; Calnan, 1987; Cornwell, 1984; Pollock, 1993; Radley, 1993; Williams G, 1993).

In the same vein, Locker (1981) explores how individuals perceive illness, and make sense of symptoms. He set out to examine how people construct definitions of illness based on their common sense knowledge of illness *per se*, and shared assumptions about appropriate behaviour when ill. Fundamentally, he was interested in how people

interpreted, and acted to bring order to, problematic experiences that disturb 'normality'. He identifies such disturbances as noticeable changes in the body or social function. He describes cues to identifying such disruptions as: symptomological; behavioural; and communicative. These involve changes in physical or psychological states; observed changes to one's normal activity; and claims made about symptoms or behaviour. He points out that when symptoms cannot be contained, ongoing monitoring and interpretation takes place. However, only when such symptoms are ongoing, is something perceived to be wrong. He states: '*It is the departure from the normal which signifies illness*' (Locker, 1981: 57).

Locker notes how the ability to construct causal explanations is important in assessing what action to take and when to take it, particularly when deciding to consult a general practitioner. For example, some disorders are seen to be the consequence of life stages. He also refers to aspects of severity and significance of the symptom in terms of its consequences and context, and invoking Zola's 'temporalizing symptomatology', says if something gets 'worse' one may be inclined to consult a doctor. Similarly, the way in which a disorder affects functioning is to be read as an indicator of its severity.

Locker describes how the respondents in his study referred to particular behaviours such as going to the doctor, lying down, or being released from social obligations, as rational, common sense responses to illness, and thus the speakers could be seen as morally competent individuals. The accounts included occasions when a refusal to see the doctor was acceptable, but always justified. For example, not wishing to 'bother' the GP was a reason given for not consulting. Role obligations, such as child-care or paid employment, were also noted as reasons not to seek health-care. That these are regarded as appropriate explanations for the failure to display illness-relevant behaviours requires that common sense knowledge of roles and social obligations is used to recognise limitations on behaviour in particular contexts. The need to fulfil roles in the family, for example, swamps the requirement of particular actions. This illustrates the moral superiority of the individual who places obligation above self-interest. There are clear similarities between Locker's findings and Parsons' formulation of the sick role. Accounts of action when ill

are directly related to shared assumptions about appropriate behaviour; the motivation to get well, and the legitimacy of the consultation are morally imbued.

Locker's respondents said they would visit their doctor if symptoms were serious or ongoing, or for critical incidents. Alternatives to seeing the doctor included strategies which had been successful in the past, or doing nothing, because 'nothing could be done'. Locker's work is particularly helpful to my analysis. It tackles how people make sense of symptoms, and account for actions, in the course of their daily lives, and emphasises that decisions to act are also constrained by broader cultural and structural factors, which inform common-sense notions of appropriate behaviour.

Similarly, Blaxter and Paterson explored lay meanings of symptoms and linked them to consulting behaviour (Blaxter, 1985; Blaxter & Paterson, 1982). They observed how women interpreted and conceptualised illness in their daily lives, and identified how past experiences, expectations, networks, attitudes to professionals, and life circumstances all combined to influence the dynamic and complex decision making process. Cornwell (1984) also focused on common-sense ideas and theories about health, illness and health services in the context of daily life. In her analysis, she identified 'private' accounts, which involved talk around moral issues and identity whereas the more 'public accounts' drew on a formal type discourse of health management. The 'private accounts' in particular identified the influence of work and the family on decision-making. Cornwell identified the duty to keep working and not 'give in' to illness as a key concept of working class culture.

Robinson too, in his study of families and illness in South Wales, demonstrated how decisions to consult involved interpreting symptoms in the context of daily life. For example, he notes:

'Analysis is based on the meaning of illness situations for the actors involved and the choices, which they make in the light of their conception of, and evaluation of, certain dangers. It is assumed that individuals act in a way designed to maximise

their gains and minimise their costs, as they define them'
(Robinson, 1971: 21).

This is clearly informed by the Health Belief Models and Rational Choice Theories. However, the analysis attempts to capture the subjective view of the respondents. Robinson identifies uncertainty, ongoing and severe symptoms as well as abnormality of functioning as reasons given to consult. He also illustrates the importance of context in the decision-making process. For example, one respondent described how despite a knee injury, he refrained from consulting his GP as he was due to play in a football match.

2.3.1.1 Lay management of illness and self-care

The literature on self-care forms a part of lay knowledge, experience, and management of chronic illness. As the basic type of health care in society (Dean, 1981), self-care features in the lives of the general population, and is addressed in health professional and academic discussion (Dean, 1989) as well as policy development (DH, 2005). Although what constitutes self-care has no unified definition, for the purposes of this thesis it is sufficient to note that it is diverse, centres on a notion of the active individual, and impacts on the organisation of health care services, and utilisation of formal care by the public (Dean, 1986). It includes self treatment, such as taking medicines, and self management, for instance monitoring and management of symptoms, as well as balancing daily life alongside actions which reduce health problems, and promote wellbeing (Kelleher, 1988).

The ways in which professional and lay worlds interact inform decisions on the nature and extent of self-care, and the utilisation of health services. Thus, self-care actions are multi-dimensional, and complex, and reach beyond the perceived seriousness of symptoms in daily life (Kelner & Wellman, 1997). For instance, confidence in the Health Services, and the extent to which the patient can discuss medical and health conditions with their doctor are seen as having a crucial impact on patient satisfaction and ultimately on health service use (Bentzen et al., 1989). Lack of confidence in doctors, combined with the interpretation of symptoms, have been strongly associated with the inclination to

self-care, and propensity to consult (Segall & Goldstein, 1989).

Reflecting the general work on lay perspectives of illness, the literature on self-care emphasises the individual's interpretation of, and response to, symptoms in the hope of gaining insight into this aspect of a range of chronic illnesses (Segall, 1990; Segall & Goldstein, 1989; Stoller, 1988). Campbell and colleagues (2003) reviewed qualitative research on lay experiences of diabetes and diabetes care, and found that people worked with medical professionals to self-care with varying degrees of success. Overall, they found that those who were able to manage their diabetes accepted the seriousness of the condition, whilst maintaining an overall sense of well-being. Importantly, they could make decisions confidently, based on their experience, and non-judgemental support from professional health care workers:

'being able to attain a balanced life with diabetes was found to be strongly associated with an approach to the self-management of diabetes characterised as 'strategic non-compliance', involving the monitoring and observation of symptoms and an ability to manipulate dietary and medication regimens in order to live life as fully as possible, rather than limiting social and work activities in order to adhere to medical advice' (Campbell et al., 2003: 681).

This reinforces the notion that the maintenance of 'normal' life is a central concern, and self-care practices need to interweave daily routine with practical medical advice and medicine regimens. An important observation made by Campbell and colleagues is how people actively make decisions as they balance daily life and diabetes which do not always correspond with professional advice. This has implications for the efficacy of formal care plans and the lay-professional relationship. Other research supports these findings. For instance, Stevenson and colleagues (2003) found that patients do not always feel at ease sharing information about self-treatment with health professionals.

Bayliss and colleagues (2003) report how people with co-morbidity face particular problems. For instance, complex drug regimens may induce anxiety and complications,

and self-care strategies may clash (taking more exercise may impact on another condition such as asthma). Moreover, attempts to change aspects of one's lifestyle for one condition may be impeded by symptoms of another. Research such as this underlines the need for an intersecting of medical knowledge and lay experience in health care, and there is evidence to show that such a relationship is developing.

Policy and practice concerns feature attempts to engage with such dilemmas. Research on self-care in the United States has focused on the efficacy of self-management programs for people with chronic illness, including co-morbid conditions (Lorig et al. 1999; Lorig et al. 2001), and has informed policy in the United Kingdom which reports the need to address the life needs of the individual with practical interventions, and combine formal and informal care, knowledge, and experience (The Expert Patient, 2000; Self Care - A Real Choice, 2005). Barlow and colleagues (2003) report on interventions for people with chronic conditions in primary care and discuss volunteer lay-tutors' experiences of a chronic disease self-management course (Barlow et al., 2005).

The nature of the lay-professional relationship has been well-documented, and I now turn to some key issues which have emerged from the extensive literature around the general practitioner consultation in particular.

2.3.1.2 The consultation: accounts and observations

Previous research has generated both interview data on the patient/practitioner consultation as well as observations of the medical encounter. These different methods have revealed some discrepancies between what people report, and what happens in practice (Stimson & Webb, 1975). Case studies based on mixed-methods go some way to providing a solution (Stevenson et al., 2000). I will outline some relevant themes of these literatures below.

Mirroring concerns around illness behaviour, the 1970s and 1980's saw theoretical questions on the medical consultation shift focus from the doctor's viewpoint to the lay

perspective (Armstrong, 1983; Strong, 1977, 1979; West, 1976). Patients' reports of help-seeking revealed both barriers and prompts to consulting (Stimson & Webb, 1975; Tuckett, 1977).

Patients' accounts of their consulting experiences contributed to the knowledge on help-seeking behaviour. Locker's respondents reported how the anticipated outcome of contact, such as gaining a diagnosis, a referral, advice, or a prescription, impacted on decisions to consult. For example, one respondent reported that a perceived lack of available treatment was a barrier to consulting a GP, and commented: *'They can't do much'* (Locker, 1981: 26).

Research also identified problems with acquiring relevant information (Locker, 1981; Blaxter & Paterson, 1982, West, 1979; 1990). In his study of colitis, Kelly (1992) noted how respondents, despite having access to a range of health workers, reported difficulties in gaining basic knowledge about stoma care. Pinder (1990) interviewed people with Parkinson's disease, and found that whilst some participants described their GPs as knowledgeable, helpful and supportive, others conveyed a lack of confidence in their GPs, commenting they were reluctant to offer a diagnosis, information and advice about the course of their illness (Pinder, 1990). The respondents perceived this as the doctor's lack of interest and/or understanding, and spawned in them feelings of dissatisfaction and frustration with the GP.

As long ago as the 1970's Stimson and Webb (1975) described how respondents reported interactional problems in the consultation. They claimed there was a power differential allowing the practitioner to impose his/her definitions of the situation on the patient, which in turn challenged the patient's status as a competent and moral individual. Similarly, Locker's (1981) respondents described feeling that their views were being swamped by the doctor's knowledge and this worked to challenge their competence as responsible patients making them more reluctant to consult.

Other research reports the complex and pivotal role of information sharing in the consultation (Blaxter & Paterson, 1982; Pinder, 1990; Schneider & Conrad 1983; Tuckett et al., 1985). West's research (1990) on children with epilepsy reveals similar concerns; parents voiced complaints about their general practitioners as inadequate information sources. He adds that, arguably, the medical encounter should be based on a more reciprocal sharing of information involving fruitful dialogue informed by the patients' concerns.

In line with West, others have found that people require their own situations and experiences to be addressed by professional health workers, and prioritise the need to be treated as an individual in the interaction process (Bury, 1988; Charmaz, 1983). Similarly, Radley comments that:

'There is a need for doctors to conduct their clinical practice without displacing (or disrupting) the integrity of the patient as person. The physical examination and the practice of bodily care provide an important medium through which this can take place' (Radley, 1994: 106, my emphasis).

Other research shows how patients convey feeling dehumanised and devalued, in doctor-patient encounters, and this, according to Coyle (1999) leads to 'personal identity threat' (Coyle, 1999). In the same vein, women patients have described their concerns to gain credibility and maintain self-esteem during the consultation (Johansson, 1996; Werner & Malterud, 2003; Werner et al., 2004); whilst others have identified how patients report on the dilemmas of legitimating back pain in clinical meetings (Ong et al., 2004). Such evidence suggests that an added burden of the illness experience is managing one's moral identity in the consultation process.

Findings based on respondent accounts have been identified as problematic; reports of consultation communications may not concord with what occurs (Annandale & Hunt, 1998; Fitzpatrick & Hopkins, 1983; Locker & Dunt, 1978). Related to this, the nature and purpose of accounts have been discussed (Radley & Billig, 1996). For example, Stimson and Webb (1975) claim participants use interviews as vehicles to reclaim power lost in

the medical encounter, rather than to tell 'what happened', as they emphasize their active consulting role alongside a relatively passive health professional. Others have described patient accounts of the consultation as ways to articulate moral adequacy (Locker, 1981, Baruch, 1981). Thus, accounts of the consulting process are often regarded as a way to learn about the perceptions of individuals situated in a social and cultural space.

Other studies have focused upon the medical encounter itself, rather than reports of it. Building on earlier work (Balint, 1957), research has revealed various aspects of 'what goes on between doctor and patient' (Barry et al., 2000; Barton, 2000; Bloor, 1976; Bloor & Horobin, 1975; Britten et al., 2000; Neighbour, 1987, Stevenson et al., 2000; Stimson & Webb, 1978; Tuckett et al., 1985; West 1976, 1979, 1990). For instance, Tuckett and colleagues' observational data (1985) on the consultation process reflects some of the findings based on patient accounts outlined above. They claim that in practice, there is a lack of information sharing; patients' knowledge and experience is neglected, and tends to be devalued. Following this, Strong (1988), studying doctor-patient interaction, noted the negotiation work of patients, and claims every consultation is a threat to the patient's morality.

Case studies, combining interview and observational data add a depth of understanding to knowledge around the consultation process. For example, whilst during interviews some GPs noted being happy for their patients to use self-treatment, in practice, few discussed such use, or offered encouragement to patients who mentioned it during the consultation. Stevenson and colleagues point out that although the GPs did not explicitly make negative comments, patients could interpret their attitude as disinterest, and disapproval (Stevenson et al; 2003: 525).

Other findings based on the same study identified how patients' voiced and unvoiced agendas were presented differently in the research interview and the medical consultation. The complexity of patients' agendas was revealed alongside a higher degree of unvoiced agendas than was previously thought. Overall, miscommunication led to non-adherence (Barry et al., 2000).

To explicitly compare findings gathered in interviews and observations does not lead to prioritising one data source; they are different types of evidence, and underscore the similarities and differences between accounts, and practice. Analysis and interpretation of case studies highlight the importance of combining data on patient accounts and the actual consulting process in understanding the complexities and subtleties of the doctor-patient relationship, and show that interview data on patient satisfaction is an incomplete way of assessing the outcome of consultations (Stevenson et al., 2000).

Building on such research, the consultation process has been formulated as two experts sharing different types of knowledge. From this has emerged the ideal of a more patient centred approach to the doctor-patient relationship (Mead & Bower, 2000; Paterson & Britten, 2000; Sullivan, 2003), and for the patient voice to be heard in evidence based medicine (Lockwood, 2004). Underscoring this view, Guadagnoli and Ward (1998) conducted a review on research about patient participation in decision-making, and found that patients wanted to be more actively engaged in any decisions about treatment. They concluded that doctors should engage more with patients about this process, and need to avoid a paternalistic approach. Frank, based on his work on chronic illness, advocates a scenario whereby the doctor considers the complete patient story, rather than only attending to diagnostic features. He describes such listening as part of a 'gift relationship', which is based on reciprocity, and beneficial to both doctor and patient. In this way, Frank claims some of the status of authority and expert is diluted (Frank, cited in Gabriel, 2004: 182).

This dialogue is mirrored in policy and practice, where there has been a shift in emphasis from the authoritative and paternalistic doctor, with a patient who adheres to, or complies with, professional instruction, to the notion of concordance. A consultation process where power is shared, and lay and professional knowledge and experience is given equal value, based on a reciprocal relationship (Barry et al., 2001; Cox et al., 2004; Levinson et al., 1997; White, 2003).

Following this, there are signs that some efforts are being taken to re-orientate the medical profession to a more concordant relationship with lay people. For example,

Campbell and McGauley (2005) found that collaborative management of chronic illness is undermined by the neglect of emotional and psychological factors in both the patient and doctor, and add that the General Medical Council has identified the need for innovative training programmes. They note the introduction of courses which have been developed to help students relate to, and develop skills for, patients with chronic illnesses. However, May and colleagues (2004) argue that to understand the consultation process as a series of interactional strategies which can be improved by mechanical techniques is to neglect the complexities of the interactional process. They maintain that better communication skills alone are not the solution, because the dilemma is more deep seated:

'...doctors' interactional behaviours and communication skills are exercised through their own contextual experiences of types of patients, types of problems, and types of disposal options - in other words, through a repertoire of routine judgements about the possibilities presented by the individual patient, and the routinely available means of solving these' (May, 2004: 153).

Other attempts to improve the relationship between health workers and patients involve training professionals to listen to people's stories in the context of their life worlds, and practice more empathic consulting (Charon 2001, 2004). Another recent innovation involves patients and their doctors collaborating to write about the experience of chronic illness from their corresponding perspectives (Ong et al., 2005). It is to the body of literature on the experiences of living with chronic illness to which I now turn.

2.3.2 The lived experience of chronic illness

The literature on chronic illness includes investigations into the experience of living with specific chronic illnesses, revealing particular problems are linked to certain conditions. The embarrassment and technical work associated with an ileostomy (Kelly, 1992); the stigma of epilepsy (Schneider & Conrad, 1983; West, 1979); the loss of mental and physical capacities with Parkinson's Disease, (Pinder, 1990); the physically burdensome

and often 'invisible' Rheumatoid Arthritis (Bury, 1988; Williams, 1993; Wiener, 1975); the debilitating and stigmatising effects of depression (Brown, 1978), which may be considered a chronic condition (Andrews, 2001; Maxwell, 2005); all illustrate varied dilemmas of specific conditions.

Conrad observed that when a range of conditions 'are lumped together' in research under the term chronic illness, important differences may be lost (Corbin & Strauss, 1988: 13). However, like Corbin and Strauss (1988: 14), my study design requires me to focus on a range of conditions; I am comparing and contrasting experiences of multiple morbidities and consulting patterns. Whilst individual conditions are commonly studied, in daily life, they are likely to be experienced in conjunction with other conditions, or associated morbidities. Further, it is important to note that whilst both mental health and physical problems hold distinct dilemmas for individuals, the traditional 'mind body' split has been problematised (Bracken & Thomas, 2002). Also, they often overlap to form particular conditions of co- and/or multiple morbidities. Finally, although the experience of chronic illness varies according to type and combination of conditions, individuals also experience some common problems, and share a number of core concerns upon which I will base my analysis, interpretation, and this review.

Problems about *functional* ability are paramount; the nature and levels of incapacity, and attempts to limit it, fundamentally affect daily life. People also voice concerns about unpredictable symptoms and uncertainties about the course of the illness, leading to feelings of a lack of *control*, which in turn, impacts on activities. Subsequently, 'normal' life is often threatened or *lost*. As a result of this *identities* are fractured, which often lead to challenges to a coherent sense of self. Interpretivist sociology, is particularly suited to explore such practical and existential experiences, and has spearheaded investigations into how people live with chronic illness, aiming to explore the meanings individuals apply to their situation, and the practical accomplishment of the self (Bury, 1991; Charmaz, 1990; Gerhardt, 1990).

2.3.2.1 *The impact of chronic illness*

Chronic illness can lead to painful, stigmatising, fluctuating, distressing and debilitating symptoms (Charmaz, 1983, 1991, 1999, 2000; Frank, 1995; Herzlich, 1973; Robinson, 1990; Sontag, 1983). For example, Charmaz (1991) reports how people describe being unable to perform basic actions, routine activities and undertake social obligations, often diminishing and disrupting lives, and challenging a coherent sense of self. When symptoms are unpredictable a major concern is a lack of bodily control, leading to a scaling down of activities, and routines, which often combine to impact on one's sense of a 'normal' life (Charmaz, 1991; Frank, 1995; Kleinman & Seeman, 2000; Scambler, 1989; Locker, 1981; Schneider & Conrad, 1983; Wiener, 1975). In Frank's words: *'Everyone must ask in every situation: 'Can I reliably predict how my body will function; can I control its functioning?'* (Frank, 1995: 31, emphasis in the original).

In order to investigate the impact of living with chronic illness Bury (1991), echoing Herzlich (1973), distinguished between two types of meaning. First, the meaning of chronic illness lies in its *consequences* for the individual, for instance, the practical implications. Second, the meaning of chronic illness can be seen in terms of the *significance* of the consequences for people. Different illnesses are imputed with a host of characteristics; individuals experience a range of symptoms with varying degrees of severity, longevity and uncertainty, as well as embarrassment. In turn such experiences are perceived in various ways by different people in the context of their daily lives, constrained by particular and more general cultural and structural factors.

Charmaz (1983) has shown how these consequences may impact in practical and existential ways to varying degrees. When individuals are incapacitated, unable to fulfil roles or carry out tasks and social obligations in their daily lives, illness constitutes a threat to one's self-esteem. Charmaz describes how functional restrictions can impact on the consciousness of the ill person, and threaten identity. In a study investigating the impact of chronic illness on individuals, she found that when individuals lost the ability to function in familiar ways, or as others of a similar age did, they felt they were no

longer 'normal'. In these circumstances chronic illness subsumed them and became part of their daily lives and their self-image, and challenged their sense of a coherent self. Respondents talked about how their functional problems led to feelings of social isolation, being discredited, and burdening others. In this way, the significance of inactivity extends well beyond the practical limitations. One becomes distinct from, and different to, the well and active and socially marginalised by chronic illness (Bury, 1991).

The connection between the body and sense of self has been emphasised (Bury, 2001; Kelly & Field, 1996). This is especially important when changes in the body clash with culturally approved appearances, particularly for example when there are no visible signs of illness. *'Here it is the person's self image, and identity as a culturally competent person, that comes to the fore'* (Bury, 2001: 280). For instance, Robinson (1990) found that multiple sclerosis sufferers felt at risk of being labelled as mentally ill, malingerers, or 'drunk', by people unaware of their condition. Thus meanings imputed to bodily deportment, action, or inaction may put people's identities at risk, and their integrity at stake. Charmaz (1983) argues that in such circumstances challenges or losses to one's identity and self-esteem result in a diminished self. However, whilst there is a need to have symptoms and illness recognised to legitimate certain behaviours, one's identity is in danger of being trumped by the chronic illness label, thus tensions and ambivalence typify the chronic illness experience (Bury, 2001).

Consequences of physical incapacity need to be understood in the cultural context of daily life. For example, Reisine and colleagues (1987) researched the impact of rheumatoid arthritis on the homemaker and found that both instrumental and nurturing functions associated with the role of homemaker influenced the impact of rheumatoid arthritis on women. The inability to 'do emotion work' as well as more practical tasks heightened the significance of illness. They concluded that the impact of being ill in the context of the family would seem to be greater for women's (typically the homemaker) daily life regarding their ability to fulfil their nurturing role as well as more instrumental requirements. More recently, Charmaz (2002, 2004) revealed in her studies on chronic illness that women were likely to feel an added burden and frustration in the home when

they were ill and their symptoms prevented them from fulfilling tasks and social obligations. They described feelings of guilt, and a sense of fractured identities.

So, research shows that the consequences of suffering functionally disruptive illness, extends to fundamental challenge to one's familiar sense of self. In response to such findings the concept of 'biographical disruption' has emerged (Bury, 1982). This prioritises the link between functional disability and identity, when the unity between self, body and society are fractured. It is to the literature about how people tackle these practical and existential dilemmas in a bid to manage chronic illness to which I now turn.

2.3.2.2 Managing daily life with chronic illness

The sociological literature has shown that people talk about using a combination of practical and emotional strategies to manage living with chronic illness. Such talk is set against a moral backdrop, as individuals describe how one's 'attitude' contributes to the ongoing negotiation of daily life (Baruch, 1981; Blaxter, 1983, 2004; Bloom, 1990; Pollock, 1993; Radley, 1993; Williams G, 1993). As Robinson maintains: *'Illness is a particular form of failure at everyday life'* (Robinson, 1971: 79).

Studies reveal how people use a range of resources and adopt a series of strategies as they strive to accomplish *normalisation*. Practical efforts to mask and alleviate symptoms, control illness and live a normal life colour the chronic illness experience (Charmaz, 1983, 1999, 2000; Frank, 1995; Kelleher, 1988; Radley, 1994; Robinson, 1988). Normalising reduces disruption, and cushions the impact of illness. This often means adopting techniques to conceal one's limitations, and difference from people during interaction (Charmaz, 1991, 2004; Kelly, 1991).

West (1976) has shown how people who suffer with epilepsy attempt to pass as 'normal' as far as possible. He noted how concealing the condition was a major strategy employed to attain normalisation. Techniques to deal with events in daily life meant avoiding particular situations and covering for particular behaviours. Likewise, Wiener's (1975) study revealed that people who suffer from arthritis employ ways of playing-down

impairment and maintaining appearances. Wiener's findings demonstrated that in attempting to accommodate symptoms and function 'normally', people were willing to endure discomfort. Similarly, Hardiker and colleagues found that chronic renal patients acted as normally as possible and avoided disclosure (Hardiker, cited in Radley & Green, 1987: 185).

Keeping busy, is another way to try to resist illness, and has been reported as a strategy for heart patients (Radley & Green, 1987) and those experiencing pain. Murphy and Fischer (1983) noted that people with low back pain denied they had permanent conditions and attempted a healthy image by bodily comportment. Overall, research reveals that people attempt to 'keep up appearances', struggle with symptoms, and emphasise their healthy status through normal activities (Radley & Green, 1987). Ways of achieving this goal include the ability to undertake meaningful activities, and fulfil social roles and obligations.

Pacing, (regulating activities) is one innovation which people adopt in order to be able to function (Charmaz, 2000). However, as Herzlich has commented this strategy can be risky:

'Individuals lose patience and don't pace; in the reality of their daily lives, it is more important to fulfil roles, and tasks, and act as 'ordinary' people and risk a deterioration of their symptoms' (Herzlich, 1973: 121).

So, attempts to accomplish normalisation are tinged with ambiguities; people monitor, 'listen to their bodies', and pace, but they can misjudge and get it wrong. Like Herzlich, Charmaz (2000) found that people often paced, but depending on the context still undertook particular actions and activities, which exacerbated symptoms and caused further harm to already vulnerable bodies. However, others described scaling down daily life, routinely adopting techniques and re-negotiating what they perceived 'normal' to be in their attempts to normalise, and maintain a salient sense of self:

'Through normalising, ill people take their way of being and the changes they have endured for granted. As their lives become more restricted, their world shrivels, frame of reference shrinks, and self contracts. The ability to normalise then is fundamental to a positive sense of self' (Charmaz, 2000: 280)

Another normalising strategy is medication use. This complex and multi-dimensional process is addressed by a body of literature around drug use¹ (Britten, 1994, 1996; Conrad, 1985; Donovan & Blake, 1992; Faircloth, 1999; Morgan, 1996; Stevenson, 2003; Van der Geest & Whyte, 1989). Managing medicines, alongside other techniques, becomes part of the chronic illness experience, in order to alleviate symptoms, control illness and manage daily life. Pinder's study (1988) on Parkinson's Disease highlights the central role that drug taking plays in people's lives. Patients had to negotiate complex regimens in order to gain maximum benefits and minimise side-effects. West (1976) found in his study on childhood epilepsy that taking medication extended beyond physical problems, and that parents claimed that drugs had *'quite marked side effects'* as well as *'the symbolic significance attributed to 'being on tablets''* (West, 1976: 21).

Bury also notes how drug use can be problematic in both practical and symbolic ways. He describes complex regimens, in which symptoms need close monitoring in order to gain knowledge of the disease process. In this way treatment not only offers relief, but can also be onerous, time consuming and anxiety inducing. He adds that the constant need to experiment with different medications and varied regimens signifies hope. In a world which is characterised by uncertainty, drugs can offer a management routine, a level of control and dilute feelings of futility. Whilst one tries different drugs, there is always the possibility of respite. This resonates with Herzlich's and Parsons' conceptualisations of illness behaviour. The aim is to keep trying to improve. Hence, ongoing medication use symbolises not only hope, but in this context conveys moral adequacy (Bury, 1988).

¹ See Appendix A for Townsend et al. 2003 which is based on this study.

Equipment can be an important resource employed to help minimise or overcome dysfunction (Charmaz, 2000). As Verbrugge and colleagues (1997) observe, it is often used to allow activities or routine actions, and can become a feature of daily life. They report that although equipment may help maintain some autonomy, often it is highly visible, and a tangible reminder of one's debility, for example a walking stick may be used with ambivalence. Other equipment may require patience, skill, effort and monitoring in order to gain efficacy. For instance, Kelly (1991) notes that when an ileostomy has been performed, techniques have to be mastered, and strategies have to be devised in order to manage the body. Overall, the evidence suggests that, using equipment alongside medical and everyday routines may offer respite, whilst adding to the frustration and ambivalence which is part of the chronic illness experience.

Another way of normalising is to keep silent about suffering (Werner et al., 2004). Charmaz (2002) revealed how respondents were reluctant to share their experiences of symptoms for several reasons. First, they felt it a threat to their moral identity. Second, on a more practical basis, one respondent was anxious that she might lose her job, whilst another feared revealing his depression would mean returning to a residential home. Others said they resisted discussing their illness lest it became more real; they feared a self-fulfilling prophecy.

Studies show that individuals discuss 'being positive' as a major means to confront, fight, and endure illness, often to combat anticipated criticism, and build self-esteem (Pill & Stott, 1982; Radley & Green, 1987; Blaxter, 1990). People are keen to avoid being labelled as malingerers (Blaxter, 2004; Robinson, 1978) so often attempt to convey that they face illness with optimism, fortitude, and a sense of responsibility, and can indicate a degree of control in the face of considerable suffering. To persevere and 'get through the day' permeates the chronic illness experience. As Frank comments:

'In Parson's sick role the ill person as patient was responsible only for getting well; in the remission society, the post-colonial ill person takes responsibility for what illness means in his/her life. The status of moral responsibility is a central issue for postmodernity' (Frank, 1995: 30).

Thus illness is seen as a 'loss of virtue' and a state which challenges one's moral identity.

In Pollock's words:

'Regardless of whether it is considered preventable, illness spoils identity and threatens to diminish the person. It is in this context that the ideas about attitude of mind can be brought into play to offset this threat, and even override it' (Pollock, 1993: 67).

It is unsurprising that individuals are concerned to describe their efforts to cope with chronic illness by drawing on their inner resources, thus indicating their moral fibre in times of adversity (Bury, 1991; Williams G, 1993). Studies show that when people feel their integrity is challenged through illness, they give accounts which distance themselves from those who do not fight. This underlines the 'meanings at risk' (Bury, 1988: 89) people are faced with when ill, and their efforts to construct coherent identities, and maintain moral adequacy when faced with challenges to their self-image (Lupton, 1997; Riessman, 2003; Robinson, 1990; Stimson & Webb, 1975).

In response to findings around the experience of chronic illness, the concept of 'narrative reconstruction' has been developed (Williams, 1984). This prioritises the significance of damaged identities, precipitated by chronic illness, and the subsequent need to form a coherent 'sense of self'. Williams addressed the ways in which individuals who experience such disruption in their daily lives, work at maintaining cohesive identities through talk. In his words:

'Narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams, 1984: 197).

Hence, individuals are able to construct positive identities, through making sense of their lives by narrativisation, despite massive life changes, loss, and disruption. However, people's personal accounts are also informed by cultural and structural contingencies, and the availability of a range of resources to which they have access. Charmaz notes:

'Social, economic, and psychological resources expand possibilities and options. Without such resources, possibilities and options rapidly contract.... Economic resources allow an individual to purchase objects and services that make life easier' (Charmaz, 2000b: 286).

Charmaz acknowledges social location, and the central role of social activity, employment and the family in illness management and daily life, and observes that this extends to fundamental concerns around identity: *'As resources dwindle, identity questions and changes of self may be forced much earlier'* (2000b: 287). Thus the availability of resources has both practical and symbolic consequences for individuals.

Other research has revealed how structural constraints influence the availability of resources, and the ways people actively manage and adjust to chronic illness (Blaxter, 1976; Radley & Green, 1987; Radley, 1989; Riessman, 2003). Based on research on 'styles' of adjustment to coronary graft surgery (1985), Radley and Green (1987) noted that the ability to manage, or adjust to, illness is heavily influenced by one's social position. They concluded a person's social location offers opportunities to, and limitations on, managing illness. For instance, they found that when employment opportunities and social networks were limited, respondents were more inclined to become resigned to illness; those with fewer social and economic resources appeared to face illness with futility.

Along similar lines, Pearlin and Schooler's research (1978) illustrated that the effects of chronic illness can be cushioned by economic resources. They observed that those who enjoy material benefits are able to draw on more favourable aspects of life, and this in turn equips them to deal with the consequences of chronic illness. So, for those with fewer benefits and resources, illness may be magnified, and its consequences have more significance in daily life.

For the purposes of this thesis it is useful to address Radley and Green's analysis in more detail. Drawing on Bourdieu's theory of practice, they explain how different socio-economic groups relate to their bodies, or have ways of 'being in their bodies' in different

ways, which has implications for how people adjust to, and face, chronic illness. For example, manual workers are particularly reliant on their physical fitness, thus their bodies may become 'unfit' for work sooner than the bodies of professional men. Furthermore, for the working class man, the body and its associated power is integral to a sense of self, thus, masculine identity may be fractured, as physical power wanes. The working class man risks losing his status, his means of financial support, and his role of wage-earner, but also chronic illness may interfere with:

'the distinctive and stylistic bodily comportment by which working class men, in particular, distinguish themselves (Bourdieu, 1984). (The heart patient who cannot chastise his child, for fear of bringing on chest pain, is an example). By contrast, the middle class patient afflicted by chronic illness has a different relationship to his/her body, on which s/he relies in a different way, such that not only are other non-physical areas of life less affected but the idea of one's body as something to be maintained and monitored is a familiar one' (Radley & Green, 1987: 201).

From this perspective, the body and its limitations are perceived and experienced differently depending on one's social location, and this in turn could have a fundamental impact on one's ability to continue or scale down a 'normal' life. People may or may not be able to resist the label of their illness or have the ability to continue to function in their roles due to a combination of their illness *together with* their social location.

Still following Bourdieu, Radley (1989) extends this analysis. He observes that, incapacitated by chronic illness, people face a wide range of concerns engendered by cultural and structural constraints. Stressing that physical symptoms are inseparable from the social conditions in which they are experienced Radley notes how 'styles' of adjustment to illness need to be understood in these terms. Ill people are anchored in social spaces:

'embodied in the execution of their rights and obligations, different people experience illness within a particular set of concrete circumstances, which is their life world. It is because individuals enjoy definite relationships to society, are located

concretely in these interactions, that chronic illness involves not mechanical resolution, but engages people in a moral debate about the legitimacy of their adjustment to their situation' (Radley, 1989: 235).

Radley's analysis illustrates that people have different resources on which to draw depending on their position and role in the social structure, and maintains that how one adapts to illness, is guided by what resources (cultural, social, economic, material) one has to adapt *with*. By recognising that people experience symptoms and bodily incapacities in cultural and structural locations and therefore experience and manage illness as moral agents, constrained by external forces, Radley goes some way to overcome the structure-agency debate in (medical) sociology.

In claiming this, Radley echoes Bourdieu's insights into the link between the physical body and one's constant search for moral competence or distinction. According to Bourdieu, the body is a bearer of value, or a 'sign system' (Shilling 2003: 111). In other words, depending on one's social location, individuals have a predisposition to act or 'fit' one's body to activities in particular spheres, or what Bourdieu would term '*fields*' (for example, employment and the family). Pressure is exerted on people to act according to common sense assumptions about appropriate and 'natural' behaviour (what Bourdieu calls '*symbolic violence*') in particular contexts (Williams 2003: 30). This understanding allows us to grasp the *significance* of the *consequences* of sick bodies, and suggests the emotion work involved in attempting to 'keep up appearances', function, and fulfil social obligations and remain a member of the moral community (Crossley 2001: 106).

With this in mind, there is evidence to suggest that women are likely to have a predisposition to fulfil instrumental and expressive roles in the family and this has implications for how they experience chronic illness (Wiener, 1975). Wiener found that a sense of 'normality' could be maintained with the help of family members, but there was ambivalence about such support. She observed that the more an individual gains help from others, the more his/her sense of self as independent, healthy person is fractured. In concealing disability with help from others, disability is reinforced. Wiener found that for women, the constant re-negotiation of roles in the family was an added burden as they

attempted to manage their symptoms. As one of the female respondents suffering from rheumatoid arthritis commented:

'My son was then 5-years-old, and he had to take care of me. I'd sit on the side of the bed at night, and he'd put my legs up he'd tuck me in' (Wiener, 1975: 101, emphasis in the original).

Others have also found that role obligations influence how individuals perceive and respond to symptoms (Nathanson, 1975). This is interesting for the purposes of this thesis, as it may have implications for how help is perceived and received in the family. In other words, and relating to Bury's two pronged impact of illness (1991), the *significance* of the *consequences* of being ill in the family may well differ for men and for women, and so effect how they gain support from family members. Wiener and Nathanson's studies are 30 years old, but more recently Charmaz (2004) has mirrored these findings. She too identified the complexities of accomplishing a coherent sense of self in the female family role whilst gaining support from family members. Others have identified how women in particular have a moral imperative to appropriate parenting, whereby their self-esteem is interweaved with their child's well-being (Ehrich, 2003). This may well have an impact on the ways in which women manage their symptoms and perceive the family as a support system.

Radley comments that it is not sufficient to reduce the problem of adjustment to illness to structural differences, but rather to show that chronic illness is something worked out between people in concrete situations, and this needs to be explored from a broadly interpretivist perspective (Radley, 1989: 245). In an attempt to gain deeper insight into the subjective experience of the unfolding nature of chronic illness, set against a moral backdrop, researchers have turned to the 'situated narrative'.

2.4 Illness narratives

Illness narratives are currently of considerable interest in health related literature (Charmaz, 2004; Charon, 2004; Hurwitz et al., 2004; Stensland & Malterud, 2001) and for over a decade they have been associated with the study of chronic illness in medical

sociology (Charmaz, 1999; Frank, 1995; Riessman, 2003; Robinson, 1990). The combination of the questionable potency of the 'grand-narrative' (Hyden, 1997; Williams, 1999) and its focus on the temporal and its moral purpose (Riessman, 1993) make it particularly pertinent for the study of chronic illness and have allowed lay narratives to flourish (Bury, 2001). They are seen to offer a means of gaining an 'insider view' as well as capturing the ways in which people talk about the unfolding detail of their illness experience. Further, the concepts of 'biographical disruption' (Bury, 1982) and 'narrative reconstruction' (Reynolds, 2003; Sparkes, 1995; Williams, 1984), have developed from analyses of accounts of illness experience, and bring into focus the ways in which people, through their illness talk, attempt to construct coherent and moral selves.

Riessman has commented '*There is no binding theory of narrative but instead great conceptual diversity*' (1993: 16-17). However, she goes on to give a working definition of the 'personal narrative' as:

'Talk organised around consequential events. A teller...takes a listener into a past time or "world" and recapitulates what happened then to make a point, often a moral one...Respondents narrativize particular experiences in their lives, often where there has been a breach between ideal and real, self and society... Individuals facing the biographic disruption of chronic illness reconstruct a coherent self in narratives' (Riessman, 1993: 3).

Riessman extends her definition to the analysis of such accounts. She notes that narrative analysis reveals how respondents construct coherence and make sense of events in their lives. She claims this is important in order to gain insight into what is meaningful to the speaker. The form of the account and language used is important as it can reveal themes of the broader cultural context related to, for example, gender, ethnicity and class. She notes how typically qualitative research fractures transcripts, and so misses the sequential elements and structural features of narrative accounts. Riessman adds that narratives do not attempt to uncover 'the truth' rather they attempt to gain insight into the experience of the speaker. It is commonly noted that we should conceive of 'accounts' rather than

representations of truth (Charmaz, 2002; Cornwell, 1984; Radley & Billig, 1996; Mattingly, 1994).

It has been claimed that a narrative analysis of accounts may reveal how people apply meaning to disrupted experiences in chronic illness, and illuminate why they take associated actions (Hyden, 1997). For example, in his work on the experience of multiple sclerosis, Robinson (1990) shows how analysing people's narratives, and tracing the way illness accounts unfold, adds to our knowledge of the experience. By emphasising the trajectories of illness, the impact and the strategies used to limit its impact, are highlighted. To gain insight into the episodic and the moral themes of the accounts, he bases his analysis on the work of Gergen and Gergen (2001) who claim that two crucial dimensions in personal narratives are coherence and direction in terms of a specific goal or set of goals. That is, we make sense of our lives through placing order upon them, by linking events into episodes, and linking action with a moral purpose. Although narratives can be organised along several lines, Gergen and Gergen identify three core narratives: the stability narrative (i.e. when things remain the same); the progressive narrative (i.e. when things move in a positive direction); and the regressive narrative (i.e. when things move in a negative direction). These three narratives are basic types and can exist simultaneously in people's talk, that is, it is important to recognise the existence of multiple narratives or 'nested' narratives. By focusing on this aspect in accounts, we gain insight into how people interpret their experiences, and account for action. In this way the analysis is drawn to a morally informed, decision-making episodic process. Robinson claims that *'the value of such perspectives is stressed in giving access to the personal world of illness'* (Robinson, 1990: 1173).

Charmaz (2004) has illustrated how narrative analysis may shed light on how people use health professionals. People may avoid viewing themselves as chronically ill for as long as possible, because this 'image' does not match their 'familiar' sense of self. Thus, they may interpret feelings, and treatment, as irrelevant. For example, in the context of a person's biography, it may become clear why they put off, or decline medical help. Charmaz uses the concept of 'habit' to understand such behaviour. She defined habit as:

'patterned predispositions that enable people to respond to their situations with economy of thought and action...Habits not only link self to the social world but also form the self...These habits of acting toward self and as self become defining characteristics that simultaneously constitute the self and distinguish it from others' (Charmaz, 2004: 2).

Charmaz goes on to illustrate how an analysis which focuses on the past helps explain decision-making, particularly when certain decisions conflict with one's familiar self concept. A female participant, whose account prioritised her role as mother, and her identity as carer in the family, illustrated how she found it difficult to attend to her own symptoms and body. However, eventually, *'Her definition of herself as the center of the family, the one who kept everything going, spurred her quest for help'* (Charmaz, 2004: 8). Charmaz comments:

'Habits must be understood in their biographical context. What may appear in the present as unrealistic or even destructive has its roots in the past. Knowledge of ill people's past from their point of view gives researchers and practitioners greater understanding of why they act as they do in the present' (Charmaz, 2004: 8).

Charmaz then indicates a particular use of a narrative informed analysis which focuses on the temporal, the moral, and action; it elucidates the ways in which the 'self' is a reflective, social process; ongoing, and anchored in a cultural and structural context.

Robinson also emphasises the merits of narrative analysis to reveal links between the personal and the structural, employing the *'notion of the universal singular'* (Robinson, 1990: 1177), he cites Denzin:

'Denzin's analysis of the life stories of alcoholics points to the complex marriage between the personal and the social, and the individual and the universal by suggesting that at one and the same time "Every life story is unique, yet representative of every other life story" (Robinson, 1990: 1177).

Robinson's analysis of illness narratives of those who suffer from multiple sclerosis reveals the ways in which they apply meaning to their quest for a 'normal life'. He notes of narrative accounts:

'Their importance lies in the fact that...making sense of illness, and understanding the meaning of sickness and disease is not just a passive response to external events and circumstances but is an active construction and selective process. Such an active process is complex and involves ordering and sequencing the myriad range of phenomena in everyday life which may or may not be perceived as related to health and illness. One way of achieving this ordering is through a narrative, or storied, framework' (Robinson, 1990: 1185).

As has been established, identity is threatened in chronic illness (Hyden, 1997; Charmaz, 2002; Bury, 2001; Williams, 1984; Riessman, 2003), and individuals often feel compelled to reconstruct their personal narratives in an attempt to maintain a sense of identity (Bury, 2001). For example, aspects of normalisation, coping, and strategic management of chronic illness figure prominently in patients' narratives (Riessman, 1990). Thus, narratives become vehicles through which individuals present their positive moral characters, describing how they face adversity and displaying their moral worth. Thus narratives are not simply ways of gaining a 'truer' picture of illness, but they reveal how people manage positive presentations of self, and feature deep-seated cultural values (Bury, 2001).

Radley and Billig agree, and claim that illness narratives are ideological. Individuals are keen to construct their identities in positive ways, and they do this in relation to others. This is particularly when their personal worth is challenged (Radley & Billig, 1996). They provide the means to establish *social distance* as well as build moral identity, and in so doing articulate deep seated cultural and structural characteristics.

Narrative analysis has revealed a crucial feature of illness accounts is that they draw on shared cultural assumptions about ideal behaviour to construct positive identities (Clarke & James, 2003; Werner et al., 2004). Bury notes the 'style' of managing illness illustrates the 'cultural repertoires' that people draw on. Others claim that through the narrative form

issues around class and gender can be explored. For example, Riessman (2003) uses two theoretical perspectives to interpret a narrative analysis of accounts of illness. She applies the structural approach of Bourdieu and describes how the contexts of the respondent accounts reveal the reproduction of social inequality in 'personal' narratives of illness - how social structures work their way into personal experience.

Riessman also shows the benefits of close textual analysis to demonstrate how the speakers' strategic choice of genre, or forms of narrative, guides the impression we form of them. To do this she uses two theoretical approaches, one based in interactionism, the other from a more structural perspective. Riessman notes how the general narrative perspective emerged in:

'Goffman's brilliant use of the dramaturgical metaphor: social actors stage performances of desirable selves to preserve face in situations of difficulty such as chronic illness' (Riessman, 2003: 8).

Summarising Goffman, Riessman explains how speakers do not simply relay information but accomplish performances in a drama which they present to an audience, thus building their identities through talk. She emphasises such presentations are favoured, rather than inauthentic, and selected from a wide range of experiences, and identities. She is concerned to contextualise such identity construction, and describes how social location places constraints on lives, and ways of narrating them. Structural contingencies then work their way into accounts, as the speaker is anchored in specific, and more general social space. Thus Riessman echoes Radley's conceptual points also drawing on the theory of Bourdieu. In her narrative analysis of masculine identities and multiple sclerosis, she focuses on the content, and the context, of the unfolding stories. She also details the form the talk takes in order to investigate how the actors accomplish positive identities through their narratives, and specifically, their use of rhetorical devices to position characters, audience, and self (Riessman, 2003: 8).

To illustrate her analysis Riessman referred to two case studies, men, one working class and one middle class, both out of work due to their debilitating illness. She describes how

the freedom of the working class male to build a positive masculine identity as a 'working' man is limited due to cultural and social arrangements. This aspect of his moral identity is challenged as a result of his unemployment status, and his problematic economic situation. However, the professional man is able to find other ways to express his identity and manage his illness, enjoying a private pension, and describing the loss of his physical power as a less significant part of his masculine identity.

Because this resonates with my findings and discussion, I will detail some of Riessman's study, focusing mainly on her analysis of the account of Burt, who talked of loss, but accomplished a positive portrayal of 'self', as he managed to construct himself as a responsible husband, father and worker.

Looking at the transcript as a whole, Riessman noted that Burt spoke about paid work, often and extensively, constantly 'bringing up' stories about his employment experiences. She interprets this as a way of him displaying a favoured identity, that of hard worker, which was central to his masculine identity. She gives an example of how Burt inserts a long story, relating his last day at work:

'This poignant narrative about the failure of the masculine body is a classic story in a formal sense. Burt uses the narrative devices of setting, plot, and characters (including dialogue between them) to make identity claims, and to draw me into his point of view. He gives speaking roles to his boss, the two doctors, and himself... He positions himself in a moral story about what it means to be a virtuous man. As the interview is ending, he performs his preferred self – responsible worker – not other 'selves' he had suggested earlier (e.g. lonely man living in isolation)' (Riessman, 2003: 19).

Riessman refers to Radley's (1989) analysis which I outlined above, and identifies how structural contingencies thread through the personal, in the illness narrative. Following Radley, she contrasts the ways in which the manual worker and the professional talk about, and experience, their bodies. Burt's (working class) masculinity is linked to how his body is 'fit' for specific activities, which give meaning to him, and his social location.

But, his moral identity is challenged, as he is no longer able to demonstrate the power of his body, because of ill health. A particular work ethic runs through Burt's identity performance; he tells of his repeated efforts to return to work, contain illness, and 'embody the value of a man in his economic world'. Riessman notes how it is unsurprising that Burt repeatedly conveys his wish to return to work, and is able to build a positive identity as a worker in his account, because 'it gives meaning to one's place in the social structure'. Furthermore, he has economic problems, and is unable to draw on other ways of presenting himself, whilst the professional participant notes his pension, and the ability to enjoy material comfort. As Radley says:

'becoming chronically ill does not remove one from society; if anything it amplifies one's position in it, so that what people adjust with is as important a matter as what people attempt to adjust to' (Radley, 1989: 243).

Riessman summarises Bourdieu (1993: 621) who maintains that through a detailed analysis of accounts, structural inequalities and cultural ideologies are revealed. Such things are part of an often taken-for-granted world view which people are both unaware of, and in another sense, know better than anyone. Riessman agrees, and explains how a fine-grained analysis of narrative accounts can reveal the contrasting consequences, meanings, and significance of the multi-dimensional illness experience. She adds that narrative analysis also illustrates:

'shifting' and locally articulated identities, consistent with contemporary symbolic interaction theory: the self no longer references an experientially constant entity, a central presence or presences, but, rather, stands as a practical discursive accomplishment. Alongside this interactional order, however, stands an institutional order – structures of power that work their way into what appears to be 'simply' talk about lives affected by illness (Riessman, 2003: 23).

Riessman's work is particularly relevant for my thesis because it resonates with my ongoing analysis. She undertakes a narrative analysis which is informed by Bourdieu's structural theory of practice, and therefore attempts to address the ways in which people

talk about the personal experience of chronic illness constrained by cultural and structural factors. Such talk, she claims, adds insight into how people experience chronic illness in their daily lives. Furthermore, her discussion helped me extend my analysis, combining the usefulness of a narrative approach with the advantages of Bourdieu's more structural theory of practice, and his theory of the body. As such, her analytic stance offers insight into the methodological, substantive, and theoretical aspects of my thesis, and informs the discussion of my findings.

2.5 Summary

This chapter has focused on the wide ranging literature around consulting behaviour and illness experience. First, I outlined the dominant models which have been used in an attempt to understand what leads people to use the health services. I then referenced research which was informed by these frameworks, and reported that there is substantial research that has attempted to predict or explain health service use based on measurements of a range of variables such as burden of illness, and social and individual factors. However, the research was unable to explain how individuals experienced illness in the context of their daily lives. The methods used could not investigate the subjective experience of chronic illness and how this informs decisions to consult.

I then moved on to the sociological literature on illness behaviour. Earlier work revealed how responses to symptoms and decisions to seek help vary according to cultural and social contingencies. Although this literature allows for a range of responses to illness, based on social location, it fails to explore the experiences of individuals as actively interpreting their symptoms in the context of their daily lives, and likewise, falls short of seeing help-seeking as an active social process. Overall it paints an over-socialised view of individuals, which develops the knowledge of illness behaviour, but does not extend to an understanding of how people make sense of illness in their daily lives.

As attempts to gain insight into the subjective experiences of those with illness developed, a body of evidence on lay perspectives of illness flourished. Concerns around functioning abilities and activities emerged as key features of the illness experience. A

quest to avoid disruption, and maintain a 'normal' life, informed the decision to practise types of self care and seek professional help. Experiences of consultation, commonsense ideas about social obligations as well as the detail of daily life were found to contribute to any decision-making process.

The lived experience of chronic illness literature, builds on the understanding of 'lay perspectives' in an attempt to gain further insight into the subjective experience of chronic illness, identifying specific condition-types with associated problems, but also reporting common concerns and overlapping characteristics of different chronic conditions. The literature underscores how the impact of chronic illness extends beyond the physical. Key concepts have emerged, such as 'biographical disruption' and 'narrative reconstruction', which highlight the fundamental significance of functional problems on self-hood, and the need to maintain a sense of a coherent self. To aid conceptual clarity, in addressing the complex area of management of chronic illness, and its practical and symbolic impact, responses have been divided into: 'coping' (attitudes to management of illness), 'strategy' (practical management of illness) and 'style' (ways of managing illness). It was also noted that broader structural and cultural issues inform management strategies. An individual's social location influences the availability, perception and use of a range of resources.

The final section focused on narrative analysis to extend the discussion in an attempt to get closer to the personal experience of living with ongoing illness, by analysing the unfolding accounts of how people experience and interpret illness in the context of personal biographies, anchored in cultural and structural contexts. In so doing, this approach sheds further light on the significance of the impact of illness in both practical and symbolic ways. It also offers insight into how concerns to manage positive presentations of self throughout the accounts reveal how people were fundamentally challenged by the losses they described, and the need to draw on cultural ideals of behaviour suggested an added burden in the lives of those with chronic illness.

In this review, I have reported that, in order to explore the experience of chronic illness

and consulting, one has to move beyond the variable and symptom based research, much of which has stemmed from the dominant explanatory models of help-seeking in formal health care. I have focused upon what has been termed an 'insider' approach to understanding the chronic illness experience. This involves investigating how individuals interpret chronic illness, manage strategies and resources, and make use of the general practitioner consultation, in the context of their daily lives. A 'situated narrative' stance allows for this, but does not lose sight of the broader structural and cultural contingencies in which personal interpretations, experiences and accounts take place. The next chapter describes my methodological approach in order to accomplish my aim.

Chapter Three

Methodology and methods

3.1 Introduction

In this chapter I discuss my methodological approach and describe the methods I selected to investigate how people with chronic multiple illness, but contrasting consulting rates, manage their illnesses, and make use of the general practitioner consultation in primary care. First, I set out my philosophical position, and identify how the interpretivist approach informs my choice of method. I then discuss interpretivist interviews, and describe my interpretation of the status of interview accounts. In the next section I outline how I searched for relevant literature for the review (Chapter Two). I go on to detail the study design, and describe the pilot study before describing the main study, including ethical issues, sampling and recruitment procedures and the diary-interviews. Finally, I report how I managed and analysed the data.

3.2 My philosophical position

To help locate the approach taken in this study, I will clarify my philosophical position on the nature of 'reality', and the best way to study it. Two world views, positivism and interpretivism are often dichotomised in discussions about how the world can best be known. Whilst simplistic, I will use this schema in order to highlight core characteristics of each perspective before going on to address aspects of interpretivism in more depth.

Although not a unified approach, positivism broadly asserts that there is an objective world, from which facts can be collected and measured, and 'reality' captured, using the methods of the natural sciences. The task for the positivist researcher is to gather valid and reliable data, from which the truth can be told. The procedure involves treating social facts as 'things', which can be collected as variables for systematic and rigorous analysis,

involving comparisons, correlations, causal relationships and replication. With such evidence, hypotheses can be tested, and conclusions about the social world can be made. From this perspective, the truth is out there waiting to be discovered.

The often cited alternative approach is interpretivism, and despite lacking a clear cut definition, it is possible to identify core characteristics of this world-view. Broadly, knowledge is provisional, and fallibilistic and research is context bound. From this perspective, the methods of the natural sciences are unsuitable to study the social world, as people interpret the world around them in active and ongoing ways. Thus, in order to investigate social action, one needs to 'get beneath the surface' and attempt to understand how people make sense of their worlds. In lieu of an exact definition, I share the view that interpretivism is: *'all of those approaches to research that prioritise the interpretation of the actions and meanings of agents, over measurement, explanation and prediction'* (Williams, 1998: 7).

Interpretivism covers a range of perspectives, for example: action theory, symbolic interactionism, phenomenology, ethnomethodology and social constructionism. These off-shoots themselves have flexible boundaries and different priorities. In this chapter, for the sake of brevity I focus upon the aspects of interpretivism which are particularly relevant to my study. I will draw mainly on symbolic interactionism, which itself has a contested history (Rock, 2001).

Interpretivism has emerged in part as a result of Weber's social action theory, and the phenomenology of Alfred Schutz. Firstly, prioritising the need to understand the meaning people apply to social action, Weber noted:

'Sociology is a science which attempts the interpretive understanding of social action in order thereby to arrive at a causal explanation of its course and effects. In 'action' is included all human behaviour when and in so far as the acting individual attaches a subjective meaning to it... Action in this sense may be either overt or purely inward or subjective; it may consist of positive intervention in a situation, or of deliberately refraining from such intervention or passively

acquiescing in the situation. Action is social in so far as, by virtue of the subjective meaning attached to it by the acting individual (or individuals), it takes account of the behaviour of others and is thereby oriented in its course' (Weber, 1964: 88).

From this perspective we cannot know why people behave as they do, unless we know how they experience their social world. This understanding informs my approach. I want to explore the meanings individuals apply to their situation. For example, the ways in which the participants apply meaning to symptoms, as well as how they perceive the availability of a range of resources, in the context of their daily lives, and how, as a consequence of this they reportedly take, or do not take, different types of action.

Schutz extends Weber's theory, emphasising that our social position, moral standing and personal biographies are essential in the interpretive process, which guides action:

'the place which my body occupies within the world, my actual Here is the starting point from which I take my bearing (not just physical but also moral and ideological)... And in a similar way, my actual Now is the origin of all the time perspectives under which I organise the events within the world' (Schutz, 1971: xxxi).

Further, Schutz claims that Weber neglected the *inter-subjective* nature of the social world. People share common-sense understandings and share notions of *'the way of life considered to be the natural, the good, the right one by members of the "in-group"'* (Schutz, 1971: 13). In other words, our physical biographical social and moral positioning in a shared world combine to inform our interpretations of, and actions in, daily life. This interests me, as these aspects of the chronic illness experience have been the focus of a great deal of attention. For instance, it is well documented that people with chronic illness share concerns about their roles, identities and moral adequacy, which are inextricably linked to their personal biographies (Charmaz, 2000b).

Both Weber's 'action theory' and Schutz's philosophy inform a sociological theory of enquiry; symbolic interactionism. Again not a unified theory, I will identify some

essential characteristics, stemming from Mead's theory of social behaviour and how 'the self' experiences social life (Mead, 1967). This approach is concerned with the shared everyday worlds in which we all live, and how, through symbols and communication, the most important of which is language, people create order and meaning out of their daily interactions. For Mead, to have a self-conscious mind is fundamental to social action. To be self-conscious; to be aware not only of one's own feelings, motives and views but those of others; and to be able to take the 'role of the other' and see oneself as others do, informs both how we see ourselves, and action.

Concerning the relationship between meaning, action, and the self, Mead distinguished between the 'I' and the 'me', between a person's inner self and his/her public front, or how we present ourselves to others in particular situations or environments. From a practical point of view it is not possible to predict accurately the expectations of everyone we meet, so we create a generalised other, an image of what we think other people would think of us, and try to act accordingly. Mead notes: *'The self is not something that exists first and that enters into a relationship with others, but it is, so to speak, an eddy in the social current and so still a part of the current'* (Mead, 1967: 182).

Therefore, Mead maintains the self is a social process, we can only be a self, and realise a valued self through social contact:

'It is the realisation in some sense of this self that we are continually seeking... Since it is a social self, it is a self that is realised by others to have the very values which we want to have belong to it. It realises itself in some sense in its superiority to others... We do belong to the community and our self-respect depends on our recognition of ourselves as such self-respecting individuals... we want to recognise ourselves in our difference from other persons' (Mead, 1967: 204-205).

So, according to Mead, the sense of self we gain is ongoing, based on shared understandings about valued behaviour, to which we aspire. There is a constant dynamic between our inner selves, our projected image, and the society in which we live. The consequences of this, impact on our actions. What makes this particularly relevant for my

study, is that the participants all have multiple chronic illness, and it is well documented that those with chronic illness often face, an inability to fulfil social roles, obligations, maintain identities, and sustain a coherent 'sense of self' (Charmaz, 1983). Mead's notion of self-respect and how people self-consciously reflect on their situation, experiences, and interactions resonates with how people with chronic illness attempt to make sense of their symptoms, and act accordingly.

Blumer noted that Mead's theory of human behaviour has implications for how knowledge about the social world can be collected (Blumer, 1969). He argued that in order to study social life one has to get close to it, and become familiar with what is going on. Researchers need to 'dig deep' to get close to what they study, attempting to describe social reality by interpreting the views, feelings and actions of people in a social context. In this way Blumer took the social behaviourism of Mead, and used it as a basis for a sociological approach which he named symbolic interactionism.

Another theorist who informs my thesis, and who extends the thinking of Mead, is Goffman. He was concerned with the micro-structure of interaction, and the relationship of both individuals and society to that structure (Strong, 1988). Like Mead, his interest was in analysing human interaction and the 'self' in everyday situations. The central aim of his work was to dramatise the way all of us try to establish and defend our self-image, both publicly and privately, and to illustrate the wide variety of 'fronts' and strategies we employ to manage positive presentations of our 'selves', and preserve our moral identities. In particular he offered an explanation about how those who are most at risk from negative labels, and who face stigma, seek to maintain their self-esteem and personal identity. Goffman notes:

'A status, a position, a social place is not a material thing, to be possessed and then displayed; it is a pattern of appropriate conduct, coherent, embellished, and well articulated. Performed with ease or clumsiness, awareness or not, guile or good faith, it is none the less something that must be enacted and portrayed, something that must be realized' (Goffman, 1969: 65-66).

This adds another dimension to my study. I am exploring the experiences of those with

chronic illness. Illness itself and the ways in which it is managed, is morally infused. When one is ill meanings about the self and the place which one holds are at risk. How do people manage to portray themselves positively in daily life; how do people *realize* their status? This is a key dilemma for those with chronic illness (Riessman, 2003).

Schutz, Mead and Goffman link the subjective, interpretive process to the social, and the accomplishment of the self to one's relationship to others. Strong noted that Goffman, touched on, but then failed to engage with the crucial macro dimension, adding that *'the fact that he did not, does not mean we cannot'* (Strong, 1988: 246). Others agree, and say that in order to gain an understanding of how people experience their worlds, and accomplish 'self', analyses should link the macro and micro aspects of the social world. As reported in Chapter Two, the situated narrative makes this possible. To reiterate, Riessman used a Goffman and Bourdieu informed narrative analysis in order to investigate accounts of chronic illness experiences. Charmaz (1990) too used structural theory alongside a symbolic interactionist tradition to *'provide tools for linking subjective consciousness and choice to larger social structures'* (Charmaz, 1990: 1161). I follow their example, and use the theory of Bourdieu and his concepts of habitus, field, capital and symbolic violence, to discuss my analysis in Chapter Eight.

As I was not hoping to uncover 'the truth' from the interviews, but accounts of how people experienced illness, it seemed plausible that the ways in which they accounted for their actions, and presented themselves in the interviews might add insight into the overall experience of chronic illness. However, the status of the interview accounts (and *any* research data) is a fundamental dilemma which begs further attention. I will address this problem in the following section.

3.3 Interpretivist interviews

Although not a unified field of inquiry, and associated with research traditions such as positivism (Charmaz, 2000a; Denzin & Lincoln, 1994), qualitative research is usually linked to the interpretivist paradigm. My aim is to investigate how people with chronic multiple illness, but contrasting consulting rates, manage their illnesses and make use of

the general practitioner consultation. In order to do this I wanted to explore the meanings symptoms had for participants, in the context of their daily lives, and further, how they perceived their situation and the availability of resources. I hoped to investigate how commonsense ideas drive behaviour around health practice and management techniques. I had access to the Twenty-07 data-set, a longitudinal health survey (see 1.1), which I used as a sampling frame. Thus, I had the opportunity to explore the interpretations of people who had reported similarly high levels of illness, but varying general practitioner consultation patterns.

3.3.1 Interviews

As a framework for data collection, interpretivism provides guidelines to suitable strategies of data gathering, rather than advocating a particular method. The interview is regarded as a method suited to the ontological position '*which supports the notion that people's knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties to explore*' (Mason, 1996: 40). Often used in medical settings (Britten, 1995), fundamentally, the qualitative interview should be an arena in which the researcher gains an insight into the participants' experiences.

I chose to use in-depth interviews, which allowed me to gain detailed accounts of a small number of topic areas, based on a topic guide. In line with good practice my subsequent questions consisted of prompts and probes for clarification (Britten, 1997). This meant the interviews were flexible, and allowed for modification of the order and content in the light of responses, or lack of responses of participants. I wanted the participants to talk freely about their experiences in order to gain 'thick' description, and to generate 'rich' data. This method also enabled a level of comparability between the accounts. I wanted to compare the experiences of the participants to glean similarities and differences between them. I considered the selection of in-depth interviews would provide me with a way to address my aims, and gain useful data.

I chose one to one in-depth interviews as my main research tool as I felt this was a practical, ethical, and useful method of inquiry in order to gain insight into the ways people actively, interpret symptoms, and perceive resources, in the context of a daily life often organised around the family, work and leisure. However, problems of validity, and the status of interview accounts are pivotal to concerns about the usefulness of the data generated (Silverman, 1998; West, 1990).

3.3.2 Status of interview accounts

Broadly, regarding the status of interviews, at one extreme the positivists claim to seek the truth from a sterile interview context, and the use of robust design and analytic techniques. Alternatively, are those who can be termed social constructionists, from the interpretivist camp, who claim that there is no reality 'out there' to be uncovered, but rather multiple truths, perspectives and interpretations of the social world. Consequently 'facts' are fluid.

To accept such an opposition means either claiming we can gain a representation of the real world from interviews, or that they bear no relation to anything beyond the interview context. If realities are socially constructed, as a result of how individuals make sense of the world and the interpretive process, this extends to knowledge produced by research. From this perspective there are no truths, no objective facts to make statements about, and the researcher's interpretation is one amongst many. This core dilemma about how we can know the social world has been addressed by Hammersly (1998).

Hammersly disagrees with the positivist position which claims that research is able to provide a window on reality (Hammersly, 1998: 49). He also disputes the view that the only alternative is to claim that we cannot 'know' the social world. He dismisses the notion that the researcher's interpretation of evidence is one reality amongst many, and has no more or less credence than any other knowledge statement. Rather, he maintains that there are multiple realities, based on people interpreting, and actively making sense of, their world. But, importantly, he suggests that it is possible to attempt to 'get at' a

range of realities, gain an understanding of the perspectives of others, and assess the validity of interview accounts. Thus he offers a pragmatic approach to social research which he terms '*subtle realism*'. He notes that although we can never be entirely sure of truth claims:

'often we can be reasonably confident about the relative chances of validity of competing claims. Assessment of claims must be based on judgements about plausibility and credibility, on the compatibility of the claim, or the evidence for it, with the assumptions about the world that we currently take to be beyond reasonable doubt...The aim of social research is to represent reality, but this is not to say that its function is to reproduce it (that is, to represent it in its own terms)...Thus there can be multiple, non-contradictory and valid descriptions of the same phenomenon'. (Hammersly 1998: 51, emphasis in the original).

I take a pragmatic view here and adopt the '*subtle realist*' dictum which has emerged out of such philosophical debates. Subtle realism accepts interview accounts as social constructs, but at the same time sees such talk as referring to realities which extend beyond the interview set-up. In so doing, it is informed by the dialogue which prioritises robust research, but avoids being limited by inflexible paradigmatic constraints.

3.3.2.1 Validity

Having both reported on a key dilemma, and offered a solution in the way of subtle realism, I am faced with another problem. How valid or 'true' are my findings? In other words, how closely do they represent what the participants have said; how closely do they portray the participants' experiences, and how far do they relate to an external reality? Finally can I make any claims of external validity? In my analysis and interpretation of the data, I treat the interview accounts as situated narratives. This needs explaining in more detail before answering these questions.

The narrative analysis approach suits the interpretivist sociological position. It treats in-depth interview data as narrative in an attempt to see the world explored through the eyes

of the participants (Charmaz, 2002b; Holstein & Gubrium, 1995; Silverman, 2000). It potentially facilitates both an understanding of overarching themes, and the more finely grained context of the experience of daily life. It assumes multiple realities, and demonstrates the impact of structural constraints on personal experience. Fundamentally, it traces episodes, and links what may seem disparate 'pieces of talk' by avoiding fragmentation of accounts as far as possible. It also prioritises the core role of language and merges with Goffman's theory, treating talk as part of the analysis and addressing how individuals construct realities in the interview situation. Importantly, some see narratives as having another dimension which moves beyond accounts of experience and positive impression management.

The notion that narrative accounts are not simply representational, but also constitutive has been adopted (Kelly & Dickinson, 1997). According to Somers, '*narrative is an ontological condition of social life*' (Somers, 1994). She reports on research which maintains:

'stories guide action; that people construct identities (however multiple and changing) by locating themselves or being located within a repertoire of emplotted stories; that "experience" is constituted through narratives; that people make sense of what has happened and is happening to them by attempting to assemble or in some way to integrate these happenings within one or more narratives; and that people are guided to act in certain ways, and not others on the basis of the projections, expectations, and memories derived from a multiplicity but ultimately limited repertoire of available social, public and cultural narratives' (Somers, 1994: 614).

So, although Somers is clear that narratives are selective, she also sees them as sites where '*agency is negotiated, identities are constructed, and social action mediated*' (Somers, 1994: 620). She maintains that people are guided to act by their structural and cultural contexts, *and* by the stories through which they construct their identities. She argues that *not* to act in particular ways, would '*violate their sense of being at that particular place and time*' (Somers, 1994: 624, emphasis in the original). This resonates with the symbolic interactionist emphasis on the importance of language, the inter-

subjective Here and Now of Schutz's work, the concerns to manage positive presentations of self focussed upon by Goffman, and Bourdieu's concept of *habitus*. From this perspective, people may offer favoured accounts, but nevertheless a systematic and rigorous analysis which looks for coherence and consistency, whilst attending to the construction of identities, also sheds light on an external reality.

The narrative lens enables the systematic analysis of data (Riessman, 1993), which I undertake. With this in mind, I will address the four aspects of validity I noted above. I want to show that, as far as practicable I have tried to represent what the participants *say*. I have also attempted to build into the analysis as far as possible, checks that the accounts are *credible*, in that they relate to how the participants experience chronic illness. Because I suggest that it is plausible to say that aspects of the accounts are *compatible* in some way to an *external reality*, I have, where possible, checked for consistency and coherence throughout the interpretive and analytic process, and checked detailed field-notes. Finally, I have applied sociological theory to the narrative analysis to try to strengthen any general claims about social action.

First, how closely does my interpretation of the accounts represent what was said in the accounts? In order to make convincing theoretical claims about what the participants have said, I have supported my claims with evidence. I hope to show through my analysis and use of data extracts in the findings chapters that I stay 'true' to the concerns voiced by the participants. To aid this, I have undertaken rigorous and systematic analysis, illustrated in the findings chapters, as well as in my discussion of the analytic process (see Appendix B for examples of the analysis).

I also need to demonstrate internal consistency and overall coherence of my interpretations. Riessman (1993) identifies three main levels of such coherence, which I will briefly note. *Global coherence* relates to an overall theme which permeates the whole account. For instance, I claim that the participants in this study work to manage a positive impression of themselves, constructing their moral identities as they speak. *Local coherence* is the form of the language used. A close analysis of how the participants

speak offers ways of gaining an understanding of the significance of what is said. For example, I have pointed out how the participants use rhetorical devices, such as positioning whereby they juxtapose their behaviour alongside others who behave in less 'ideal ways'. Finally, *thematic coherence* refers to the content of the accounts. For instance, the participants were concerned to give examples of their stoic resolve in the face of symptoms, and also spoke of consulting the GP as a last resort. *'If an utterance is shown to be understandable in terms of the three kinds of coherence, the interpretation is strengthened'* (Agar and Hobbs cited in Riessman 1993:67). By building these guidelines into my analysis, I have demonstrated an overall coherence of my interpretation of the accounts.

The second major concern is how do I know the participants are not lying? I cannot know for sure. But I can build into the analysis ways of minimising inauthentic accounts, and maximising the trustworthiness of what is said. Bearing in mind that I perceive the interviews as situated narratives, which assumes that the talk is a favoured point of view, I still want to discover, as far as possible, how far the accounts relate to meanings and interpretations which the participants apply and construct. In order to aid this process, I have looked for consistencies and coherence (as noted above), both between and within transcripts. I also asked open questions, giving the participants the opportunity to prioritise their concerns. For example, I asked: "Tell me about your conditions", rather than "Tell me about your problems with your conditions". Both offer open responses, but the second version assumes the condition has been conceptualised as a problem, thus missing the opportunity to explore how the participant applies meaning in an open way. Another example would be "What helps?", rather than "How does your family help? Again, the second question is open, but makes assumptions, that the participant has interpreted the family as helpful. Such questions offered the participants the opportunity to give detailed responses and prioritise their concerns. For example, the participants talked about medication, which I had not built into the topic guides (see Appendix C for topic guides), but was indicated as a major theme in response to being asked what helped. Field notes also helped support the trustworthiness of the accounts (see Appendix D for example of field notes).

Next, how confident can I be that the accounts are more than vehicles to construct positive moral identities? There is no way of knowing *for sure*, based on my data, whether or not what is described concords with what happens. However, it is plausible to suggest that, the accounts do relate to an external reality, *depending on the transparency* of my interpretations and analysis. I have attempted to illustrate a systematic, rigorous analysis which focuses on the content, the context and the form of the talk, and allows for comparisons to be made between and within transcripts, and looks for consistency and coherence throughout. The interview-diary-interview strategy, and the extensive use of field notes to supplement any knowledge claims helps build confidence in this aspect of the findings (See Appendix E for diary). Related to this, I want to comment on the participants' reports of the medical encounter (Chapter Six, 6.6 and Chapter Seven). The accounts of the consultation itself do not offer the opportunity to check for consistency and coherence beyond the context of the interview, nor do they benefit from notes and observations in the field. Further, as I identified in the literature review (2.3.1.2), there is evidence to show that what people report about the medical encounter does not always reflect what happens. With this in mind, I cannot make 'reality' claims about this aspect of the data.

Finally, how far are the findings of this study relevant to other settings? Generalisation or what is often termed transferability in qualitative research is a contentious issue. I would agree with Williams (2000) who maintains that moderate generalisations can be made from interpretivist findings. That is, that cultural consistency needs to be clear in the analysis, making theoretical generalisations possible (Williams, 2000: 221). I would add that the *external validity* of any general statements made, however moderate, are aided by the transparency of the analysis, which I have attempted, and the application of sociological theory, which I have used.

Although a contentious issue from within the interpretivist camp, I would agree that triangulation, for instance findings from other types of research such as the survey, adds to the validity of any general statements made, as does the synthesis of qualitative studies (Campbell, 2003). One shortcoming of this study is that I have not used triangulation. For

instance it would have been worthwhile, but not feasible to have interviewed the GPs of the participants in the study, or to have gained observational data of the consulting process. Also regarding this study, I have not undertaken a systematic review of similar research, but, building on my literature review in Chapter Two; in Chapter Eight I have explicitly related my findings to relevant qualitative studies.

Essentially, I would agree with Charmaz who states of the validity of narrative accounts, the aim for the researcher is to: *'portray participants' lives in all their complexity – from silent moments to storied claims – while revealing their empirical and theoretical significance'* (Charmaz, 2002b: 307). This is what I have aimed to do.

3.4 Reviewing the literature

From the early stages of the research up to the penultimate draft of the thesis, I read but did not carry out a systematic review, as the range of reading was so vast and wide ranging. Although I did not follow a formalised procedure, there was logic to my method. I attempted to trace a path through the enormous amount of literature which seemed relevant to my study. Here I will outline this attempt.

Initially, I explored two broad areas; literature relevant to the topic, and literature related to methodology and method. I defined the topic, and identified that the main disciplines were sociology, medical sociology and the more medically based 'paradigm' of General Practice. The reading around the method and methodology was to be found, to varying degrees in each of these areas.

This reading helped me to identify work in the area and find gaps in existing research and helped with the study design based on both philosophical and practical considerations. I searched for different kinds of materials: books; journals; conference papers; theses; government documents; web-based information including electronic journals and particular web-sites and discussion groups.

I selected a core number of medical sociology journals, and text books. The journals offered a way to trace ongoing debates in the area of chronic illness, and how best to study it. The text books offered me an insight into the way in which medical sociology had developed, and how concerns around chronic illness had been well documented. Both of these sources also revealed first order theoretical texts from mainstream sociology, and 'classic' monographs on illness and consulting behaviour. In this way I soon familiarised myself with primary and secondary texts relating to both topic and method. I constructed a timeline to organise my reading into a logical format, and trace the development of theoretical approaches and research on illness experience

I searched journals for articles using electronic data bases, such as medline, embase, web of science and bids. I used terms such as: chronic illness; multiple morbidity; co-morbidity, primary care; general practitioner; consultations; frequent consulter; and self-care. I later added terms to my search, such as, narrative and biographical, as a result of my reading, conference attendance and analysis. I gained access to the abstracts online, and decided whether or not to read the full article, based on the topic, and the method of enquiry. Any article I chose to read, I downloaded in order to read, annotate and file. I received ongoing web-mail alerts from a limited selection of key journals, and continued to undertake web-searches throughout the course of the study, and up to the final draft of this thesis.

Because I wanted to use diaries as a research tool, I searched more systematically for articles which had included diaries in the research design. Again I used the electronic data bases, and identified a number of articles from different journals. In reading the articles initially I took special note of the method design, looking for particular characteristics such as diary content, duration, and completion rate. I then charted a total of 21 diary studies, noting the study population; any other methods which had been used; the duration of the diary; the purpose of the study; the purpose of the diary; the diary contents and the completion rate. I also gained example diaries from five of the studies (Burman, 1995; Elliot, 1997; Freer, 1980; Kasl et al., 1975; Verbrugge, 1985). As a result

of this review, I constructed and piloted a symptom diary, which formed part of the study design (see Appendix F for diary table).

3.5 Study design

I used a three stage process to collect my data: an in-depth interview, a two week self-complete symptom and symptom management diary, and a second in-depth interview conducted approximately 3 weeks after the first interview. I intended the diarists' comments be used as an information source or *aide memoire* for the post-diary interview. Such a format gave the participants further opportunities to place their priorities on the second interview agenda, and potentially offered me the opportunity to explore the unfolding nature of chronic illness through prospective accounts. I hoped that this would be a way of revealing something of the relationship between perceptions, actions and consultations and potentially improving validity.

I decided to organise the pre-diary interviews around three broad overlapping sections: conditions and symptoms, the impact and management of conditions on daily life, and the use of formal services. The second interview allowed greater focus on management of symptoms (which had been recorded on a daily basis in the symptom diary).

I considered the methods would offer me an opportunity to get as near as possible to the experiences of individuals, and limit the possibilities of misrepresenting the participants. I also felt that two interviews would aid validity, giving me an opportunity to develop rapport, and gain participant 'validation' of the first interview, as well as allowing me to 'follow-up' points for purposes of clarification. It also meant that if I became aware that the participant felt tired or uncomfortable, I could draw the initial interview to a close in the knowledge that there would be a second opportunity to ask questions which may have been neglected. Based on my reading, I also felt that a two-week symptom diary was the optimum length of time to gain data, and to prevent participant fatigue. I felt such a research design would best accomplish the generation of data which would allow me to achieve my aims.

Here I describe the pilot work I conducted to prepare for the main study. I identify my observations, which both confirmed aspects of the research design and revealed problems leading me to introduce changes. The reflexive process and the robust nature of the research are therefore indicated. I go on to detail the subsequent methods I used, and outline sampling considerations.

3.6 Pilot study

Early sensitising work and the pilot study allowed me to test the feasibility and appropriateness of the research design. I was also able to develop my interview skills, and appreciate the importance of detailed field notes as well as gain early indications of participant concerns, and my own anxieties about amassing data.

As preparatory work I observed two sessions of one general practitioner's consultations. I noted the reasons given for the consultation, how patients described their symptoms, the overall interactive order in the consulting room, and the language used. This informed the development of the topic guide, and prepared the way for the interviews.

Four participants took part in a pilot study. They were asked to take part by their general practitioner who had offered help with the early stages of the project. The general practitioner explained the study to two male and two female patients all of whom agreed that I could contact them. Interviews were arranged by telephone. The participants were interviewed in their own homes, completed a symptom diary, and interviewed again approximately three weeks after the first interview.

Interview one was organised around three broad but overlapping sections (symptoms, daily life and use of the general practitioner). At this pilot stage, the second interview was loosely structured around two sections. The first part focused on the initial interview, and the second part on the symptom diary.

The four participants described their symptoms in detail, and spoke extensively about how illness impacted on their daily lives. They described management techniques which

involved intricate planning of their daily routine, complex management strategies and practical and emotional support from their friends, and particularly their families. The personal stories they told merged with talk of their symptoms. The pilot participants spoke extensively about their relationship with their general practitioner, always in positive terms, which was perhaps unsurprising as they had been recruited via their doctor. However, they also made negative references to other health workers including other general practitioners.

The agenda within the three areas of the first interview was flexible and explored what people said in as much detail as possible. Thus I adopted the use of a topic guide rather than a more structured interview schedule. I transcribed all of the pilot interviews. This was a worthwhile experience, although time-consuming.

As a consequence of undertaking the pilot interviews, I became aware that I needed to give clear guidance at the interview outset as to the detail of answer I required. I also became aware that I needed to check my understanding of what participants were saying throughout the interview. Problems emerged in terms of my interviewing skills, which I attempted to address for the main study. For example listening and remembering proved harder than I had anticipated, and I introduced a 'prompt sheet' for myself, on which I made notes, in order to help my listening skills, and as a memory aid.

As a result of the pilot process I decided that two to three interviews a week would be the optimum number to aim for. This would allow me to focus on field notes, reflect on the interview content, and on my technique, allowing for maximum concentration. All of these factors added rigor to the study in that this exploratory work sensitised me to shortcomings, new concerns, and clarified the research purpose. As a result of the pilot I decided to use a more structured approach in the study for the second interview, to encourage elaboration and clarification of both the diary and the first interview.

This pilot work was useful for a range of reasons. First, in terms of the method used it confirmed the decision to utilise the interview-diary-interview structure, although it

prompted me to change the format of the diary. As a result of these initial interviews I decided to add more structure to the diary. I included more prompts in an attempt to encourage the participants to include more information.

Transcribing the pilot interviews alerted me to some details of the interview process which I had not noticed at the time. As I listened to the taped interviews, I became aware of over talking; background noise; and the variety of ways a tape recording can be transcribed (the silences, tone of voices, dialects, accents, repetitions). Also, it highlighted how easy it is to mishear something, and so misrepresent what is being said. It also sensitised me to the importance of cross-checking the transcripts against the tape-recordings of the interviews. Furthermore, it prompted me to situate the microphone at a distance from any over zealous budgerigar, or persistently growling dog. I also learned that at times I was not achieving a good balance between talking and listening. This came to light as I transcribed and annotated the pilot interviews, as I noted all of my comments, questions and responses in relation to the participants' talk. This seemed to be in part as a consequence of my fear of silences, which I attempted to curb in subsequent interviews.

These pilot interviews also revealed the complex nature of the data I would be gathering and raised real concerns about how I would organise, describe, analyse and present my data. Finally, it allowed me to explore whether different age groups should be included in the study. Another important decision made as a result of the pilot interviews, was that our original notion that equal numbers of men and women from a range of socio-economic backgrounds should be included was confirmed. This facilitated a sufficiently heterogeneous group for comparisons. As a result of the pilot we concluded that including a further structural variable such as age would hinder an in-depth analysis and hence we restricted the sample to a single age group. All of the factors identified above informed the main study design which I discuss below.

3.7 The main study

3.7.1 Ethical issues

Because I intended to sample from the quantitative data-set of the West of Scotland Twenty-07 study, a longitudinal, community survey of the social patterning of health, consent to undertake this study was sought first from the Twenty-07 Steering Group. Ethical consent was then gained from the University of Glasgow Ethics Committee. To maintain the confidentiality of all those taking part in the study I have anonymised all participants by giving them pseudonyms and allocating numbers to the interviews and diaries.

The participants received details of the study design through the post (see Appendix G for letter and information sheet), and then had telephone contact with me, so I could answer any queries. At the start of the first interview, I reminded them that they could withdraw from the study at any time, and assured them that if they chose to do so this would not affect their continued participation in the Twenty-07 study. I went over the information sheet with them, and explained the consent form which they signed (see Appendix H for consent form).

I asked again for permission to tape the interview, and explained that the participants could request for the tape recorder to be switched off at any time. At the end of the first interview I explained the format of the diary, and commented that if they felt unable or disinclined to complete it, they could stop filling it in at any time. At the start of the second interview I checked my understanding of the first interview by summarising the points which had been discussed. I also asked for clarification throughout both interviews to avoid misinterpretation as far as possible. This limited the possibility of misrepresenting the participants' views and reported experiences.

I also remained aware that the completion of the interviews and diaries could affect the participants. For example, they could dwell on their conditions, and may become

sensitised to aspects of their lives which they had previously taken for granted, as I was asking them to reflect on their symptoms and how they managed in the context of their daily routines. This necessarily involved talk around thoughts and actions, which would have the potential of bringing into a sharper focus the more negative aspects of their lives. I needed to remember this, practise reflexivity, and try to strike a balance between facilitating talk which would generate 'rich' data, and framing questions in a sensitive way and order. For example, I attempted to finish the interview on a positive note.

As all of my participants had several chronic conditions, I also needed to be sensitive to any signs of discomfort or fatigue throughout the interviews. I did occasionally draw interviews to a close for this reason.

Participating in a three stage interview-diary-interview study demonstrated a level of commitment that could pose practical problems for the participants, thus as recompense for taking part the participants were paid £20. Paying participants may be questionable, as it could be regarded as an inducement to take part in research that might be a burden. But, on balance, I felt that this was a tangible way of demonstrating that the experiences of the individuals were of value, and that their efforts and time were appreciated.

I made copies of the tapes and all were kept in a locked filing cabinet for access and security purposes, as were the paper transcripts. The tapes were numbered, and the transcripts were given corresponding numbers and pseudonyms.

3.7.2 Sampling

The sample for the main study was selected from the West of Scotland Twenty-07 study. This is a Medical Research Council (MRC) funded longitudinal survey of the social determinants of health in the Central Clydeside Conurbation in three age cohorts. Participants in the Twenty-07 study were in their mid-teens, mid-thirties and mid-fifties when first interviewed in 1987/8. In addition to the baseline interviews, participants have taken part in face-to-face interviews in their own home with qualified nurses in 1990/1,

1995/6 and 2000/3. When first recruited the participants were told that this would be a twenty year study. They were also informed that they might be selected to take part in further studies. As described in the introduction (p10), analyses of data collected in 1995-6 showed that, although reported morbidity and symptoms accounted for about a quarter of the variation in general practitioner consultations, much of the variation (c.70%) remained unexplained even after taking account of other factors (Wyke et al., 2003). In order to explore this further we conducted this study.

The aim of the study is to investigate how people with multiple chronic illness but contrasting consulting rates, manage their illnesses and make use of the general practitioner consultation. Thus, in designing this project, we aimed to *minimise* variation in the burden of ill-health but *maximise* a contrast between high and low users of general practitioner services. Twenty four participants were purposively sampled for more detailed investigation based on a number of criteria. Firstly, we chose to subsample only from the middle cohort of the Twenty-07 study who were then (June 2001 - June 2002) aged around 50. The cohort was chosen because it allowed me to avoid potential age differences in approaches to managing illness and consulting. The proportion of the younger cohort with multiple morbidities was much smaller and they were likely to be a very unusual group. Further, this younger cohort's experiences of consulting would be confounded by child-bearing. Selection of members of the older cohort would not have allowed an exploration of paid work, and participants may have felt ageing issues to be important too. Thus sampling from the middle cohort allowed the possibility of exploring the experience of multiple morbidities in daily life at a relatively young age and the impact this has on one's identity in terms of family and employment status as well as leisure activities.

Secondly, we had to operationalise our aim to minimise (or 'control for') morbidity and maximise variation in consulting. On examination of the distributions of numbers of chronic illnesses together with GP consulting patterns, we defined 'high' morbidity as having reported four or more chronic conditions in the most recent nurse interviews (in 2000-3). The definitions of 'frequent' and 'less frequent' consultation rates were

constructed on the basis of answers to the question (in the 3rd sweep in 1995/6): “How many times have you consulted the GP at his or her surgery on your own behalf?” and we took the lowest and highest tertile to define our two contrasting groups. Thus half of the participants had ‘frequent’ (seven or more consultations, i.e. within the highest tertile) and half had less frequent (three or fewer consultations, i.e. within the lowest tertile) consultation rates in the previous 12 months.

Finally, because consultation rates have been linked both to socio-economic circumstances and to gender (Wyke et al., 2003), the study was also sampled on the basis of these variables. Again we aimed to achieve a sample that had similar numbers of men and women, and a balance of people from more and less deprived social circumstances. Housing tenure was used as indicator of socio-economic circumstances. Employment status was considered unsuitable as many of those taking part were unemployed due to their health status. In this way the sample offered participants with a range of characteristics to allow important comparisons to be made, but the number of variables was limited to facilitate an in-depth analysis, and robust comparisons. This was a pragmatic decision based on practical considerations of time and money as well as analytic rigour.

3.7.3 Recruitment

One of my supervisors provided me with a list of the 95 participants in the middle cohort who fulfilled the morbidity and consultation criteria. The list detailed the participants' illness conditions, sex and housing tenure. Each participant had an identification number for reasons of anonymity. First, I selected those from the list who seemed most appropriate for comparative reasons in terms of conditions (most similar combinations of illness and symptoms). I then gained the names, addresses and telephone numbers of the selected cases from the survey support team.

I sent approach letters and information sheets to 41 potential participants (see Appendix G). The remaining 54 were not contacted as a result of the target number for interview

being reached (24 had agreed to take part, at the time of interview the 24th participant was unwell and was unable to meet on two occasions; due to time it was decided to finish the fieldwork phase). A senior researcher involved in the Twenty-07 study signed the approach letter. The information sheet explained that taking part would involve two interviews, about three weeks apart, and the completion of a symptom diary for two weeks between the interviews. Participants were informed that they would receive a phone call from me within a week of the letter's arrival to discuss participation. The letters and information sheets were dispatched in three batches. Twenty three people participated, 20 took part in two interviews, about three weeks apart, and the completion of a symptom diary for two weeks between interviews. Three female participants took part in only one interview; one could not be re-contacted, one had family illness, and one became more ill between the two interview dates.

In the early stages of recruitment there were no significant problems. Contacting participants was relatively straightforward. Arrangements for the interviews were made on the phone, allowing me to introduce myself prior to the first interview contact. Occasionally arrangements were made through a third party; for example, the partner. The main problems I encountered in securing agreement to participate were due to individuals being ill, working away, or holidays. The fact that the participants needed to be committed for a period of three weeks seemed to have minimal impact.

As a consequence of the three week interview-diary-interview design, and in an attempt to minimise my confusion in terms of interview content and initial observations of cases, it was considered appropriate that I would conduct the interviews over four phases of approximately four week blocks. This would allow me to analyse initial data in terms of comparisons between interviews and participants. Thus around six participants were contacted at any one time. We estimated that the interviewing phase of the study would take around six months. However, the schedule was affected by holidays, illness, employment commitments and bereavement, and the time scale stretched to 12 months. I conducted the interviews between August 2001 and July 2002. Of the 41 participants contacted by letter, 23 took part. Of the 18 who did not, three could not be contacted,

eight refused, and seven were unavailable at the allotted time, but were willing to take part if needed subsequently.

As a result of purposive sampling the first 12 cases included an equal number of men and women, with seemingly similar levels of illness, and opposing consulting rates (identified as frequent and less frequent consulters). Despite sampling from a large quantitative study, filling the proposed cells was not unproblematic. We screened the lists of chronic illnesses that each potential participant had reported to try and rule out people with more minor morbidity (e.g. allergies etc.). The characteristics of those who had agreed to take part in the study was monitored at key points in the fieldwork, and midway through the fieldwork it was noted that most of the first 12 participants were home owners. During this phase it was found that there were fewer participants in rented accommodation to contact (see table 1), and of those suitable some had moved house, and others did not want to take part. The problem of recruitment in areas of high socio-economic deprivation has been identified in the literature (Parry et al., 2001). Those who declined to take part could well have had other priorities in their attempts to juggle their chronic conditions and their daily life. During the second half of the study, it became more difficult to identify suitable male participants, particularly who live in rented accommodation. The group who took part comprised 13 women and 10 men; 13 home owners and 10 renters.

Those interviewed, had a range of social characteristics, and formed a small group of self-selected participants. The participants had already shown a level of commitment and interest in the topic of health research, and a willingness to take part in research, by taking part in the Twenty-07 study. Due to resource and ethical constraints the conditions and consultation rates were self-reported and have not been triangulated against surgery notes, nor have general practitioners or family members been interviewed. However, there is evidence to show that self-reported attendance does accord with general practitioners' records (Little et al., 2001). Table 1 summarises the recruitment according to characteristics used in purposive sampling.

Table 1: Numbers of participants who fulfilled study criteria, numbers contacted and numbers interviewed by consultation, gender and housing status.

	High female rents	High female owns	High male rents	High male owns	Low female rents	Low female owns	Low male rents	Low male owns	Total
Sample frame	12	17	3	6	7	24	5	21	95
Contacted	6	5	3	5	6	6	4	6	41
Interviewed	3	3	2	3	3	4	2	3	23

* In text high = frequent, low = less frequent

Early analysis and writing up was conducted 'blind'. All of the transcripts were analysed and the main themes identified prior to organising the findings around frequency of consulting 'types'. Early drafts of chapters were based on themes which had emerged from the data, and organised around differences and similarities between (groups of) participants. Only then did I check the participants' consulting patterns. Of the 23 participants, 6 no longer fitted their original categories, and interpretation was based on their most recent consulting pattern. Their accounts reflected the corresponding consistently frequent or less frequent consulters. However, 2 of the 6 did not fit into either category, but had reduced their consulting from 12 to 5, and 9 to 5. Their accounts revealed associated reduced impact and increased ability to manage, thus no significant or deviant results were identified from these two participants' accounts.

I identified 7 consistently frequent consulters, and 10 consistently less frequent consulters. Based on the aims of my study, that is, to allow for explicit comparisons between frequent and less frequent consulters, I then organised my findings chapters around the 2 consistent 'types'. However, all accounts had been analysed in-depth, and interpretations and theory building were based on a consistent comparison between and within all of the transcripts.

Subsequent analyses and interpretations which focus on different aspects of the accounts may reveal differences between groups of 'consistent' and 'inconsistent' consulters. For

example, an analysis which compares and contrasts the accounts of relatively 'recovered' and 'still ill' individuals may be particularly useful in trying to understand the different ways people talk about their experiences in terms of retrospective and prospective accounts. This was not within the scope of this thesis, so for pragmatic reasons I have not used the 6 'inconsistent consulters' to illustrate the data generated from the 23 accounts.

As the field-work progressed, it emerged that some of the participants had more severe illness than others. Preliminary analysis of the findings supported this observation, although there was also evidence to suggest that social positioning, and symptoms combined to impact on the participants. Subsequent analysis revealed that the participants could be divided into broadly, three groups: those with consistently long-standing, severe symptoms which had a major impact on daily life; those with long-standing, less severe conditions which had less impact on daily life; those who moved between severe and less severe conditions or episodes, and associated impact on daily life. As I continued writing and I organised chapters around 'types' of consulters, it became apparent that, typically, the consistently severe groups were the consistently frequent consulters, the less severe group were the consistently less frequent consulters, and the inconsistent group were the inconsistent consulters. Any deviant examples are addressed in the findings chapters.

Regarding mental health and associated patterns of consulting, of the 23 participants on whom the analysis and interpretation was based, 13 had reported depression and/or anxiety in the survey interview. Of these 7 were women and 6 were men; 4 were 'consistent' frequent consulters and 4 were 'consistent' less frequent consulters; 5 lived in rented accommodation, and 8 were home owners. During the study interviews, six reported depression or anxiety as their main health problem, whilst 3 reported their main health problems were physical but, at times, caused them to feel depressed. Although this is a qualitative study, and numbers not prioritised, it is worth noting that according to these figures, depression and anxiety were not linked to consulting patterns. This supports the fact that the impact of different types (mental/physical) or specific conditions are not discussed in the findings chapters. As my aim is to understand the experience of living

with a range of chronic conditions, I have focused on accounts of core experiences shared by people with a range of chronic illnesses, as outlined in the literature review (2.3.2).

Despite the study design there was variation in numbers of consultations within the frequent consulting group. Whilst the less frequent consulters had reported from 1 to 3 consultations, the frequent consulters had reported from 8 to 20 surgery visits. Also, despite our attempts to 'control' for morbidity by selecting people with 4 or more self-reported chronic conditions, it became clear that this was an inadequate measure, which was confounded by severity of condition, and level of impairment. Thus, a shortcoming of this study is that, despite attempts to compare and contrast groups with similar levels of morbidities and opposing consulting patterns, this was not fully realised. Table 2 shows the balance of participants achieved through the sampling strategy.

Table 2 characteristics of the participants (the 17 participants used to illustrate the findings of the whole group are in bold, the remaining 6 in italics). * In text high = frequent, low = less frequent

<i>Pseudonym</i>	<i>Housing tenure</i>	<i>Conditions reported at wave 4 of Twenty-07 study 2000-2</i>	<i>Consultations in previous year*</i>
Dick	Rents	Angina, anxiety, depression, asthma, hypertension, liver problems, hernia, cataracts	High (12) Stayed at 12
Jim	Rents	Disc injury, kidney problems, depression, arthritis, hypertension, penicillin allergy	High (8) Increased to 12
Ian	Owns	Asthma, sore stomach, abdominal hernia, hypertension, angina, 2 heart attacks, spondylitis, back pain, worn discs	High (10) Decreased to 8
<i>Rick</i>	<i>Owns</i>	<i>Osteoarthritis, depression, anxiety, bronchitis, heart murmur, pins and needles in both hands, alcohol problems</i>	<i>High (9) Decreased to 5</i>
<i>Roger</i>	<i>Owns</i>	<i>Depression, disc problem, hypertension, high cholesterol, anxiety, osteoarthritis, migraine</i>	<i>High (12) Decreased to 5</i>
Janet	Rents	Asthma, hypertension, diabetes, osteoporosis, blood clots, anxiety, depression	High (12) Stayed at 12
<i>Barbara</i>	<i>Rents</i>	<i>Hypertension, angina, 2 heart attacks, depression</i>	<i>High (12) Decreased to 4</i>
Betty	Rents	Hypertension, irritable bowel syndrome, sinus problems, sciatica, ovarian cyst, migraine, tinnitus	High (12) Stayed at 12
<i>Louise</i>	<i>Owns</i>	<i>Cystitis, arthritis, depression, breast cancer</i>	<i>High (8) Decreased to 3</i>
Lesley	Owns	Hypertension, asthma, colitis, duodenal ulcer, thyroid problems, anxiety, depression	High (20) Stayed at 20
June	Owns	Emphysema, angina, asthma, hypertension	High (16) Decreased to 12
<i>Tommy</i>	<i>Rents</i>	<i>Ulcerative colitis, arthritis, gastric problems, hypertension</i>	<i>Low (3) Increased to 12</i>
Derek	Rents	Diabetes, depression, schizophrenia, peptic ulcer, hiatus hernia, hypertension	Low (3) Stayed at 3
Johnny	Owns	Diabetes, kidney problems, hypertension, depression, alcohol problems	Low (2) Stayed at 2
Paul	Owns	Mechanical back pain, joint pain, photosensitive, stomach problems, hay fever	Low (3) Stayed at 3
Peter	Owns	Proctectomy & Ileostomy, pelvic abscess, asthma, eczema	Low (2) Increased to 3
Sarah	Rents	Irritable bowel syndrome, migraine, hypertension, inner ear problems	Low (1) Increased to 2
Mary	Rents	Osteoarthritis, partial deafness, gastric ulcer, sinus trouble	Low (3) Decreased to 2
Martha	Rents	Hypertension, collapsed lumbar disc, osteoarthritis, longsightedness	Low (1) Increased to 2
Jane	Owns	Stress, anxiety, oesophageal reflex, numbness in right hand, back pain, patchy keratosis	Low (1) Increased to 2
Marie	Owns	Myalgic encephalitis, cyst on thyroid gland, palpitations, allergy to dust	Low (2) Decreased to 1
<i>Susan</i>	<i>Owns</i>	<i>Depression, irritable bowel syndrome, sinusitis, hay fever</i>	<i>Low (2) Increased to 6</i>
Rita	Owns	Breast cancer, anxiety, depression, panic attacks, gastric ulcer	Low (1) Stayed at 1

* Number of consultations reported in previous year at wave 4 of Twenty-07 study in brackets. Based on this, those with 7 or more were classified as 'high' and those with 3 or less as 'low' consulters. Second figure, consultations reported in previous year at study interview.

See Appendix I for an outline of the 17 participants who feature in the findings chapters. This is to give some background information about the individuals, and might help when reading the analysis. It includes brief statements about the participants' family, employment, illness, consulting, management of daily life, and their use of services, particularly the role of the GP.

3.7.4 Conducting the interviews

Of the 43 interviews, 40 took place in participants' homes and three were conducted at the University. The University setting was formal and unfamiliar and although practical, I felt that this could have had an adverse affect on the interview process in comparison to interviews conducted in the homes of the participants.

A topic guide was used for the initial interview. This allowed for a degree of flexibility in that participants' priorities could be articulated and explored. As for the pilot interviews, the guide was organised into three, broad, overlapping knowledge sections: conditions and symptoms; the impact and management of conditions on daily life, and the use of formal services. I was careful to use open questions which did not impose my assumptions on the participants (see section 3.3.2.1). I attempted to elicit description in a range of ways which included the use of prompts and probes, such as asking for examples, elaborations and clarifications. I also attempted verification by 'understanding checks'. I summarised my interpretation of the talk, avoiding making leading remarks. Throughout the interviews I was careful to allow silences and wait for participant responses which I had failed to do in the pilot study. All of these approaches to interview were an attempt at internal validity.

The tape-recorded interviews lasted between fifteen minutes (1) and one and a half hours (1). Typically they were about one hour in length. I asked the participants to complete a check list of conditions and gave them the symptom diary to complete, explaining completion details (see Appendix J for condition list).

3.7.5 Diaries in the study

The completion rate for diaries has been recorded as high as 82% (Roghamann & Haggerty, 1972). In this study the completion rate (for the 2-week symptom diary) was lower. This could have been for a variety of reasons: fatigue, low priority, postal problems, time constraints, or nature of illness. Diary data was gained from 15 of the 23 participants (LFCs: 4 x 14 days, 1 x 11 days, 1 x 8 days, 2 x 0 days; 1 lost diary, 1 diary lost in post; FCs: 3 x 14 days, 1 x 13 days, 1 x 9 days, 2 x 0 days; inconsistent consulters: 3 x 14 days, 1 x 4 days, 1 x 0 days, 1 lost in post). Completion of the symptom diary did not appear to be linked to frequency of consulting.

Towards the end of the two week interview period I sent a letter with a pre-paid envelope to the participants. I thanked them for participating in the first interview, and explained I would phone them on receipt of the diary to arrange a subsequent interview. If I failed to receive the diary I phoned participants.

Although the diaries often did not contain much in the way of volume of information, they did provide a prompt for the participant to talk about personal reflections which gave me the opportunity to explore in more detail the meanings that they applied to symptoms in the course of their routine lives, and the possible actions (or inactions) which followed. In the analysis the diaries have not been used as a source of data in their own right.

3.7.6 Post-diary interview

It is claimed that *'Multiple interviews are likely to be more accurate than single interviews because of the opportunity to ask additional questions and to get corrective feedback on previously obtained information'* (Reinharz, 1992: 37). The second interview was longer and more structured than the first. It was divided into three sections. First, with Reinharz' comments in mind, I re-capped the main points of the first interview to check my interpretation; this was intended to strengthen the internal validity of the study. As Charmaz comments: *'...by making our early drafts available to those subjects who*

wish to read them, we make it possible for them to challenge and correct our views' (Charmaz, 2000a: 531n25). In summarising the gist of the initial meeting, this principle was observed. The second stage was based on questions relating to interview one. This was for clarification and elaboration, again adding validity and detail to the findings which would contribute to the richness of the data set. Finally, I asked detailed questions about the diary. Typically this meant reading through the extracts verbatim; this prompted the participants to remember, elaborate and explain. Thus the diary worked well as an *aide memoire*.

The post diary interview was an opportunity to develop rapport, and also on a more practical level it meant that the participant was not over-burdened due to time. The second interview was particularly long when the diary had been completed. There was also a discernible attitude change between the two interviews, particularly cogent if the participant had completed some or the entire diary. At times I felt that the diary had given a fresh perspective on experiences. Participants seemed more likely to write personal, sensitive and emotional information down in the diary than refer to it in the first interview. However, it is questionable as to how far the diary allowed for more sensitive talk, as opposed to simply conducting a second interview, which itself added a feeling of familiarity and contributed to a relaxed atmosphere. In some cases, the second interview was harder for me to conduct; the participants seemed more relaxed and open, which typically led to more informal conversation. This is something I noticed particularly when listening to the recordings of the interview. I attempted to overcome this by doing as others have suggested (Wengraf, 2001) and explained the interview format to the participants at the outset, adding that any questions or queries they had could be answered after the interview. I had learned from the pilot study that my normal response to chat to the interviewee was counterproductive to data generation.

3.8 Data management

3.8.1 Collection and storage

On completion of each interview, I made field notes organised around three main areas: a summary of the gist of the talk, which included my main impressions and hunches; a more practical description of the whole process; and my perception of how the interview 'had gone'. At the earliest opportunity I listened to the tapes and added to my field-notes, all of which were numbered, pseudonyms applied, and stored in a locked cabinet.

I transcribed the initial interviews. Subsequent tapes were transcribed outwith the Unit with instructions from me. Tapes were transcribed verbatim, and on completion I checked the transcripts for errors against the recordings, and made amendments. This was an onerous task but I felt was a worthwhile contribution to validity. Electronic copies of the interviews were stored in Word, and transported to Nvivo at the earliest opportunity. Hard copies were numbered and kept in a locked cabinet. Analysis was ongoing from the earliest stages. I constantly re-visited the paper transcripts to re-read and note my thoughts.

3.8.2 Analysis of the data

My analysis was informed by aspects of grounded theory, framework analysis, narrative analysis, and the structural approach of Bourdieu. Grounded theory has a contested history, and is related to both positivist and interpretivist based qualitative analysis (Glaser & Strauss, 1967). Its early version challenged assumptions that qualitative research techniques are impressionistic and unsystematic, and that qualitative research could produce only descriptive case studies rather than theory development.

My analysis is informed by Charmaz, who uses a 'social constructionist version' of grounded theory to explore the experience of chronic illness: "*Constructionism assumes the relativism of multiple realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims towards interpretive understanding of subjects' meanings*" (Charmaz, 2000a: 510). Thus, flexibility replaces a more formulaic approach to the research process, which was more characteristic of the original grounded theory.

The features of grounded theory I have used are: simultaneous collection and analysis of data; two-step data coding process; constant comparative methods; and memo writing. I attempt to construct theory from the data, based on, as far as possible, the lived experiences of the participants. I emphasise my active role in the grounded theory method, in my attempts at interpreting the data and getting close to the realities of the participants, rather than trying to discover 'the truth'.

I organised the data in several ways. I soon realised that I would amass a substantial amount of information. As interviewing and analysis progressed, I continued to work with both hard and electronic copies of the transcripts. At this stage, I used Nvivo for storage and easy access, but worked with paper based methods

First I annotated the paper transcripts, *coding* line by line. The initial codes were topic based; *the family, work, leisure, medication, the general practitioner*. I then *categorised* the paragraphs based on *positive* and *negative* aspects. I started coding using action and emotion codes, as well as topics, but still in broad ways, for example in relation to actions: *doing*, and emotions: *feelings*. I then added another category: *significance*. I now had three categories cross-cutting the codes. I constantly read and re-read the transcripts comparing different people, and data from the same individual, as well as comparing codes and categories. I also noted similarities and differences in the margins.

I spider-graphed and mind mapped developing ideas on paper. At times I felt swamped by the growing bulk of information, but this rather chaotic phase helped the process of analytic induction, and deduction. This early lack of coherence prevented premature theorising which may have impacted on the emergence of new themes and a higher level analysis.

During this stage, I was not constrained by looking for anything in particular, or forcing the data into schemes, or formalised charts. I tended to read and re-read the transcripts as a whole, in order not to lose the context of the codes and categories. I avoided

fragmentation as far as possible. This allowed me to engage with the whole 'story' of each participant. This initial lack of structure signified, in part at least my inexperience, and in some ways my panic (*What to do with all of this data?*).

I then began asking questions of the data, for example how did the participants talk about positive and negative aspects, and how did they communicate significance. What were they talking about? What did they mean? For example, as they spoke of *the family* (a *code*), what were the *positive* and *negative* aspects (*categories*), and further, how did they convey the significance of such aspects (see Appendix B for examples). The early codes and categories combined with early observations, thoughts, comments and queries were combined to form *memos*, as part of the analytic process towards theory development. As a result of this I hoped to get at the meanings that the participants applied rather than impose my own.

As a result of writing memos based on initial codes and categories I developed broad themes, corresponding to my research aims. I developed the broad theme of *impact* of chronic illness in a range of life areas. The *consequences* of the impact, and the *significance* it held for the participants became sub-themes, as did concerns around *function*, *control*, and *loss*. I was also able to explore the ways the participants talked about their attempts to manage illness and identified *resources/strategies* as another broad theme, with sub-themes such as *keeping busy*, and *GP as last resort*. I now had two major themes: impact and resources/strategies, divided into sub-themes based on the early topic, action, and feeling codes, as well as the original categories: *positive*, *negative*, *significance*.

I constantly compared transcripts, within and between participants in terms of general themes. I looked for more themes and re-visited transcripts as new interviews revealed new properties. My two supervisors independently read several transcripts in the early stages, and more during the later stages. Discussion hinged on thematic content, and interviewing technique. Agreement was reached with some negotiation and flexibility. This process was to heighten issues of validity. I hoped to represent as far as possible

what the participants had prioritised from their experiences. It also contributed to reliability; it was important to know, as far as possible, if I was being systematic, and identifying similarities and differences where these occurred. This added to the overall rigour of the analysis.

My next step was to combine my field notes and make a thumbnail sketch of all the participants, to which I could refer when I undertook further analysis, and as I visited and re-visited the transcripts. This I felt aided an understanding of the experience of the participant when I was attempting to interpret the significance of their words in the context of their daily life.

I then used a Framework Analysis approach to further synthesise the themes (Spencer et al., 2003). I formulated paper matrices, but because I continued to look at the interviews in their entirety, I was mindful of the contextual basis of the themes which were emerging and chose to include extensive quotes as well as named themes. This was to keep the context of the points made and prevent too much fragmentation.

Developing from this, I introduced the codes, categories and themes into Nvivo. I organised the text extracts into nodes. I used the free node facility, and introduced the node trees, but did not use the automatic coder, as I felt this would decontextualise the talk too much, and I felt using the free nodes and the node trees was sufficient. I used large sections of text for each node, which often overlapped; the same extracts could be used in a range of nodes. I constantly checked and re-checked the nodes against the transcripts, and as new themes emerged, I would re-visit earlier transcripts to search for the theme, which may have been present but implicit. Although I continued paper analysis, and only used a few of the facilities which Nvivo offered, it was a crucial resource which allowed me more time to move between the transcripts for comparative purposes, and ultimately encouraged analytic rigour.

One error I made initially was naming a node *identity*, which was based on original line by line extracts coded simply *self*. This was hugely problematic, and seemed unworkable.

However, it revealed the ways in which the participant talk was infused with the presentation of self and the maintenance of moral identity. *Identity* then, for example, had to be broken down into sub-categories or tree-nodes, as well as being seen as one coherent whole. Concerns around constructing a moral self was subsequently a major theme in the research. It was at this stage that I applied a narrative analysis approach.

As I re-read the transcripts alongside my analysis, I noticed the overarching concern with self-concept and identities were particularly linked to a previous sub-theme, a sense of loss, or a concern to resist loss along two dimensions, practical (involving doing) and symbolic (involving being). As a result of conference attendance, discussion and further reading, I realised that I had started to use a narrative lens for my data. I was focusing on the temporal; the episodic; and, at its core, action which has a moral purpose. I then systematically applied a type of narrative analysis which looks explicitly at the form of narratives (Riessman, 1993), and informed by Labov's structural model of narrative form, I once again, read and annotated the accounts asking myself why particular rhetorical devices were used, and how they helped to build positive identities (see appendix B for examples).

During this process, the analysis also revealed how broader institutional values and cultural norms were expressed in the language. The fine grained analysis of the talk, (Riessman, 1993) showed a consistency between the cultural values of society in general and those of the participants. To construct a core identity through narrative, the speakers needed to accomplish a constancy of values based on their decisions and actions which reflected common cultural values. It was crucial that in the context of the interview, they communicated their experiences and actions from within a framework, which positioned them as morally adequate. In this way, personal accounts were informed by deep-seated structural and cultural factors. Following Riessman (1993), I agree that this type of narrative analysis, informed theoretically by both interactionist (e.g. Goffman, 1969) and structural traditions (e.g. Bourdieu, 1984) contributed to a greater understanding of the illness and consulting experience (see appendix B for examples).

Another way to organise narratives is to see the structure of the accounts as stable, progressive or regressive, over time (Gergen & Gergen, 2001). In this way, a plot is identified, and what may seem like disparate themes are connected. I wanted to gain insight into the nature and extent of the elements of disruption and normalisation, and so, using memos, I mapped the accounts, based on the codes, the categories, the themes, and the rhetorical devices used, along these narrative forms. In this way, I gained insight into the overall experiences of the participants in terms of disruption and normalisation. In particular, the narrative lens led me to look at the accounts in relation to what the participants had *done* in the past, and who they had *been* in the past. Different directions were identified in the same narratives. Overall, I focused on the form of the talk, and impression management (Riley & Hawe, 2005), as well as the overall direction of the narratives (see appendix B for examples).

I revisited all of the transcripts to compare how the participants had conveyed disruption and normalisation in their lives. I synthesised the ways the participants had described impact, and referred to resources (using topic and active codes, and categories). By constantly comparing between and within transcripts, I was able to provide a systematic analysis. After organising early drafts of chapters around major themes, and similarities and differences between (groups of) participants in terms of impact, management strategies and consulting, I then organised the groups into the original consulting types, and found that they typically corresponded to the initial groupings. As outlined above (3.7.3), 6 of the participants could not be identified as consistent consulters, but were still part of the analysis. After this stage, I then looked for differences and similarities systematically between men and women. Finally, I checked the housing tenure of participants, and looked for similarities and differences in their accounts as part of my interpretation of the analysis. It was at this stage that I found no clear pattern between 'renters' and 'owners' in terms of the impact of illness, management strategies and consulting the GP.

A primary aim has been to demonstrate transparency so others can see how my data driven claims have emerged. However, the generative process has been mine. I have

attempted ongoing reflection to facilitate flexibility, refinement and revision. Two such processes have been described; inter-researcher checking and noting the detail of the process and context of data gathering and analysis in order to understand and review what the emerging themes are, how they connect to one another and what part context plays in them. Built into the analysis at every stage was the search for deviant cases. This was in order to prolong the theory building stage, which was necessary to allow for an ongoing flexible approach in terms of concepts and the overall analysis. In accordance with the interpretivist concern identified earlier in the chapter, the transparency of the findings are paramount, with this in mind further examples of the analysis are found in appendix B. The findings of the study are presented in the following four chapters.

A final point; throughout the findings chapters I have used three terms when referring to the participants' multiple chronic illness. I have used the term illness when referring to the ramifications of physical symptoms, and any health conditions that the participants have talked about as impacting on their lives, thus illness encapsulates their subjective experiences. Condition was typically a more objective term, relating to health disorders overall and not necessarily associated with troublesome symptoms. Symptom is used to describe the 'felt disorder' which participants commonly talked about as a sign of their illness or, much less often their condition. Typically, the participants discussed their experiences of symptoms and daily life, conveying illness, so these terms are most often used throughout the thesis.

Chapter Four

The impact of chronic illness: the importance of 'doing'

4.1 Introduction

This chapter addresses the impact of multiple chronic illness. I explore how the participants discussed the consequences, and the significance, of illness experiences on daily life. I also demonstrate the ways in which the participants were keen to present themselves positively throughout the interviews.

The accounts featured concerns around the ability to carry out daily tasks, and attempts to maintain familiar activities and a sense of continuity with past lives, and 'former selves'. The participants spoke of experiences of paid work, family life and social contact and leisure pursuits. The talk extended to a moral discourse about appropriate behaviour and concerns around identity.

The chapter is written in three sections. First, I outline how participants talked about their concerns around functional ability; then I discuss how this was related to how far they felt they could control their bodies and illness. Finally, I address how the participants conveyed loss, and attempts to resist loss, in their lives. In all of the sections I distinguish between, and compare, the accounts of less frequent and frequent consulters.

4.2 The impact of chronic illness on daily life

Participants conveyed different experiences, yet shared fundamental concerns. They described living with illness as a constant, fluid and complex problem solving exercise. A major concern in the accounts was *functional* ability. The participants from both groups conveyed how the taken-for-granted aspects of routine actions posed problems and

described frustrated attempts at activities in order to convey the nature and extent of their illnesses. It became clear in the early stages of the interviews that the focus on function was fundamentally a problem of bodily *control*.

The participants described their desire, and hampered efforts, to control their symptoms in a bid to manage and contain illness, and minimise disruption in their lives. This discussion commonly revealed references to *loss*, around aspects of past lives, present concerns or anticipated futures.

4.2.1 Functional abilities: 'I can't do lots of things...'

I asked the participants to tell me about their conditions at the beginning of the first interview in order to understand how they prioritised their concerns. In response both the less frequent and the frequent consulters spoke of common tasks being impeded by both psychological and physical symptoms: *'I can't do lots of things like gardening...'* (Martha, LFC); *'... I wouldn't wash, I don't talk to anybody...'* (Derek, LFC); *'I can't walk to the end of the street'* (Janet, FC). However, the less frequent consulters described their problems as surmountable. The consequences of their functional problems were not described as impacting on their daily life. For example they were able to 'normalise' their symptoms:

'I broke my ankle. That's sometimes a wee bit awkward. When I'm walking down the stairs I find I'm going down you know one, just the one foot you know just slowly down the stairs which is a bit awkward... but it's just general wear and tear. It's just, it's just I've lived with it you know' (Jane, LFC).

Jane describes her symptoms as *'general wear and tear'*, highlighting the 'normal' life trajectory. In contrast, the frequent consulters' descriptions of problems with routine actions often conveyed an emotional impact of the struggle to take part in typically straightforward actions, and suggested a disruption to their daily lives:

'I'm struggling with the stairs. When I come down in the morning I dread having to go back up to the toilet, I dread it' (June, FC).

For June, it is not just the physical struggle on the stairs, but the dread that accompanies it which impacts on her life, indicating the emotional significance of her symptoms. The following extracts demonstrate the differences between the two groups further. First, the less frequent consulters refer to physical symptoms that have a functional impact, but note that the changes are relatively inconsequential:

'... I can't stand, you know, for long or up and down my leg you know, which is er, a pain, but its, its, no sore, I mean there's lots of things I do do, if you know what I mean... It doesnae' hold me back... I got so used to it I think that's maybe why I er, never really bothered that much about it' (Martha, LFC).

'I don't bother (with pain), just take no notice, have a sit down, do the jobs sitting down, that's all, peeling potatoes, you know' (Mary, LFC).

'Yeah I just cope with it (pain), it's there and I'm aware of it you know but I've just got so used to living with it that it doesn't bother me too much' (Sarah, LFC).

Martha has *'got so used to it'*, and Mary doesn't *'bother'*. Sarah describes her symptoms as familiar and non-intrusive; she just *'copes'* with her pain. The words used denote a lack of impact on daily life, which was typical of this group. As evidenced, they demonstrated a concern around the ability to function, but also described an ability to *normalise* and *accommodate* symptoms.

In contrast, the frequent consulters described frustrated attempts to undertake a range of activities. Their detailed descriptions revealed a fundamental lack of bodily control and an inability to contain symptoms which impacted severely on their daily lives:

'I can't wash my own hair, I can't wash my back, because I cannot raise my hands above my head. It's actually reduced me

to tears in the last few months with this. Em, it has restricted me...When I'm in the bath I try when I come out then to, to use the shower, but because of the, restriction with my breathing and my cramps, I can't bend over the sink or the bath for any length of time. And when I'm in the shower I just cannot raise my hands up to wash my hair and I'm actually. I actually feel like I could pass out with it's so horrible it's, not a sharp pain that goes away. It's a dragging pain that takes quite a few eh, not quite a few minutes, I think that would be an exaggeration but it takes a little while, to settle down, its awful' (June, FC).

June's words illuminate the consequences of illness, as she details the problematic nature of basic actions, which highlights her inability to function 'normally'. Her use of language reveals the impact on her daily life. She repeats that she '*can't*' do things and her use of the words '*reduced*' and '*restricted*' underline the extent of her inability to function. The words '*horrible*', '*awful*', '*sharp*' '*cramps*' further emphasise the emotional aspects of her experience. The content, the context, and the form of the talk combine to reveal *disruption* rather than a sense of *normalisation*. Mirroring the extract above, Ian describes how he struggles to undertake the most routine of activities:

'Aye, well I mainly do everything for... I can do it... hobble from there with the crutches into the kitchen, pull a wee chair out, sit down, the kettle's no full, I've gotta sit on the chair, turn it round a wee bit, struggle round, hold onto the sink, fill the kettle up, struggle round again, put it back down again. It's an effort, but it can be done... it's hard, even the now I'm feeling the strain in this leg the now, this leg's killing me' (Ian, FC).

Ian, like June, describes routine movement as laborious. His 'drawn out' account reflects the 'drawn out' nature of the action. He constructs a picture of constant exertion in his detailed account. He '*hobbles*', he '*struggles*', '*it's an effort*', '*it's hard*', it's a '*strain*', it's '*killing*' him. Ian's rhetoric conveys an ongoing negotiation with his body and the physical world. He exemplifies one who is 'consumed' by his illness.

In comparison, the less frequent consulters expressed experiencing symptoms alongside their normal routine lives:

'Well just, I don't sleep Sunday nights, things like that. And I'm normally sick on the Monday morning before I go (to work)' (Johnny, LFC).

This extract illustrates a common theme in the accounts of the less frequent consulters. Their symptoms did not prevent them from filling social roles and fulfilling social obligations. However, the frequent consulters' descriptions about an inability to function 'normally' included an inability to go out which demonstrated how their symptoms engendered a shrinking world:

'... You get a bad (pain), you, you know, you don't go out. You basically stay in the house...' (Jim, FC).

'I don't go out by myself. I will only go out with my familythey don't leave me in the house by myself... even going to the shops would be a good thing, you know' (Dick, FC).

The extracts above provide good examples of commonly expressed experiences of this group. In contrast to the less frequent consulters, they recounted the ways in which the inability to function seeped, and at times streamed, into daily life. The spontaneity of the references offers insight into the illness experiences, and the diminished worlds of this group. Dick (above) demonstrates that 'normal' life escapes him, his phrase *'even going to the shops'* appeals to a shared understanding about routine adult behaviour, and the tense he uses denotes his situation is ongoing. The accounts revealed severity, constancy, and an inability to contain symptoms that are presented as severely limiting daily life.

The less frequent consulters did refer to past experiences when symptoms had severely limited them, disrupting their routines:

'I was very ill... I couldn't come out of my bed, couldn't get out of bed. I was suffering from depression...' (Marie, LFC).

'I wouldn't go out of the house; I thought people were after us... that was a while back' (Derek, LFC).

It is notable that the less frequent consulters described previous episodes of severe illness

revealing they have experienced the debilitating impact of symptoms in the past. This contrasts with the sense of stability they conveyed with reference to their current situation, but importantly shows the contingent nature of such stability.

In summary, both the less frequent and frequent consulters conveyed their illness experiences by referencing functional problems and their impact on daily life, and both groups detailed times when they felt swamped by illness. However, the less frequent consulters noted an ability to typically *accommodate* and *normalise* their symptoms and any descriptions of severe debility, related to the past, revealing a sense of *contingency*. In contrast, the frequent consulters conveyed frustrated attempts at basic, routine, and social actions; as symptoms spilled over into daily life they were locked into illness. Their fundamental lack of functional ability was in stark contrast to the less frequent consulters. The form of the language used, and the context of the accounts, highlighted the differences between the groups. The analysis revealed that integral to the functional problem, were issues of control.

4.2.2 Talking about control: '*hit it on the button*' or '*like a cat chasing its tale?*'

When asked to elaborate on the ways in which their conditions affected them, the participants indicated the critical place of control in their illness experience. Again, the groups conveyed contrasting experiences. The less frequent consulters spoke in the following terms: '*Aye I've got it (pain), hit it on the button*' (Mary, LFC); '*It's routine (pain) though. ... I've got that under control, yeah*' (Sarah, LFC); '*I just don't let it (anxiety) get the better of me anymore*' (Rita, LFC). In contrast, the frequent consulters commonly described how problems of control invaded daily life. Their use of language highlighted their experience: '*My head starts, once something goes in my head it just goes round and round*' (Dick, FC), '*I'm fighting with maself...*' (Ian, FC), '*... it just hit me like a bolt from the blue...*' (Janet, FC), '*I feel it never ends. I wake up in the morning when I wake up I go "What is it today"?... but it's just seems to always be something*' (Lesley, FC), '*... as I think I'm getting on top of things something else smashes... my life is turned upside down*' (Betty, FC), '*So it's a catch 22 situation you know, it's like a cat*

chasing its tail' (Jim, FC). The rhetoric suggests a sense of 'emotion work' involved in constantly facing unpredictable and ongoing symptoms, due to multiple illness, and adds to the sense of helplessness, frustration and lack of control which this group conveyed. Thus, when comparing the groups, the accounts suggest that control has an inverse relationship to impact.

The less frequent consulters' accounts of control extended to descriptions of why symptoms presented when they did. They commonly made sense of their symptoms:

'Just trying to do too much in a day, fit too many things in, too much housework or doing housework and going to the gym and doing a couple of hours work teaching, you know, I can't do it all. Or try and do that, and the shopping, combine more than one activity you know, I'm pushing it then' (Marie, LFC).

It is notable that Marie describes a daily life which is organised around a range of activities. She does housework, she goes to the gym, she teaches. If she undertakes a combination of these activities she knows she is *'pushing it'*; she is able to predict that this exacerbates her illness. She conveys a sense of control when attempting to juggle daily life around her symptoms; the context of her talk illustrates a lack of impact, as she references her busy schedule. Others described the aftermath of taking part in rarely practised activities. For instance, Martha describes feeling sore after a concert:

'I think that's it, the standing, even the clapping you know and you just end up...It was really quite sore that day but that's all kind of went...' (Martha, LFC).

Martha shows no concern about her symptom, she *'thinks that's it, the standing'*, thus rationalises her pain. She adds that it *'all kind of went'*; this supports her explanation, and denotes lack of impact. There is an unconcerned tone to her talk which implies the significance of being able to explain why and when a symptom develops. The following is another example of this sense of normalisation:

'... I'm stiff when I get out of bed... And also I get the odd kind of twinge, you know, sometimes when I'm walking just sort of

on the lower back... And obviously as you get older... you get a wee bit more sort of heavier around that. And it puts a strain on your back... (Jane, LFC).

Jane implies that she expects to feel stiff on rising; and notes the '*odd kind of twinge*'. However, she explains that she is '*older*' and '*heavier*'. The combination of lack of severity, and the ability to *normalise* symptoms adds to an overall sense of control. Peter comments:

'I can see the reasons why I am the way I am and in that way I'm quite confident in that. There's nothing really happening that's out of my control I don't believe, you know, or it's out of my expectations' (Peter, LFC).

Peter's words typify a major strand, which emerged from the accounts of the less frequent consulters. He has confidence in his ability to control his illness because he is able to explain and predict his symptoms. This recurring theme had implications for the daily life of the less frequent consulters. The impact of illness was cushioned because they felt, and achieved, a level of control. Peter states explicitly what the others imply; he can see the '*reasons why*'.

Analysis of the frequent consulters' interviews also revealed the importance of control. However, they described unpredictability to their illness which permeated daily life. Indicative of this was how they talked about '*good*' and '*bad*' days:

'It's difficult. It's very, very painful some days; the past couple of days have been really bad. The past couple of days I couldn't walk at all' (Janet, FC).

'But in a good day I have seen me going 'n' getting what (shopping)... I cannae just say I'm going and jump in the car and go... I want to have some normality in my life but I would love to turn round and say "Right, I'm going to the shop". Turn round that corner and go to the shop. I would love to be able to dae that. I cannae dae that' (Lesley, FC).

On good days, they note an ability to do more, but a continued inability to make plans. Janet indicates the ongoing unpredictability of her symptoms, and Lesley explicitly

reveals a loss of spontaneity common in this group. She wants to be able to just *'jump in the car and go'* or spontaneously say she's *'going to the shop'*. She notes she can't. She talks of wanting some *'normality'* in her life, which underlines the significance of unpredictable symptoms. Her words reveal a common theme in the accounts of the frequent consulters; due to an inability to control symptoms, routine activity is disrupted. What she can do one day, she may well not be able to do the next. Unlike the less frequent consulters, she cannot explain why her symptoms present when they do. Similarly, June says:

'... on a day to day basis, I can't get up and have a bath or plan the day. I can't get up and say "Right I'm going to have a bath, I'm going to have a shower, and I'll meet you for lunch, tomorrow". Or, "I'll do such and such tomorrow". I can't do that. I have to take it as it comes. I have to get up in the morning and see whether I'm fit to have a bath... Or I might have to stay in bed with the nebuliser... if it means putting off a bath, or putting off a visit, then I'll put that off so I can't plan...' (June, FC).

Betty talks about control in a broader context:

'But I won't, but I don't want this to em control my life and I'm not a control freak but I want to be in control. And I feel as though I'm no longer in control which I don't like' (Betty, FC).

These extracts provide a glimpse of the 'emotion work' often expressed by this group as part of the illness experience, and the ramifications of an inability to control symptoms and the body. The frequent consulters are restricted, and they 'don't like it'. The context of the talk not only portrays a limited world, but the form of the talk reveals the emotional impact of living with chronic illness.

Some of the accounts of the frequent consulters revealed that the combination of symptoms experienced in chronic multiple illness facilitated few chances for control and containment, and thus symptom free days:

'The days I am good something else seems to, that brings, the nerves seem to exacerbate the other conditions. Because stress brings your asthma, the colitis that does the same, so I mean I'm in a no win situation' (Lesley, FC).

However, the less frequent consulters' accounts demonstrated that although they described an ability to control symptoms, they continued to face adversity: *'...it (pain) wears you down, it wears you down'* (Peter, LFC). *'... it's (pain) like toothache all the time...'* (Paul, LFC). These comments give the listener some insight into the ongoing nature of symptoms, even when control is maintained, and accommodation and contingent normalisation accomplished. The 'ongoingness' of the symptoms and the work involved in containing them alongside daily life are conveyed as integral to the multiple illness experience.

The less frequent consulters' accounts also showed how control was contingent: *'Well obviously I should be able to control it (diabetes) better, obviously... just drink less'* (Johnny, LFC); *'...prefer to be on my own conditions... At home where you can control what is wrong...'* (Jane, LFC). They made references to acute episodes of chronic illness, when control was, or is, lost: *'I think eventually I just crashed'* (Marie, LFC). Peter's words underscore this sense of vulnerability:

'And it's a kind of spiral thing, where if you don't rest enough properly, I think then that you just feel kind of even worse... and just the sort of the stress and the agitation I think makes the pain worse... But it's a bit of a nuisance, a bit of a pain, if you'd like to look at it that way...' (Peter, LFC).

The accounts demonstrate the contingent nature of control as part of the illness experience. Control is neither easily secured nor permanent. As the examples above illustrate, the less frequent consulters live with the memory of a time when they had *no* control (*Marie*), they demonstrate a need to curb leisure activities in order to *gain* control (*Johnny*), situational limitations are placed *on* their control (*Jane*), or they may require rest to remain *in* control (*Peter*). Controlling illness is a practical accomplishment. However, the less frequent consulters demonstrate a significant degree of control over their illnesses aided by predictability and a lack of uncertainty which permeates their

accounts of illness experience. This typically allows them to maintain activities in the context of their daily lives; symptoms, may impinge, rather than prohibit attempts to live a normal life.

The less frequent consulters presented themselves as individuals who *'had the ability to'* control their symptoms, they described self control and *'willpower'* (Marie, LFC) thus hinted at symbolic, as well as practical benefits: *'he (GP) seemed quite happy that I was managing with diet and managing to control it'* (Sarah, LFC); *'I was determined, I was very motivated to get out of it, highly motivated'* (Marie, LFC); *'Just did it myself...it's no a problem'* (Mary, LFC); Paul and Martha elaborate:

'I think actually it's quite good, myself, I really do. I mean I think, because I don't let it get me down, emm, because I think it, it, could you know. Emm, I think I control it quite well, I think I do quite well' (Martha, LFC).

'Aye, I've got constant back and neck pain. It's controllable, you know... But it's always there... I figure I manage it quite well. It doesn't stop me doing much' (Paul, LFC).

However, the frequent consulters were more likely to indicate a lack of control, which implied their bodies lacked both functional and symbolic value:

'I just seem to, go to bed, sleep, get up, watch the television and vegetate. And I know I shouldn't be doing that' (Betty, FC).

'I know myself, personally I should be doing that (going out), but I cannae dae it' (Dick, FC).

'I felt I'm holding her (daughter) back here, I would have been as well staying at home. It's terrible to feel like that, just terrible, you feel as though you've become a burden... it's a horrible feeling, horrible horrible' (Janet, FC).

A lack of control was a common theme in this group, and suggests an added burden to those who display an inability to function in ways that are culturally valued. The frustrated attempts to keep active are deemed doubly damaging. First, there are the

obvious practical consequences, but also the symbolic notion that one is not performing as a functioning adult in morally appropriate ways. A broader cultural world is implicated, one in which particular actions are valued. Paul and Martha (LFCs) feel they do *'quite well'*; they can claim a degree of control over their bodies, whilst Betty and Dick (FCs) both note they *'should'* be behaving differently, but cannot. Betty feels she is not quite up to the moral challenge, and seems to *'vegetate'*. Similarly Janet's (FC) words are morally infused. She is unable to control her symptoms and feels a *'burden'*. Her repetition of *'horrible'* and *'terrible'* highlights the emotional impact.

Jim was a non-typical frequent consulter in that he described his ability to gain control of his symptoms, and indicated lasting improvement: *'I'll, I'll claim the benefit, I'd dig myself out of it (depression). I've not just done it for myself but my friends'* (Jim, FC). Jim's words underscore the moral value of being able to control symptoms, as he accomplishes a positive presentation of self in his interviews. However, what else distinguishes Jim from other members of this group is that he reported consulting his GP for sick lines, rather than treatment or advice. This deviant example not only underscores the moral significance of demonstrating an ability to control illness, it also helps build a link between controlling symptoms in daily life, and GP consultations. Jim was the single frequent consulter who conveyed control, but importantly did not consult the GP for symptom relief.

In summary, issues around control emerged as an important theme in the data. The less frequent consulters described illness experiences which they could predict and explain. They conveyed a confidence which was borne by their ability to understand why and when their symptoms presented, and an ability to limit the impact of illness on their daily lives. In contrast, the frequent consulters displayed emotion and concern around the unpredictability and lack of control of their symptoms, and conveyed the sense of a diminished world. Issues of control reached beyond the practical aspects, of illness to the symbolic dimension of illness management. Placed within a moral framework, the less frequent consulters were able to illustrate their abilities to control their illnesses, thus display their moral fibre, whilst the frequent consulters were less able to do so.

4. 2. 3 Accounting for change: 'normal' life or disruptive loss?

The less frequent consulters told of no longer being able to do things, due to their illness. They often juxtaposed what they used to do, with what they do now. In this way the analysis revealed degrees of perceived loss:

'I used to play sports quite a lot, but not so much now; I still play tennis in the summer. I'm up every morning by 7 o'clock at the latest, even at weekends. I'm just busy all the time' (Peter, LFC).

The threat of loss is cushioned by Peter's reference to being *'busy all the time'*. This indicates that although he describes activities that he no longer undertakes, he does not construct this as loss of a former life. There is an implicit sense of 'normalisation' in his account which concords with other accounts from this group:

'I'll be 51 this year in July and you feel, well you don't dae the same things... no got the same energy, you havenae got the same strength that you have when you're a 20 year old' (Mary, LFC).

The less frequent consulters described things they could no longer do in the context of still busy lives (*Peter*), and normalised the changes as part of life's trajectory (*Mary*). They detailed a checking of activities, which had little impact on their daily lives; there was no fundamental sense of loss in terms of a life, a lifestyle, their roles or identities.

However, loss was integral to the illness experiences of the frequent consulters. They talked about how daily life had changed for them, and commonly juxtaposed what *'is'* with what *'was'*, highlighting their sense of loss: *'I was always out and about, I was never in, now it's once I'm in, I'm in'* (Ian FC); *'I did work. And would love to more than anything to work...'* (Lesley, FC). Other examples illustrate this recurring theme:

'What is wrong with me was, I was such an active person, I was really active... I led such an active life and now I can hardly walk to the shops. It is frustrating, it's depressing, it really is...'

I was but I was a very active person and things just get on top of me being shut away in the house. Because I was so active and then nothing... Life is just not the same anymore' (Janet, FC).

'I don't get to do much... I can't shop anymore, and that was my love in life on a Saturday... I loved to walk round the shops, that came to a complete standstill... I think that might be one of the factors, I get a bit depressed about it... I don't have any hobbies or anything now, I did, I loved to keep fit, and I used to go to badminton and I loved to go swimming, but I can't do it anymore' (June, FC).

The ways in which the frequent consulters talked about loss conveyed how the frustrated attempts, and inability to contain symptoms, resulted in illness pervading fundamental areas of existence. The emotional impact of the sense of loss was a recurring theme. In answer to an open question about her daily life Betty responded:

'Frustrated that I can't, I was always active, umm, I'm a gregarious person anyway and I do find that I feel very isolated because... it's driving me up the wall. The other thing is I am not meeting people either' (Betty, FC).

Betty's words suggest significant loss in her daily life. She describes feeling '*isolated*', the 'fact' that she is '*a gregarious person anyway*' underscores her sense of loss, which extends to sense of self. A loss of spontaneity in social life which Betty relays was commonly articulated:

'I would love to turn round and say "I'm going up tae ma pals." But on the way there I know, maybe I'll take, some, a panic attack' (Lesley, FC).

Also Jim, on losing the ability to take part in leisure activities noted: '*... it was difficult... finding things to occupy me...*' (Jim, FC). The accounts revealed that loss is expressed in different ways. First, it is the loss of particular activities, which has implications for daily life and identities. Second, there is nothing to replace what has gone. The 'doing nothing' is expressed as an added burden:

'You know, if you're not well for a couple of days, you know you've no been able to get up, you get fed up, irritated, frustrated. You get frustrated because you're sort of stuck in this limbo, you know for a day or two days or so. And you know there's things you'd like to do or want to do. Also in the long-term as well, coming to think of it. I used to go sea fishing; I've hardly been fishing since I injured my back. At times you sit back and you think: I miss that, I miss doing that' (Jim, FC).

What was clear in the frequent consulters' accounts was the amount of emotion expressed by them. They found their situation: *'depressing', 'frustrating', 'irritating'*; they *'miss doing'* things, and *'would love to'* do things. The language they use denotes being trapped; *'things just get on top of me... being shut away'*; things: have come to a *'complete standstill'*...are *'driving me up the wall'*; I *'would love to turn round'*; I am *'stuck in this limbo'*. These words give the listener some insight into the ramifications of losing something that is normally taken-for-granted; spontaneity. The speakers are stuck in illness.

There participants discussed specific types of activity. For example, the less frequent consulters described how they were able to keep working. Accounts indicated an awareness that employment status was a crucial indicator of wellness, and a feature of their daily lives which symbolised their control of symptoms: *'Well it (depression) disnae stop me working'* (Johnny, LFC). *'No, no, it doesn't stop me working'* (Rita, LFC). Further examples illustrate this common theme:

'I've got that (migraine) under control yeah. I don't lose time off work really with that now' (Sarah, LFC).

'I've never really had it (back problems) so bad that, err, I wouldn't need to go to work, and I've never had any time off work' (Martha, LFC).

The relationship between symptoms and work is clear. Symptoms are contained in the realm of the personal, and 'normal' working life continues. This group demonstrated an ability to keep symptoms at bay. Accounts of work are used as vehicles to convey the state of their health, and the status of their illness. However, they expressed a precarious

strand to their routine lives. They are at work; for now. Illness does not cast a shadow over their working lives, but it hovers on the horizon:

'I had to stop work, I was so ill, but I work part time now, I manage, if I'm careful, but if I overdo it I get tired, I have to be careful' (Marie, LFC):

'I have to be very, careful eh about what I eat, very aware of what I am eating and I will give you an instance, I couldn't take soup, home-made soup for two days running or I'd be running to the toilet the next day. I couldn't get to work' (Sarah, LFC).

'I've never ever taken the day off because of, you know, just straight-forward feeling sore. I don't know how long that will last, because as I get older...' (Peter, LFC).

Equilibrium of the physical and the social is maintained. Again, the common themes of activity and contingent control occupy a central place in the accounts. Marie was forced out of work in the *past*, Sarah has to be careful *now*, and Peter refers to a *future* landscape in which unemployment beckons. These extracts reveal a vulnerability, and potential for loss, which permeated the accounts of the less frequent consulters. This fluid contingency is illustrated in the extract below:

'I've been pretty active under cars, you know, in my time, you know. I find now if I try and fix a motor I'm no well for a week. It's just, it's no even worth it, you know. You don't like to give in, although I'll need to stop' (Paul, LFC).

Paul's words encapsulate the gradual change over time; a remembered health and active past, explicitly linked to the more problematic, but still active present, and an anticipated loss in the future. He comments: *'You don't like to give in'*, this offers the listener a glimpse into the emotion, as well as the morality, which threads through such illness experience.

In contrast to the less frequent, the frequent consulters commonly conveyed a sense of loss regarding paid employment. They referred to a number of ramifications of being

unable to work. For example, June communicated the emotional aspect of being 'forced' out of employment: *'...very distressed as it was, it was terrible, when I was leaving'* (June, FC). She continues:

'I would love to be able to continue working... and that's when I feel it, and that's when I get angry and a wee bit depressed about it because I feel that my life is actually come to a stop. I know it shouldn't, emphysema should not emm, bring your life to a standstill like mine' (June, FC).

Other examples include:

'I felt great satisfaction. I also got very well paid. Em, but I felt great satisfaction I could have made something of myself there. That angers me because I'm just fifty and I just feel as though my life has stopped' (Betty, FC).

'Yeah, em played for the Fire Brigade Cricket Team, em played football for the (Fire) station, eh so you know I was out doing things all the time... all of a sudden this all came to a halt, all the activities that were no longer there...' (Jim, FC).

Jim adds:

Jim: *'I was starting to think, and brood on things an dwell on things, you know...'*

Anne: *'What sort of things were you brooding on?'*

Jim: *'... I had been fairly active up until I injured my back, an things that you take for granted you know, I mean, all of a sudden finding that you either couldn't do them...'* (Jim, FC).

June and Betty refer to their lives coming to a standstill. June sees her work as an important part of an active life that she no longer lives. Betty looks to a frozen future. She articulates the loss of a valuable opportunity, in both economic and personal terms. Jim describes his sense of loss around activities that hinged on his job, locked in the past. In this way his words illustrate the recurring theme of illness conditions streaming into daily life. Overall, the frequent consulters described disruption in their lives, but more fundamentally a threat to their 'sense of self'. As Betty states, she is angry *'because I'm*

just fifty'. This is in contrast to the less frequent consulters who identified their symptoms as part of life's 'normal' trajectory.

The frequent consulters displayed a concern to demonstrate their moral worth throughout their accounts. This was particularly apparent with reference to unemployment. In the following extract Jim conveys his moral identity is at stake in the context of official approval of his condition. He positions himself alongside other Benefits applicants and in so doing, he presents himself as a valid applicant and genuine hard worker:

'... it's done through, these doctors that are employed by the DSS... you're looking at 17, 18, 19, 20 year olds all sitting there with the baseball caps an that, an these folk had only been in five minutes... never had a job. I was in there for 40 minutes and I got put through the mill... I've worked since I left school at 16... never signed the brew, never in ma life, I've went straight from school to work, left the Gas Board an went into the fire service, left there on the Friday and went into the Fire Brigade in the Monday right up till a got pensioned off...'
(Jim, FC).

Jim's words are indicative of a recurring theme; the need to present oneself in a positive light. The analysis revealed that as the frequent consulters talked about a sense of loss, and their identities were threatened as a result of being unable to fill roles and fulfil social obligations, so they displayed concerns to manage a positive impression of themselves throughout the interviews:

'Having worked all ma life and not liking having to take sick pay... I would far rather work, em I feel depersonalised... I do have pride and... one chap came up from the social security place... I said look "I didn't take any of your money, I would work". He said: "But you've worked all your life, you are now, you are entitled to this... that's why you paid your taxes" ...'
(Betty, FC).

Mirroring Jim's experience, Betty uses the rhetorical device of direct speech, and a 'supporting cast' of an authoritative voice to draw the listener into her experience. In this

way she constructs herself as an authentic applicant. She has lost the opportunity to work, but, paradoxically, invoking the past, she presents herself as a hard worker.

All of the frequent consulters were unemployed. Their talk commonly featured an inability to work as a consequence of ill health: *'I've retired now because of the injury'* (Jim, FC), and engendered a sense of loss of past lives, and of identity. A loss of status, a lack of income and limited social stimulation all contributed to this narrative of illness and unemployment, adding to their self-interpretation as ill. None referred to giving up work to manage other aspects of their lives. Rather they commonly constructed their unemployment status as being forced upon them, whilst as June stated, they: *'Would love to be able to continue working'* (June, FC).

The frequent consulters articulated the causal connection between their illness and unemployment status. Furthermore, their talk portrayed a morally upright position. The message they relay is unequivocal; they present themselves as unemployed against their will. The talk in the interviews signals that this is an aspect of self-worth which is fundamentally fractured. They work hard at promoting positive images of themselves as workers, and, paradoxically their unemployment status as valid. However, in so doing, they underline this consequence of their illness experience. This is a tangible reminder that illness disrupts their life and restricts them.

Some of the frequent consulters mentioned their economic situation, but this was rare. Betty was unusual in that she spoke about it extensively. For example, she describes the difficulties of collecting prescriptions because of the cost of taxis and adds that she can no longer see the acupuncturist:

'If I could afford it I would go (to see the acupuncturist). But I can't. So that comes down to money which comes down to not being able to work... If I could work I would work full time and in the job I'm in, it's good money. I would then be able to afford the herbalist, the acupuncturist and a car and to have a better standard of living than I have at the moment. But I have no option, I have no option. I can't earn the money' (Betty, FC).

Betty explicitly relates the loss of her employment role to a loss of her sense of self:

'I'm (pause) I'm not the woman I was. My confidence has really been shattered em I don't like living off the State I've worked since I've been fifteen, sometimes two jobs, and I would rather be out earning my money but I can't. And it's a very hard thing to, to accept' (Betty, FC).

There were gender differences in the ways the participants talked about their family roles. Women were likely to mention the impact illness had on their family life and spoke about their traditional caring roles, whereas men were more likely to talk about maintenance in the home. The female less frequent consulters did not relay fundamental loss in their family lives, or to their identities; they neither talked extensively nor gave details of ongoing problems (for example, Mary said she could no longer play football with her nephew; Marie described an episode in the past when she could not get out of bed, and look after her children). In contrast the female frequent consulters elaborated on their feelings of loss; they expressed frustration and concerns around being unable to fulfil family roles currently, and as an important and ongoing feature of their lives:

'I would love to do is to be able to get up have a bath, have lunch, pick my grandson up from school ...and play with my grandson, you know at ball or whatever...' (June, FC).

'There's such a lot I want to do with ma grandchildren and ma family and I can't and they feel it because they want to ask me to join in and they know I'm not capable of doing it and it causes kinda (pause), not friction but it causes tension between the family. I tend to get upset because I want to do it and they get upset because they want to ask me and they feel awkward because they're not asking me which makes me feel left out which causes tension, it's terrible to be left out...' (Janet, FC).

Some of the frequent consulting women spoke of their guilt at being unable to fulfil family roles; at times they reached back into the past illustrating a temporal thread to their current experience:

'I couldn't take my daughter to school or nothing. And that's what I regret. And I feel guilty. I know there's nothing I can

do about it but I feel guilty' (Lesley, FC).

This again suggests the emotional impact which was revealed as the women talked about their inability to act in taken-for-granted ways in their family roles. As mentioned the men were less likely to discuss family roles, but when they did it was with reference to traditional masculine behaviour in the family. Again, the differences between the less frequent and frequent consulters were clear. For instance Peter spoke of his pain potentially preventing him from fulfilling family obligations:

'Obviously when you've got a family to look after there are always things that you do. I mean I would never, I mean I would never like to think I would have to get somebody into decorate the house, you know paint it or repair it or, or, do any sort of ordinary task' (Peter, LFC).

Peter presents such activity as 'appropriate' behaviour, based on commonsense assumptions about gendered family roles. He would not like to think that he *'would have to get somebody in to decorate'*. Again, this indicates that practical activities have symbolic value.

Although Ian was distinct as the only male in the frequent consulters who spoke about frustrated abilities to undertake traditional masculine tasks in the family home, his words are particularly interesting when compared to Peter's account above: *'I always could do anything... and I cannae do it now...'* (Ian, FC). He elaborates:

'Cannae do wallpaper or anything like that, thingamy it. Can do things if I'm sitting doon, likes o' sorting a plug socket or something like that thingamy. I plumbed in the washing machine myself you know just sat on the floor and done the thingamy, but when I got up it's like sore because it's sitting in that position...then try and get up, it's murder...So in the toilet the wife's bought... plywood, it's all cut and everything...It's in sections, but the toilet's too narrow for me to move about, or put it down myself...' (Ian, FC).

Ian's functional debility incapacitates him. The listener gains insight into his experience through the story he relates. He says *'it's murder', 'it's sore'*. He describes how he

struggles, and explains his wife has bought the work materials, highlighting his domestic role. This level of detail offers a glimpse into Ian's life. In a bid to do what he has always done he faces frustration and 'failure'. This is a fundamental loss to his identity, and mirrors commonly expressed experiences of the frequent consulters

The frequent consulters' accounts were distinguished by a sense of loss of a 'normal' health status, and the implications of this. For instance, they communicated an inability to talk about their feelings and experiences to others. Having high levels of illness at a relatively young age set them apart from their peers. There was a sense of losing one's moral status reflected in statements about the 'generalised other':

'Folk'll say to you "I understand". They don't understand... they don't know until they're in that position themselves, really don't, see folk that patronise me. I can't stand that' (Janet, FC).

This reveals a sense of isolation, which is part of a longer narrative on an inability to identify with others. They also described being misunderstood by others which extended to a moral discourse around their behaviour:

'And then people say to you: "Pull yourself together"... That's pure hell. But people just don't, they don't understand. I don't say they don't care, they don't understand... I would just love to be normal' (Lesley, FC).

'I can talk to somebody they don't know what's wrong with me, and they say, "What's he saying?" an' all that. "Look, he's in his moods." You know' (Dick, FC).

'That's what I was saying to people: "See if I had my two legs I'd loss yous". It's just really frustrating when people starting moaning about things that ye cannae dae and aw that. See if I had two legs I'd do it. Know what I mean. And it is, it is depressing, but there ye go as I say that's life' (Ian, FC).

The frequent consulters' accounts featured uneasiness about projected image. They conveyed fears around being misjudged for their lack of ability to function 'normally'. The need to be recognised as authentically ill permeated their accounts, but they indicated

ambivalence about sharing their experiences of illness with others. They were faced with the possibility of being regarded as ‘complainers’ and ‘moaners’. Ian refers to how he *‘keeps cheery’*, despite his illness status. Betty’s words below illustrate this common theme:

‘Because I found that people really don’t want to know, my friends do but not all the time, my sons do, but not all the time, and it’s a very true saying, ‘laugh and the world laughs with you, cry and you cry alone’ and it is so true. So I tend to over compensate... big cheesy grin on the face, laugh a minute and inside you’re crying and then you come home and you take it all off and you cry’ (Betty, FC).

In summary, the less frequent consulters referred to illness incidents, or past episodes when they *‘couldn’t do’* what they wanted to. They described activities which they are unable to undertake, but emphasised that these lacked significance. They spoke of how they continued to work, enjoy leisure activities and live full social lives. They relayed symptom *containment*, *accommodation* and a *contingent normalisation*. In contrast, the frequent consulters’ accounts displayed a fundamental loss, which was communicated in the content, the form, and the context of the talk. The extracts illustrate how they compared the past with the present. They constructed stark differences between their life *‘now’* and *‘then’*. This goes beyond the physical restrictions that symptoms often impart. The sense of loss is constructed as fundamental; it spills into all areas of life and experience. The frequent consulters built vivid images which illuminate the disruptive impact of their illness. They are frustrated, depressed, annoyed. Their accounts also suggested that they felt their moral competence was questioned due to an inability to function and fill traditional roles. Despite their high levels of illness they felt compelled to legitimate their inactivity and mask their suffering.

4.2.4 Summary

This chapter has pinpointed key issues in both groups’ accounts of multiple chronic illness as interlocking concerns around; *function*, *control*, and *loss*. The ability ‘to do’

was paramount, and it became clear that this had both practical and symbolic dimensions. What the participants could or could not do in the course of their everyday lives revealed the extent to which they experienced diminished worlds, and fractured selves.

Both groups noted problems in their ability to *function* and undertake routine tasks and activities. However, the less frequent consulters described lower level illness problems with fewer consequences and limited significance in their daily lives. They did refer to episodes of core functional dilemmas, but these were occasional or often long past incidents. In contrast, the frequent consulters' accounts featured detailed and frustrated attempts to do routine and basic actions, as well as an inability to undertake more wide-ranging activities, and fulfil social roles and obligations, such as continue in paid employment, adhere to family roles, and pursue a range of leisure activities. An important finding was that none of the 7 frequent consulters worked, whilst 8 of the 10 less frequent consulters were employed. All of the frequent consulters conveyed that their unemployment status was a consequence of their multiple chronic illness.

Overall, the less frequent consulters expressed an ability to contain their symptoms, and *control* both their bodies and their lives. On the whole, they could predict when and why symptoms flared, and were able to explain the course of their illness. Although they reported rare times when they had lost control, this worked to illustrate the stability which more typically they achieved. However, the frequent consulters relayed their frustrated attempts to control and contain their symptoms. This sometimes involved a range of symptoms from 'unconnected' conditions or co-morbidities, which the frequent consulters tended not to describe. The frequent consulters discussed ongoing crises, tinged with uncertainty as unpredictable symptoms spilled into daily life. As a consequence of this they conveyed disruption to their familiar lives, as well as fundamental challenges to their identities. In this way control had both a practical and a moral significance. They were unable to manage illness, they were thwarted in their attempts to maintain daily life, and their coherent identities were challenged.

The less frequent consulters noted minor losses, with little impact on their lives or

coherent identities. At times, they referred to occasional episodes or incidents when they had lost the ability to function (for example when they had been forced to stay in bed or away from paid work), which served to highlight their current but contingent ability to *normalise* and stave off *disruption*. In stark contrast, the frequent consulters described clear and often permanent losses. Furthermore, they described the emotion work and frustration which these losses entailed. Permeating such talk was the ongoing frustrated quest to hang on to familiar selves. Their own self-image was often based on particular behaviours they were no longer able to perform with impunity, or in some cases, at all. Their experiences were conveyed as fraught with loss, juxtaposing what *was* with what *is*, and at times, what *might be* in the future, with *what might have been* in a ‘frozen’ future.

An important strand of the analysis was how illness talk clearly emerged as a moral discourse. The participants were concerned to present themselves in positive ways. This may have been a particular burden for the participants in this study, who are relatively young to have such high levels of illness.

The less frequent consulters positioned themselves as morally competent in a number of ways. First, they demonstrated an ability to overcome their symptoms and illustrate their self-discipline and stoic attitude in the face of adversity. Moreover, they talked as fully functioning adults, who managed illness around a range of responsibilities and roles and were able to build favourable impressions of self throughout their accounts. As they relayed lack of impact on their familiar life worlds, they implied they were able to manage *living with illness*. This was something of a ‘moral coup’, and they were able to communicate feelings of satisfaction throughout the accounts, as they drew on common sense assumptions about illness behaviour.

Interestingly, the frequent consulters were also able to build positive identities throughout the accounts, as they described severe, unpredictable symptoms and a diminished world. Despite discussing their often futile attempts at controlling illness and their lives, relaying feelings of frustration and impotence, they accomplished moral adequacy as they spoke.

Overall, their talk was characterised by a need to display biographical continuity, in the face of fractured identities and lives disrupted by illness. In order to maintain moral adequacy they described how they adhered to common sense views of appropriate behaviour, anchored in cultural norms of 'ideal' ways of coping with illness. They managed positive presentations of themselves in their discussions of ongoing quests to ease symptoms with a stoic resolve. Furthermore, they were able to construct coherent identities as workers, parents and partners, even whilst noting extensive losses. This paradox was a further indication of the tensions and ambiguities which were expressed as integral to the chronic illness experience, particularly for the frequent consulters. To present their moral identities, they often referred to past lives and selves, which did not reflect their present circumstances.

Regarding validity, and as noted above (3.3.2.1) I have tried to represent what the participants said, by systematic analysis, and using illustrative examples from a range of participants. I have also attempted to build into the analysis as far as possible, checks that the accounts are *credible*, in that they relate to how the participants experience the impact of chronic illness. I have also claimed that although interviews are favoured accounts, they can be said to relate, in some way, to an external reality, if checks, which I have undertaken, for consistency and coherence, are carried out throughout the interpretive and analytic process. I have also used detailed field-notes to strengthen the validity of the findings in this chapter.

A core theme in the accounts was how the participants adopted strategies and used resources as they strove to minimise the impact of illness on their daily lives and their self worth. This is the topic of the next chapter.

Chapter Five

Managing chronic illness

5.1 Living with chronic illness

The last chapter showed how the impact of chronic illness evoked practical and existential dilemmas for the participants. I now report on how they talked about living daily life around such problems. In answer to open questions about how they managed their illnesses in daily life, all of the participants described their attempts to ease symptoms, minimise the impact of illness, and maintain 'normal' lives. Their descriptions of the benefits of 'keeping busy' and the merits of paid work in coping with illness underscore the importance of continuing to function 'normally' as far as possible. They also talked about the importance of social contact, and particularly support from family members. Managing illness around family, leisure and work, often depended on practical strategies such as pacing, and using other resources including alternative therapies, and equipment. The analysis continued to reveal concerns around moral adequacy, which were articulated through metaphors of battle, and references to the use of one's inner resources. The participants also spoke extensively of medication and the GP consultation as resources in their ongoing attempts to juggle symptoms around daily life. These areas are the subject of analyses in Chapters Six and Seven.

5.2 Keeping busy: the importance of 'doing'

The participants talked about keeping busy as a way of managing illness. In response to being asked what helped him manage, Johnny (LFC) noted that '*going out*' took his mind off his symptoms. Similarly, the frequent consulters noted activity as important. '*... if I keep active...That's the best way I feel...*' (Janet, FC). Martha was typical of the less frequent consulters as she spoke about the importance of 'doing' something, in the context of a busy social, working and family life:

Anne: *'Any advice for others that you can think of?'*

Martha: *'Mainly to keep yourself occupied, that's what I find, that people need something to do... I mean I've done it all, I have went to all these things to keep myself busy, I like, you know, to get out and about. I think if it's something to occupy...'* (Martha, LFC).

In contrast, the frequent consulters described the need to keep busy, but in the context of an already scaled down life. For instance, Betty describes what *'keeping busy'* means to her:

'Keeping busy could mean watching the television. Keeping busy could mean reading a book. Keeping busy could mean cleaning the bathroom. If I'm keeping busy by cleaning the bathroom it's not as sore 'cos the pain isn't as sore. I've just got to watch when I turn round and thingmy and that because the balance goes, or erm keeping busy could be phoning ma cousin and talking to ma friend' (Betty, FC).

The practical accomplishment of keeping busy is constantly renegotiated, depending on symptoms, and, implicitly, what one has to keep busy with. It was clear that symptoms, combined with structural contingencies informed what keeping busy meant for the participants. For instance, one thing which distinguished the accounts of the less frequent consulters was how they noted a range of activities, such as holidays, concerts, sport, shopping, and going out for dinner, which both implicitly and explicitly related to helping them live with chronic illness. Some spoke of shopping, in the context of what helped them manage: *'I just go shopping, it cheers me up'* (Rita, LFC), whilst others cited sport:

Marie: *'Swimming and a sauna makes me feel very, very good.'*

Anne: *'Yea, so that is something that you try to do?'*

Marie: *'Yes, oh yes. Uhuh, I pay a membership and I wouldn't like to have to give that up. I like going... I feel very relaxed... it's a nice way to exercise... something that you like doing, that isn't... going to exhaust you and gives you a bit of pleasure and you know well-being, that's nice'* (Marie, LFC).

Being able to pursue these leisure and other activities often involved not just physical ability, but also financial resources. To Marie the pleasure and relaxation which

swimming and a sauna give her are important aspects of her management strategy, as she gains an overall sense of well-being. However, this is contingent on her ability to *'pay a membership'*.

The frequent consulters were as likely to note the need to be occupied, but reported more frustrated attempts at basic, and less varied activities. For example, they described the need, but not always the ability to get out of the house, as a way to divert their attention from their symptoms:

'Once I seem to be getting out, I seem to get a lot better. I don't know whether it's just I'm sitting in the house just thinking about it that gets me that way, you know... It's a great good sunny day that the two of us can get out, you know, the weather for a start, you know. If the weather's good, you know, the two of us will go out on a walk, you know. That certainly helps a lot, you know, so it does' (Dick, FC).

Betty says she is *'going spare in the house'*, and wants to take a college course, her GP has told her that she can (take the course):

'... "only if it's like one half day a week or two half days a week, something that's not going to tire you because you cannot get tired" ...' (Betty, FC).

Ian details the difficulties he faces in order to undertake what would typically be the most straightforward of activities. He describes going to play Bingo, something that *'keeps him going'*:

'Because over in the Bingo there's a lift you go up, that's alright. Then there's another wee lift you go down, there's about maybe 6 or 7 stairs. That's broke the now, so I just hold onto the rail and hop down, that's alright hopping down. Your weights going down with you, but coming back up again I've got to sit on the floor and bump up... Then the lift, main one broke down. So the guy says: "You'll need to go down on the escalator". So I'm not going down on that... I say "I'll just bump down the stair" and there's quite a few of them. But when I went up he says "What we'll do is we'll stop it and you

can hop on". So a guy went in front of me, he stopped it all going and got to the bottom stopped it again, it was just the fear going on there and holding on, that's moving. So if anything happened you fall... you're away. It does, you're a wee bit apprehensive in doing things, you know what I mean. But I cope' (Ian, FC).

Keeping occupied helped the frequent consulters manage, but they described limited opportunities, and reported negotiating a range of obstacles in order to enjoy the benefits. Physical strains and the risk of exacerbating symptoms had to be balanced against the gains of keeping busy. These extracts reveal difficulties associated with undertaking various activities which the frequent consulters commonly talked about. Ian relays the emotional ramifications of physical debility in daily life. He describes effort, risk, anxiety and dependence on others. His account also suggests a need to present oneself in a positive way, despite the problems he faces. He uses the rhetorical device of a short phrase to end an extensive description of his functional problems and ongoing obstacles, he states: *'But I cope'*. This extract goes beyond the practical problems involved; the form of his talk also suggests the symbolic importance of managing illness, both in the context of the interview, and in daily life. Overall, the frequent consulters' accounts of frustrated attempts at activity relayed a strong sense of limited opportunities.

The inability to be active extended beyond the practical to the symbolic. The extracts below underscore the importance of activity as a way of managing illness, whilst conveying the struggle to remain active against a moral backdrop: *'As I told my daughter, I know I should be getting out. I know myself, personally I should be doing that, but I cannae do it, you know'* (Dick, FC). As indicated by Dick, there were tensions around activity, linked to an inability to control symptoms. Dick notes he is not always able to go out. In the context of an extensive account of how he equates improvement with activities, and being ill with his inaction, being inactive suggests a moral inadequacy, brought into focus by his words *'I know myself, personally I should be doing that'*. He continues to discuss how he is trying to overcome *'doing nothing'*:

'...a carer coming out to me who's going to take me out... and get me some interest. We're going to make shelves or

something like that, or whatever it is, just to get me out the house, and think about things, something different, instead of me sitting in the house, getting worse... (Dick, FC).

The moral dimension is underlined in Lesley's account:

'I'm no' in control... I couldnae go out myself no way... Sometimes I say: "Right I'm doin' it, I'm doin' it"... And I get so far and I have to turn back. I don't try to, stay myself here... I know people... Got a friend that just sits in the house... She chooses to sit in. She can go out and she doesnae. So to me, she's making it worse... She's sitting in the house dwelling on it...' (Lesley, FC).

It is notable that as Lesley describes her own inactivity, she positions herself favourably alongside a friend who she uses as a 'supporting cast', who '*chooses to sit in*'. Lesley is not in control, but in this case constructs this as legitimating her inactivity. In so doing she identifies that inactivity is morally suspect, but her own behaviour is not. These extracts reveal that 'doing' relates to 'being'; it has existential properties.

Jim is distinguished from the other frequent consulters, and describes how, over time, he has adapted to doing less, and thus he appears to have accepted a scaling down of his familiar life. As part of an account which features his unemployment, and few leisure and social activities, he conveys his new routine:

'At the moment, at first it (inactivity as a result of an accident) affected me quite badly. I was badly depressed, but as time goes on you just adapt and accept it. Either that or I'm getting lazy subconsciously and don't want to admit it (laughs). You know, I don't know which to be perfectly honest with you... You get into another routine and eventually over time you just come to accept that. That's part and parcel of how things go. That sounds very cynical, doesn't it? (laughs)' (Jim, FC).

Jim's words underline the moral significance of 'being busy', both in the interview, and beyond. He adds however: '*I didn't want to adapt, but the circumstances made me adapt*' (Jim, FC). Jim does seem to have adapted to his illness. He cannot keep busy. His life has changed, his expectations have shrunk. He manages his illness, by lowering his

expectations. But his account reveals his ambivalence, he risks being seen as '*lazy*', and marked as '*cynical*'. This reveals the contradictions, of accomplishing a positive identity for those with chronic illness.

5.2.1 Paid work

Some of the less frequent consulters' accounts suggested that activity incorporated opportunities to reaffirm one's identity in the face of threats that their illness posed to it. This included the ability to take part in paid work, which they communicated in very positive ways for a range of overlapping reasons. When I asked Jane how she had coped with an illness crisis in the past, she responded: '*I had a job and I had a house and I had things to keep me going*' (Jane, LFC). Martha says:

'I think work keeps you going, you know that? If emm, if you didnae' have, work, if you were just sitting about, it would make it 10 times worse, because it's on your mind constantly... It emm keeps you going, and that, 'cos you don't think about it as much... You really need something to keep you going. That's it... If I didnae have that (work) what, what would I be, just sitting here' (Martha, LFC).

Hence the less frequent consulters spoke about work as a way to cope with their illness. It diverted their attention from symptoms, as well as helping them construct a positive self-image. Martha describes how she experiences pain, discomfort, and functional impairment, yet she is able to work full-time. In this sense her paid work is an important part of her identity and her self-esteem.

These benefits extended to the ability to enjoy the social side of work:

'I love my work, I was sorry to give it up before; my social life is there... I'm only working 12 hours a week now, and I started last week, so that is very practical' (Marie, LFC).

It is notable that Marie works part time. In this way she identifies how the structural

features of work combined with her financial situation are important. This combination allows her to work at a level which is not detrimental to her health, and pick up her 'normal life'.

Paid work offered a focus, and financial, material and social gains, as well as contributing to self-esteem and identity. The data revealed these benefits were contingent on the ability to organise work around symptoms, in the context of utilising other strategies and resources:

'I don't know, it's, it's emm, I don't feel it so much when I'm standin' in the shop, if you know? It's more when you're walkin' cos you're movin' and that, whereas I don't really get that much walkin' about in the shop, you know. It's just a Newsagent, it's just probably, in the one place, I am, I have a wee sit down whenever (laughs), its not very busy anyway so' (Martha, LFC).

As Paul noted, taxi driving *'is probably the only job I could do. I probably couldnae stand on my feet in a factory now'*. His words go on to capture the role of work: *'Just got to keep working...I wouldn't have a half decent house if I wasnae working'* (Paul, LFC). Similarly, Peter goes on to talk about the importance of the *type* of work done when he responds to a question about how his symptoms affect his working life. He notes:

'... it could be a lot worse. I mean as I say I could, could have a job digging roads. I think if you're a road digger and all of a sudden somebody said to you: "Look, you can't dig roads anymore", I mean what would you do? You know, if you were in your forties' (Peter, LFC).

Although unusual, both Peter and Paul talk about the financial benefits of being employed. In the following extract Paul compares earning a wage to receiving Benefits:

'Because when you get used to getting money every day, and somebody gi's you 50 quid a week to keep you, you know that's no a lot. But I don't know how people live on that kind of money to tell you the truth. But you can dae it for so long, I

suppose, and run up Visa bills and different stuff but you know you've got to pay the piper at the end of the day' (Paul, LFC).

Peter, in response to being asked what helped him cope with his symptoms, spontaneously referred to his financial situation, based on his employment status:

'I'm a lot luckier than other people... I just think that, I mean, there are people worse off than I am. I really don't have anything, besides my health a wee bit, I really don't have any real worries I mean you could worry about... the louts have just come out and bashed my car... I could take it to a garage tomorrow and pay somebody £50 to fix it, but I know a few relatives who could never do that. You know, relatives who are in their early sixties and neither of them have been able to work for the last 11 years; they're just not well off' (Peter, LFC).

In this extract, Peter notes how his economic situation cushions his illness experience. Financial security allows him to be relatively worry free. Regarding shopping, Martha explains how having a car is crucial, though she does not explicitly relate this to being employed:

'Yea well that (shoppng) you can't do at all. That is very hard. That's one of the reasons well, err got a car you know, it does help I mean for shopping. In fact I wouldnae go to the shops to be honest. I mean I really wouldn't. It would be too, too much' (Martha, LFC).

In contrast, in an account which reports financial loss and worries as a result of becoming unemployed due to illness, Betty notes how work and material implications remain frozen features in her life:

'If I could work I would work full-time and in the job I'm in, it's good money. I would then be able to afford the herbalist, the acupuncturist and a car and to have a better standard of living than I have at the moment. But I have no option, I have no option. I can't earn the money. I've got to rely on DLA, Sickness Benefit and Social Security' (Betty, FC).

In summary, both groups talked about activity as important as they attempted to manage their illness conditions. They described 'keeping busy' as a distraction from their symptoms. The less frequent consulters discussed maintaining busy working and social lives relaying their ability to keep active in a range of ways, and domains. Significantly, some noted that the *type of work* they did, determined their ability to remain in employment as they managed their symptoms alongside daily life. Furthermore, they noted the positive social and financial ramifications they gained from paid work. In contrast, and in accord with the analysis so far, the frequent consulters faced obstacles and identified tensions and ambivalence in their attempts to keep active. None of the frequent consulters are in paid work, so they were unable to draw on the benefits which the less frequent consulters noted. Further, Betty (FC) described how being unemployed lowered her '*standard of living*' in general, and prevented her from buying health therapies in particular. The accounts of both groups were infused with a moral dimension around activity, and the less frequent consulters were able to draw on their ability to remain active to construct themselves in positive ways throughout the interviews. In contrast, the frequent consulters were unable to do so, but were apt to describe their frustrated attempts at activity, relaying their stoic stance, in order to build positive identities throughout their accounts.

5.2.2 Social contact

The participants talked about how different types of social contact helped them manage illness. A recurrent theme was the role of talking: '*... I just believe in talking...*' (Jane, LFC); '*I talk to friends I talk to my sister...*' (Sarah, LFC); '*Just to talk it takes my mind off it*' (Lesley, FC).

Talking was referred to as an important way to take one's '*mind off things*', and in this way echoed the role of activity. The less frequent consulters described talking to close friends as part of an active social life:

Anne: '*So what do you think is the most crucial thing in helping you manage your symptoms...?*'

Rita: *'I don't know, I just try and get on with it and I phone ma pal and I blether. If she knows I am down in the dumps she'll phone me and she'll phone me back an hour later. She always comes up with something funny you know to take your mind off things...'* (Rita, LFC).

In contrast, the frequent consulters described barriers to contact with friends, whilst noting the emotional sustenance they gained from talking:

'I think it was because I hadn't seen ma friend for a long, long time, quite a few months actually and when she appeared I felt really good in myself and so on... she's ma confidante, she's ma closest friend... I was so glad to see her I felt this is it I can pour ma heart out to her... I told her how stressed I was and how upset I was. I got that all out' (Janet, FC).

Janet relays pleasure at seeing her '*closest friend*', her '*confidante*', who she can pour her '*heart out to*'. However her account illustrates that such contact is neither spontaneous nor frequent. Janet has intimated that her friend lives a busy life. This indicates Janet's difference and isolation, as an integral part of her illness experience, and was a recurring theme in the analysis of this group's accounts. Overall, close friends were seen as important for support; they engaged with, and responded to, the concerns of the sufferer. In so doing they offered moral support, literally. Being taken seriously was important, friends then authenticated illness experience. In a culture which rewards stoicism, and is critical of 'moaners', the role of friends who offer positive regard is important. Both groups relayed this, but the frequent consulters had fewer opportunities to enjoy such support, and more illness experiences to relate. In such a context the role of friends is magnified.

The frequent consulters conveyed how the role of friends took on new meaning in a diminished world: *'Well, I love to go and visit, I love to blather, umm, in, in my spare time, I don't get to do much, except I like to go visiting'* (June, FC). The following extract illustrates this further:

'I speak to Margaret every week because she stays in Newton. Again it's the trying to speak to Barbara at least every week.'

Susan at least again every week to a fortnight. She's busy just now, she's a Social Worker and she's doing an Open University course. But about four weeks ago we went to a Craft Fair in the Exhibition Centre and... once she gets all her exams passed she is coming up here and she's bringing the video (Chocolat) and I'm supplying the chocolate' (Betty, FC).

Betty lists her friends and how often she sees them; they are busy women, she has spoken about her sense of loss in terms of career, and this spills over into this area of her life. Their busy lives magnify her lost life and the different worlds they inhabit. These examples convey the importance of social contact but also a sense of loss of control, and of life-style. The frequent consulters relay how they cannot see their friends regularly, spontaneously, frequently.

The accounts featured some ambivalence as participants voiced concerns about how they were seen by friends. Ongoing social support was discussed by the less frequent consulters, which indicated potential tensions around managing symptoms in a social context. The accounts conveyed that being understood by others was important. This extended to a responsibility for, and a concern about, the feelings of others:

'It's important for me that people understand, like my friends... that they are not annoyed at me if they have to change their plans for me...' (Sarah, LFC).

'My friends were very supportive. One or two of them knew people who had ME as well, so it wasn't something that they had never heard of. Yes they were very understanding. So, I didn't feel in any way criticised...' (Marie, LFC).

The above extracts illustrate that identity concerns permeate the illness experience. Expectations are placed on participants in interaction, and there is a moral obligation to sustain their own and others' claims to relevant identities. Sarah and Marie demonstrate that identities are constantly negotiated in an ongoing process. They both describe concerns around being understood, suggesting that their behaviour is at risk of being criticised.

The frequent consulters also voiced the same concerns about self-image. For example, Jim expressed a reluctance to talk about his symptoms with others whilst describing receiving both practical advice and emotional support from his friends. When questioned about what made him feel better, he responded: *'Just talking to my pals'* (Jim, FC), but continues:

'...I get the impression that people... that, well what I've done in the past, I've put myself in their position, and the last thing you want to hear is about somebody else's aches and pains and depression... so maybe I have a tendency just to keep quiet about it...' (Jim, FC).

Betty continues on the same theme. Talking to friends who understand is important, but even this support is tempered by the need to weigh up what, and how much, to tell: *'I'd rather keep ma moanin' for the days that I really am in very, very bad pain...(or) they (friends) would all just say "Och no she's just moanin" ...'* (Betty, FC). She adds:

Anne: *'When you say true friends what do you mean by that?'*
Betty: *'People who understand exactly what this means and what has been happening to me. And it's not a case of "Oh, she looks okay so therefore she is okay". I mean I don't look ill... I know I can't go and see a counsellor forever but I do find it helpful because I can discuss the things with her that I can't discuss you know even with my best friends. I can rant and rave no problem...'* (Betty, FC).

These extracts indicate a common theme; the frequent consulters, like the less frequent consulters do not want to be seen as complainers. Their friends are important to them, for practical and emotional support, but they place boundaries around their communication. Even in close relationships, their concern to preserve self-image often overrides the desire to allow their illness and suffering to have a voice. This draws on a shared cultural understanding about valued behaviour, and is clear in Jim's words: *'I've put myself in their position'*.

Thus, the frequent consulters construct their moral status as stoic functioning adults, by referring to their use of silence, or keeping quiet about their suffering, set against the

value that they place on talking. The need to be seen in positive terms by one's social group is magnified for the frequent consulters, who have described living in shrunken worlds, and note fewer opportunities for social contact. In this way, their friends play an important role in offering them emotional support, but even close relationships are characterised by tensions and ambiguities.

For the less frequent consulters, more general socialising was important: '*Look forward to it, saying in the day I'm gaun' to my sisters tonight... it takes your mind off it*' (Mary, LFC). Johnny noted how going out for dinner with friends and '*having a laugh*' (Johnny LFC) helped him feel better, not only at the time, but before and afterwards, as it was something he looked forward *to* and reflected *on*. However, the frequent consulters' accounts revealed fewer opportunities to socialise. They intimated that they were much less likely to be able to plan, and look forward to, social events and contact, due to their severe and unpredictable symptoms.

The less frequent consulters also referred to a different type of social contact. Martha noted a wider social circle which bolstered her sense of 'normalcy':

'We (shop assistants and customers) chat about everything but eh medical things too, we do talk about that, you know, most people do. Everybody has got something wrong with them, you know, and everyday you tell somebody, they might "Oh well I was talking to somebody with the same thing". You know, and it does help people I think, you know' (Martha, LFC).

The less frequent consulters commonly referred to wider social groups as a mutual support system whereby individuals shared experiences and offered advice. This routine aspect of their daily lives added to a sense of *normalisation*, featured throughout their accounts, as Martha comments '*everybody has got something wrong with them*'. This is in stark contrast to the frequent consulters, who were likely to describe a close-knit group of friends, who they *often rarely* saw. Thus social contact could highlight how their lives had been *disrupted*, and limited by illness rather than working to *normalise* their situation.

Although the frequent consulters were less likely to refer to more general social contact, Ian (FC) clearly indicated the value he placed on being a part of the local community. But, this was in the context of severe impairment, debility and incapacity. He comments: *'I'm reluctant to go (out), it's an effort to get to here into the motor and then back out again...'* (Ian, FC). He continues:

Anne: *'And what do you like about it (Bingo) apart from winning?'*

Ian: *'Well as you know I've got the gift of the gab and I come away with all the patter with all the women down there and they all love it, keeps me going, keeps me. Boys from the walk an' a' that, we all tell jokes, it keeps me going and it keeps my mind off my symptoms and it does, it works, know what I mean. A lot of people will go "See you Ian, you're getting worse, how can you have good spirits an all that when you've lost you leg?" "What do you want me to do? Do you want me to sit and mope about all day? It's off its away, not a lot you can do about it, just means that I can't fling my leg over no". Things like that, know what I mean? And they kill their self laughing. Just ma nature I've always been like that...'* (Ian, FC).

In contrast to Martha's account above, Ian's comments underline his difference to others. However, social activity is a way of maintaining aspects of his old life. He is unable to work on the Bingo, but is able to attend, and demonstrate that he is still the same as he was. He still *'jokes'*, has *'got the gift of the gab'*, and is *'able to keep the world going'*. Ian is able to manage positive self-presentation. His words underline the moral dimension of activity and illness. He uses the rhetorical devices of a supporting cast; *'the women down there'* the *'Boys'*, and *'people'*, as well as direct speech, to illustrate that he does not sit and *'mope about all day'*. In this way social activity is indicated as a focus, and a way of bolstering identity, and maintaining aspects of an old life, and an old self. As he comments, it's *'Just ma nature'*.

Overall, in the context of a close-knit and supportive family context, two participants noted low levels of social contact, but they emphasised that this was their *'preference'* and as a consequence of their illness: Derek comments: *'... I seem to be a bit of a loner*

and to be quite honest, a group's uncomfortable like, you know... 'I wouldn't go out o' the house... I thought friends were against us 'n' that...' (Derek, LFC). In answer to a question about whether he had friends, Derek responded: *'Naw, no friend hen, naw'* (Derek, LFC). Similarly, Dick noted a lack of social contact, saying he will not go out unless it is with *'my family'* (Dick, FC). However, again, Dick identifies this situation as part of his illness. The ways in which Derek and Dick discussed not wanting to have friends as signs of illness underlined the shared cultural assumption that contact with, and support of, friends, is considered a 'normal' feature of life.

In summary, both groups discussed the importance of social contact. The less frequent consulters noted that socialising took their mind off symptoms, and were much more likely to note more general social contact which offered benefits. The analysis suggested that the frequent consulters had more limited access to social contact and support. Also, although such contact eased feelings of isolation, it was a reminder of their difference, as close friends 'made time for them' in their busy schedules. Both the frequent and less frequent consulters revealed tensions and ambiguities around social contact, as they did not want to be seen as 'complainers', or be annoying. As the frequent consulters reported more problems and fewer positive experiences in the interviews, it seems feasible to suggest that they were more likely to feel significant concerns around how far they could talk to their (relatively limited circle of) friends about their illness experiences, and thus perceive more risks to their moral identities.

5.3 Illness and family life

The family was portrayed as a central resource. In response to questions about what was most crucial when symptoms were severe, comments included: *'Talking to the wife, you know'* (Derek, LFC); *'I don't know what I would do without him (husband)...'* (Lesley, FC). The participants also revealed how family members helped them to overcome psychological symptoms. When asked open questions about the family and daily life, responses included: *'... she (wife) encourages you to get up and get out'* (Derek, LFC). Lesley notes of her husband: *'He'll help me, he'll come with me but when I'm good he'll say "No, you go yourself."'* (Lesley, FC). Both men and women described how their

families helped them cope. Derek has depression and in the context of having no friends, or contact with his wider family, he says: *'I talk to my wife hen...'* (Derek, LFC). Similarly, Dick a frequent consulter elaborates:

Dick: *'I talk to my wife all the time about it (depression), no problem, she sits and listens to us, because she actually deals with it, she knows actually more about depression than a lot of folks now, if you know what I mean'*.

Wife: *'Because I got a book all about it as well, you know, all about depression. I've read up on it. Yes'*.

Anne: *'And that makes you feel better then?'*

Dick: *'Aye, it's as if she says I've got it off my chest, you know, I'm talking to somebody about it, somebody that realises what's wrong with me...'* (Dick, FC).

The participants described a level of understanding and support that was offered by family members which was not supplied by others. The combined knowledge of the illness and the individual held by family members meant they were able to engage with the participants' needs. The importance of being heard and attended to by spouses who understood silences and symptoms was important; particularly in a social world shrivelled by illness. As Dick's word indicate he is talking to *'somebody that realises what's wrong with me...'* (Dick, FC).

5.3.1 Experiencing illness and gender in the family

The women participants were much more likely than the men to discuss how concerns for their spouses meant that they would often refrain from talking about their symptoms and illness anxieties. Sometimes this was because of their husbands' ill health: *'You just sort of try and get on with it. Cos you know he's worse than what I am...'* (Mary, LFC). Similarly, Rita says:

'I think I need to have a positive attitude because Jack (partner with multiple chronic illnesses) doesnae keep well. See he is on that nebuliser, he has got oxygen tanks in the room and he has got a heart condition. He doesnae need any more worry, he

doesnae need the stress of me being ill... when he's worried about me his blood pressure goes away up so no...' (Rita, LFC).

This suggests that the traditional expressive female role influenced women's experience of illness and family life. The combination of having an ill partner, combined with a common-sense assumption about traditional gendered roles may combine to impact on the ways the women participants perceived the availability of support for themselves in the family. This is particularly important when, as has been revealed, the family is often the core unit of support due to a diminished social circle as a result of illness.

For both the less frequent and frequent consulters, the male participants reported how their wives were involved in their medical care and illness management. For instance they referred to their wives tendency to arrange, accompany them to, and take part in, GP consultations, (see Chapter Seven), as well as organise their medication, and monitor their illness behaviour, and status, as Peter comments: *'any doctor or nurse in the world would never challenge your state of health if Alison (wife) said you were ill...'* (Peter, LFC). These accounts were supported by the fact that some of the wives of male participants arranged and took part in their husbands' study interviews, and completed their symptom diaries. None of the husbands of the female consulters did so.

Typically, men and women talked about support in the family in different ways. Whereas the women talked about their partners offering practical help with domestic chores in the home the men did not. Again, the less frequent consulters were likely to describe previous episodes, when symptoms were not contained: *'...my husband went for the shopping...'* (Mary, LFC). It was common for the women to express gratitude when they spoke about their husbands' 'helping' with house-work, cooking and shopping. However, the men did not refer to such 'help'. This could be because they took it for granted as part of traditional gender roles rather than seeing it as helping them to manage living with illness. For example, Johnny, a diabetic noted: *'I dinnae have much problem with' my diet'* (Johnny, LFC). To which his wife responded: *'I deal with that'* (both Johnny and his wife are in full-time employment). Routine household chores were talked about by the

women, as their responsibility. This was particularly vocal in the accounts of the women frequent consulters, who described help from their husbands and conveyed feelings of guilt and inadequacy:

'Well he (husband) helps me to do the housework... things I can't do, he does, em but no, he's very, very good that way, he goes to the shopping for me... I couldn't do without him, I couldn't' (Janet, FC).

'Well, Billy (husband) will, he'll take me out and he'll help me with the house because of my asthma and he is fantastic, really. If I didnae have Billy. I don't know why he's no' walked. Well, no, be honest any other man would not have put up with it. I don't know why he's no' walked' (Lesley, FC).

Lesley's husband is in full time employment, and Lesley does not work, whereas neither Janet nor her husband, are employed. Overall, the male participants did not refer to domestic help in terms of shopping or housework as aiding living with illness whilst the women did, and this was regardless of the employment situation. This suggests that domestic work is an added burden for women who articulated a responsibility for housework. There was a sense that the female participants felt they had to rely on help from family members, particularly husbands and children to do domestic tasks, which impinged on their attempts to live a 'normal' life.

'So it's gradually doing things and having to sit back and say I know the kitchen floor is manky it will just need to be manky until I have the energy or the time to do it. Also I ask people for help which was a big thing with me as well because I don't like asking for. I don't like asking for help' (Betty, FC).

The female frequent consulters also expressed feelings of guilt and gratitude about limiting the lifestyles of their families. 'For instance, Lesley describes how her husband's supportive stance limits his life, for which she feels guilty, whilst Janet relays how her family have to monitor her, and limit their activities when out, which leaves her feeling 'horrible' and a 'burden':

'I can't go nights out so he (husband) disnae go. So that makes me feel guilty I mean he's brilliant. He's fantastic...I've never had a holiday because I can't go. And it's not fair on my family and that makes me feel worse and I never, I never want to go out, and It's not fair' (Lesley, FC).

Janet comments: *'...you feel as though you've become a burden when you're out (shopping), it's a horrible feeling, horrible, horrible feeling so it is, so it is'.* These feelings of guilt meant that the women reportedly undertook actions and tasks to fulfil their roles, and maintain their identities, which in turn aggravated their symptoms. In this way family roles impacted on the ways in which they perceived and used the family as a resource in their management of daily life. Betty communicates this ambivalence:

'Right, if it's a bad day em they'll come in, David (14 year-old son) will come in from school and he'll start tidying up and whoever...I try and struggle on... I can feel absolutely rotten, I'm not going to wait on someone giving me a cup of tea, I'll get up and grab onto the walls etc using ma stick and make a cup of tea for maself, maybe even put a washing on even although I'm holding onto things and feeling absolutely ghastly but I think that's just, I don't know, it's like a mum thing, a mother thing, a woman thing. We won't just, you know it's like you don't want, I don't want this to beat me and it's very hard for me to turn and just say "Right, okay I feel lousy, I'm just going to sit where I am" and I don't think I'll be the only woman that does that. I think women are more likely to get up and get on' (Betty, FC).

Betty's words underline the notion of traditional femininity, and how her sense of self impacts on her experience of illness in the family. Her talk conveys how her inability to function, impacts on her identity, and this galvanises her into action (despite her GP's advice). The men did not talk in the same way, for example Ian explains:

'Aye, well I mainly do everything for mase' if I can but if they're (wife and daughter) in today then I'd ask them to make me tea, get me this... I'll say: "Gonna give us ma tobacco an' all that"... When you've got two legs, nae problem so you've got to depend on them. "Gonna make us a cup of tea?" I can do it but why hobble from there wi the crutches into the kitchen, pull a wee chair oot, sit down, the kettle's no full, I've gotta sit on the chair, turn it round a wee bit, struggle round,

hold onto the sink, fill the kettle up, struggle round again, put it back down again. It's an effort, but it can be done, but if there's somebody here, I say to maself, why should I put myself through all that, know what I mean?' (Ian, FC).

Ian describes his struggles, and in so doing legitimates his request for help. He goes to some lengths to justify to the listener and perhaps to himself, the support he expects at home. Implicit in the two extracts above are that whilst both the speakers present a valid need for somebody else to make them a cup of tea, in their accounts, they both draw on shared assumptions about gendered roles in the home, with different narrative outcomes.

The women also described how their roles as mothers and grandmothers helped them remain positive: '*... ma wee grandson, just melts ma heart...I am determined, he makes me that way'* (Rita, LFC). Marie spoke spontaneously about the family as a motivating force, and how she had drawn on her inner resources as a mother to overcome an illness crisis in the past:

'... I had this motivation, this thing I had motivation to get well because of the children... which I do believe made a difference you know... Mother is naturism' (Marie, LFC).

Similarly Janet invokes her role in the family and her motherly instincts as resources which help her manage currently, and on a daily basis:

'... I just cope day to day as I go along, have to. When you've got a family you just can't lie down. You know what I mean? I mean I've got grandchildren as well. I've got a daughter about to have another baby. I am not going to lie down to it; I keep going on and on' (Janet, FC).

However, as with other frequent consulters, the need to fulfil roles and maintain her identity as mother and grandmother also had a negative health impact on Janet. The extract above is part of a more extensive account in which she describes overexerting herself in her attempts to help her daughter with specific tasks, and thus aggravates her symptoms. Both the less frequent and frequent consulting women associated their behaviour in the family with traditional gender roles, but the frequent consulters

conveyed more frustrated attempts to achieve this aspect of their identities, and described more serious consequences of doing so.

In summary, the family was cited as a core resource for both groups of consultants, providing emotional and practical support. On balance, the frequent consultants were more likely to refer to their families as pivotal in the context of a limited social network. However, accounts were gendered. The female consultants voiced concerns about their partners' health, and the fear of being a burden to their husbands and children and noted this impacted on how they perceived the availability of help and support in the home. In contrast to the men, the women spoke of help from family members with housework, cooking and shopping, and expressed feelings of guilt and extreme gratitude around such 'help' implying that traditional gender roles impacted on how they perceived support in the home, as they attempted to accomplish daily life, maintain their identities, and their positive self-esteem. This notion was underlined by the male participants' lack of references to help with routine domestic tasks such as shopping, cooking and housework. In contrast, the men talked about their wives helping them with medical care and illness management whereas this was absent in the women consultants' accounts. This went further to suggest traditional notions of the feminine caring role in the family impact on illness management for both men and women.

5.4 Pacing

As I have reported, it was important for the participants to continue with daily life as far as possible; keeping busy, seeing friends, having a social life, fulfilling roles and obligations were all spoken about as ways of coping and living with illness. There was a clear sense that managing illness involved the quest to attain *normalisation* and prevent *disruption*. To this end both the less frequent and frequent consultants talked about pacing as a management strategy: *'You just sorta learn to go, you work your way round it... rest and just don't do too much, till it goes away'* (Mary, LFC). Jim elaborates:

'You pace yourself through the day, you know... if I'm hovering, I have to shift the settee and what have you. I'll maybe be doing half the floor and sit down, have a rest, have a

cigarette, shift the settee and get up and do the other bit, you know, sit and move the furniture and do the rest of it' (Jim, FC).

However, there were differences between the groups. The less frequent consulters described how they paced in order to perform tasks, undertake activities, fulfil social obligations and fill roles. The following extracts illustrate how they managed their jobs. Sarah is a school teacher and Paul is a taxi driver:

'I get up early to make sure I have extra time to get ready, and get organised, I can take my time' (Sarah, LFC).

'The best thing about the job is when I do get sore I can come in, so really when I'm moaning about my job it's probably the only job I could do, you know, or one of those you know, you can come in at any time you like, whatever' (Paul, LFC).

Sarah describes her morning routine prior to leaving for work. She accommodates her symptoms by adhering to a set daily routine. This illustrates what many of the less frequent consulters spoke about; the ability 'to carry on'. However, their accounts also indicated the fine balance between being able, or unable, to 'work'. Paul is a taxi-driver; for him too, timing is crucial, and he takes rest periods throughout his working day. His words '*... it's probably the only job I could do...*' underline the important role of pacing as a strategy to maintain a 'normal' life. But they also reveal that *types* of paid employment, combined with certain symptoms, allow pacing, which facilitates work.

Other less frequent consulters detailed careful pacing as a strategy which allowed a range of activities:

'I try and rest in between (activities). For example, I've been to work and on the way back from work I went shopping, and I'm home now and I'm dying to shut my eyes. And I've got a friend coming for tea tonight, so when you go, I'll shut my eyes then I'll prepare the meal... But, if I've to go at it without a break, I would do it, and then I would feel unwell, unwell to the point of, my heart is almost, you know, weird, that kind of tiredness, and eh, which is a horrible feeling. So, and then I could maybe

make myself feel not well for a couple of days as a result, so if I pace it out it's much better. If I pace myself I can just lead a normal life like everyone else' (Marie, LFC).

Marie demonstrates that pacing enables her to work, alongside other activities. Hence she can *'lead a normal life'*. The accounts relayed a reflexive process, whereby the less frequent consulters recognised the potential for, and avoided, significant loss by pacing. They were able to maintain social roles and identities.

In contrast, the frequent consulters' accounts described frustrated attempts at pacing, in contexts which demonstrated a shrunken world. For example, Jim notes that he can no longer work, or continue with his leisure activities of playing football and fishing. He sometimes goes for walks, but to avoid exacerbating his pain, he has to be careful not to overdo things: *'I have to stop, start, and stop again'* (Jim, FC). Janet elaborates:

Anne: 'And what about, how easy is it to get into town or go to the shops or something like that?'

Janet: 'It's impossible for me. I need to go by car or taxi. I couldn't walk any distance at all... On a good day, yeah I can go down the main street in a taxi but I can only walk about the shops for half an hour and then I've got to sit down. But apart from that I can't walk any distance at all, not at all, but I'm in a lot of pain' (Janet, FC).

Janet's words illustrate a common theme. The frequent consulters described pacing to perform basic activities and actions, rather than to facilitate paid employment, and a range of social activities. In contrast to the less frequent consulters, their attempts to reduce the impact of illness through pacing did not convey an ability to *accommodate* and *normalise*, rather it was noted as a strategy adopted to manage already disrupted lives.

Like the less frequent, the frequent consulters demonstrated that pacing involved the risk of aggravating symptoms. However, they described an often frustrated and reflexive

process, suggesting anxiety about exacerbating their symptoms, with potentially serious consequences:

'Cos I try to plan it, my day to day as much, and as easily as possible without inflicting any more stress on myself, that may cause me, to have to go to bed or to go into hospital' (June, FC).

June has to pace her life, this is characterised by risk and balance. Likewise Betty notes the risks around pacing, but adds another dimension; she is ambivalent about this strategy:

'If I get too tired I end up and it gets worse... I'll never regain it... I know I'm being daft when I say: "Bugger it I'm just going to carry on". And it's most times I think I'm sensible but sometimes I just think to myself "Och" you know, "Rebel", I want to rebel. I'm fed up I want to shout, I want to scream' (Betty, FC).

Betty's words reveal the risks and the 'emotion work' involved in pacing. Her words demonstrate that she is a responsible patient, but also convey the struggle to maintain this 'sensible' attitude. Janet gave another example:

Janet: 'Sometimes if I overdo it yeah I tend to be really, really sore at night time... But I tend to overdo it sometimes and I suffer badly for it as well, I suffer, when I overdo it I suffer'.

Anne: 'What sort of things do you do to overdo it?'

Janet: 'Well, like say, ma daughter's moving house there, giving her a hand recently, we were cleaning, doing cleaning of the place and I suffered for about three days after it, I did suffer for a few days...The illness comes secondary to your family as you'll probably know being a mother yourself, you'll probably know yourself, your illness is secondary to your family and it always will be...' (Janet, FC).

Janet's struggle to maintain normality aided by pacing is frustrated by her role as a mother. The tensions between her identity as mother and her attempts to ease her symptoms extend to her sense of self; *'being a mother... illness comes secondary to your family'*. The unequivocal nature of this statement is underlined by her personal comment

to me, illustrating shared cultural assumptions. Betty's account extends to an explicit statement about her threatened sense of self:

'Yeah, sometimes I say "Bugger it, I'm just going to go ahead and do it". It's a case of me fighting the disease and I know it's silly and I'm only hurting myself but I just think em, I've always been a fighter so my way of fighting it is like get on and do it. And I think to maself: "You're going to pay for this (laughs)"' (Betty, FC).

Hence, there were occasions when the frequent consulters prioritised role and identity maintenance over resting and pacing. For example, Betty has *'always been a fighter'*. This indicates that strategies employed to limit functional incapacity in daily life are infused with issues of identity. As a result, tensions and ambivalence become part of the illness experience, risks are taken and symptoms exacerbated in a bid to live daily life. These extracts illustrate the tensions commonly found in the accounts of the frequent consulters. They possessed valued identities that were thrown into question by their symptoms and functional debilities. As a consequence of this they took risks to reaffirm their familiar identities: mothers and fighters, they risk aggravating their symptoms in order to accomplish positive selves.

In summary both the less frequent and frequent consulters referred to pacing as a core strategy. The less frequent consulters discussed pacing in order to balance and undertake a range of activities. They described how if they did not pace with care, their 'normal' lives would be disrupted. In contrast, the frequent consulters described pacing in order to function on a more basic level, in already limited worlds. Their accounts featured the emotional aspects of such strategies, identifying ambivalence, frustration and risk.

5.5 Alternative therapies and treatments

Both groups spoke of alternative therapies. The less frequent consulters talked about alternative therapies and treatments as part of their complex management strategies, and typically described them as a supplement to mainstream treatment, whilst usually

adopting them as a last resort (although there were examples of such therapies usurping traditional treatments). The following extracts underline the experimental nature of alternative therapies and the 'trial and error' approach:

'I mean I go to a Chiropractor... Well, I've tried the deep heats n' all that. I suppose just the massage, and somebody massaging anything into your back will help a wee bit, but it's not a cure, it's a bit of pain relief, you know. I've tried everything over the years' (Paul, LFC).

'...an awful lot of these alternative therapy things. I mean I really don't see it. But I tried them, I mean the hospital has a pain clinic and eh you know as well as drugs they try lots of other things as well so you go through the whole gamut of things, you know. Eh you got acupuncture, tried that and it didn't help. They said it probably wouldn't help because of the pain and where it was coming from, and what was actually causing it...' (Peter, LFC).

The less frequent consulters described trying different types of treatments and medications, as an ongoing quest for some relief of symptoms. This experimentation was part of both formal and self-care strategies. Alongside limited success, Paul and Peter continued to rely on conventional medication.

Other less frequent consulters talked of the same process of 'trial and error', but were more critical of conventional medication. Consequently they used, and continued to experiment with, alternative therapies instead of traditional treatments:

'Well I am going to go to a Chinese herbalist in Paisley to see if they can give me something for anxiety and depression. Ma friend got me a thing... it's Chinese, Chinese remedies' (Rita, LFC).

'I was suffering from depression and was given anti-depressants for a while and then I decided to seek alternative help. I went to a homeopathic doctor... that, that got me going... I'm quite convinced, because conventional medicine had nothing to offer me other than the anti-depressants' (Marie, LFC).

In contrast to the less frequent consulters, most of the frequent consulters mentioned alternative therapies, but few adopted them. A recurring theme was concern around complications. Janet articulated that she had to be *'really careful'* and would only take what her GP advised. This suggests underlying anxieties for the frequent consulters who commonly reported taking a range of medicines for severe and unpredictable symptoms (see Chapter Six). This sense of risk was also reportedly shared by health professionals:

'She (a friend) is an aromatherapist... she wouldnae touch me because too much wrong with me, I'd need medical things signed and everything else and she said no...' (Lesley, FC).

Lesley continues:

'... I did it on my own (hypnosis), and he (GP) said, when I told him he blew a gasket. He said "If you want it come to me and I'll get you one so, a proper one". He says: "You don't know who he is... these are dangerous things, so if you want a hypnotist, you come to me", he says. "And I'll get one"...' (Lesley, FC).

The element of risk communicated reflects how this group talked about the potential costs of pacing, as well as the unpredictability of symptoms. As a consequence of these features of both illness and illness management, they described fewer opportunities to relieve their symptoms, and fewer chances to live 'normal' lives.

Both groups of participants mentioned financial costs of alternative treatments. Some of the less frequent consulters noted that lack of knowledge combined with cost was likely to influence their decision to use alternative therapies and treatments, although not enough to prevent use altogether:

'I tried different things in health shops but you just feel you're paying a lot of money and you don't know whether it's helping you or not' (Jane, LFC).

Like the less frequent, the frequent consulters talked about lack of knowledge and cost but reported that, for them, these were significant barriers to using alternative treatments.

For example, Jim, the only male in this group who described using alternative therapies, outlined a complex balancing act. He noted how conventional medical treatment fails to help his back problems, and described how his consumption of alternative treatments is mediated by financial costs and uncertain health benefits:

'It's all about this financial aspect of it, you know. It's a sort of balancing act. See how long this (acupuncture) lasts; see that's what, about a month now. It has helped, I can't deny it, it has helped a lot. But two sessions, nearly £100 and it's a hell of a lot of money... Let's be realistic, it's just not... it's a nice luxury' (Jim, FC).

Betty also refers to financial barriers to use:

'I don't really have the money to do a lot of these things in fact I may I'll need to talk to my herbalist, erm, I was seeing her once a month and I can't afford to see her once a month because I pay for the consultation. So what I'll need to do is ask her to give me 2 months supply or something. I cannot afford. I need the herbs but I can't afford I can't afford them now' (Betty, FC).

Betty's account was not typical of the frequent consulters. She described using a range of therapies and treatments alongside conventional medication. She also described how her GPs had given opposing views about her use of alternatives; one was sceptical, the other supportive. Her account reveals that she strove to manage her illness, in the face of economic barriers, conflicting advice, and the experimental nature of the treatments, alongside a complex medication regimen (see Chapter Six). Furthermore, limited by her economic situation, she displayed some frustration at being unable to utilise this resource fully.

In summary, both groups referred to alternative therapies. Broadly, use was referred to in two ways: as a substitute for (rarely), or alongside (typically), conventional treatment. The less frequent consulters noted more use, although they were sceptical about the benefits and mentioned the cost. However, these factors did not seem to prevent the use of alternative therapies and treatments to any significant degree. In contrast, the frequent

consulters talked more about cost as a barrier to use. They also expressed their own and their GPs', wariness of alternative therapies, due to perceived risk of complications. This reflects an ongoing concern around uncertainty, and a lack of control around illness, together with a lack of confidence in alternative therapies, which may aggravate symptoms further. All of these combined to dissuade most of the frequent consulters from accessing this type of resource. There was also an indication of gender differences; overall, the women described using alternative therapies and treatments more than the men.

5.6 Equipment

Alongside pacing and alternative therapies, a minority of the participants referred to using equipment to ease symptoms and aid functioning. Again, experimentation and limitations were evident as well benefits. The accounts included negative aspects of using equipment. For example, Mary wears a hearing aid and notes: *'Sometimes it annoys you. Sometimes you don't want to have it in'* (Mary, LFC). Ian notes of his false leg: *'It hurts, so I don't use it much'* (Ian, FC).

The less frequent consulters described using aids in order to help them maintain aspects of their 'normal' lives, such as employment:

'Because I'm a taxi driver when I'm working, which is normally fifty, sixty hours a week I work...But sitting all the time with my back all, I get different aids on my seats to try and support my back. Some people say sitting must be bad for you, but see to me it seems to be the best thing. I couldn't stand all day. I couldn't walk all day, but I can sit with my back padded and my back up. It's painful, you know. Now and then you've got to get up and go out from the wheel and just try and straightening and that, but it's no bad. Not the worst thing in the world, you know what I mean' (Paul, LFC).

'...you just stick it (TENS machine) in your pocket and you get a couple of wires coming from it and you stick the, you just stick the electrodes onto the skin and you know wherever, just by trial and error... You just fiddle about with it for two or three days until you get one that works the best and the best

place to put the electrodes and so on. And then you can use it for a couple of hours at a time. But you can wear it... You know I can stand in front of my class you know, this wee thing you stick it in your pocket' (Peter, LFC).

Both Peter and Paul discussed how equipment helped them manage their symptoms, whilst noting shortcomings, such as the complicated process, side effects, annoying features and limited efficacy. However, the use of aids did form part of the complex system of management strategies which they adopted to accommodate their symptoms in their daily lives in general, and working lives in particular. The important point is that such equipment helped maintain daily life, so what they gained outweighed any disadvantages.

The frequent consulters also spoke of the benefits of using equipment, but in contrast this was in the context of a diminished world, already disrupted by illness. Ian describes using a motorised wheel chair:

Anne: 'So that's how you keep yourself cheery then, that's how you cope?'

Ian: 'Down to the bingo and round about. As I says that chair made a difference because I've no' got the wife, hanging onto the back of the other one, shoving me about... So with that one there I can go out myself now. They (wife and daughter) just bump it out the close for me and I'm away with it, that's what I done this morning. When I just go it, I was down there for a few hours, scooting round about and all that. Everybody that I know, instead of having the wife with me, do you know what I'm talking about. A wee bit more privacy and all that, if I wanna. You cannae talk to a guy about things when there's women standing, you know what I mean. So if I'm there myself and it's a great, a great help that electric chair' (Ian, FC).

Ian highlights the importance of this equipment in his daily life. His wheelchair offers him a level of independence, and the opportunity for social activity. However, his account illustrates the limited ways in which equipment can accommodate symptoms and *normalise* illness conditions. Whereas the less frequent consulters used equipment in a bid to manage paid work, as in their use of pacing, the frequent consulters described their

use to facilitate more routine actions. The wheelchair offers Ian *'a wee bit more privacy'* it does not facilitate employment or a busy social life. However, it is conveyed as a pivotal coping resource, without which Ian would lose his independence, privacy and ability to socialise, all important aspects of his identity.

For the frequent consulters, the negative aspects of equipment use extended to it being a symbol of illness and premature ageing, which could threaten identity:

'... I'd like to move (house). To get away from the stairs, and yet, if I move I'm giving in. I feel as if you're not disabled yet and you're not gonna be... I don't want to think along they lines. I'm too young. I mean it's ridiculous. Fifty two, you know, at 52 eh, to think of stair lifts and toilets downstairs, do you know what I mean? But I know that if I want to make life easier for myself I have to try and do away with a couple of issues that are creating problems and the stairs is one o' them' (June, FC).

June describes a struggle to resist disruption of a 'normal' life-course trajectory. In contrast to the *normalisation* of the less frequent consulters who refer to their symptoms as dimensions of 'natural' ageing, she states the opposite view. She is too young, *'it's ridiculous'*. The equipment offers relief, but also tangible signs of chronic illness. Tensions and ambivalence which permeate the illness experience for the frequent consulters are highlighted here. The following extract extends this theme:

'I probably should use it (walking stick) more than what I do. It's basically vanity that prevents me from using it. As one of my mates says to me, you're not 25 anymore, you need to stop. This is going to sound horribly ageist, but I associate walking sticks with old people, you know, and I don't regard myself as being old, I'm sorry. I think it's more psychological than anything else. But I have to use the stick, as I say there are times that I have to use it, I use it. But it's a last resort thing' (Jim, FC).

Jim's references to walking stick use underline his frustrated attempts to accomplish *normalisation*. It potentially *disrupts* his sense of self; there are times when he has to use a stick, but only as '*a last resort*'.

In summary, both the less frequent and frequent consulters described using equipment to help them manage, noting advantages and disadvantages of such use. The less frequent consulters described using equipment to help them maintain 'normal life', for example assisting them to stay in paid employment and in such circumstances the disadvantages were conveyed as bothersome but insignificant. However, again, the frequent consulters described using resources in already disrupted worlds. It was clear that for them the disadvantages extended to the symbolic. Equipment was a tangible reminder of their illness, their lack of control, and a threat to their identities. However, whilst they reported avoiding using such 'stigmatising' aids as far as possible, the unwelcome connotations were swamped by a need to function. They would struggle to manage as long as they could, but when their choice was limited to either functioning, or not, they used equipment as a last resort. In this way such equipment was regarded with ambivalence.

5.7 Summary

In this chapter I have reported how the participants spoke of the resources and strategies they used in their quest for a 'normal' life. The analysis included the form as well as the content and context of participants' talk, and illustrated how they strove to present themselves positively throughout the interviews.

Both groups indicated the importance of 'keeping busy' as a way of coping with chronic illness. Doing things was a way of taking their mind off their symptoms. The less frequent consulters spoke of varied actions and activities, and described busy social and working lives, whereas the frequent consulters relayed a constant negotiation between symptoms and occupying themselves; they described a clearly scaled down life. The accounts revealed how for the less frequent consulters in the context of busy lives, the experience of illness was diluted, whilst the frequent consulters' lives were diminished, and illness magnified. The impact of their symptoms made it difficult for them to have a

busy schedule in order to limit the impact. Also, the less frequent consulters were able to illustrate 'keeping on top' of symptoms, as they spoke of their busy lives, whilst in contrast, the frequent consulters relayed how their moral identity was challenged due to inactivity, as Betty (FC) said *'I just seem to ...vegetate. And I know I shouldn't be doing that'*. Thus, activity had both practical and existential benefits.

One way of keeping busy was to undertake paid work. The less frequent consulters were able to draw on cultural values of the importance of paid work, and the ability to be stoic in the face of illness to build positive identities. They described the moral importance of work, but also the financial and material resources, which combined to 'keep them going'. They also noted associated gains such as social contact. Importantly, their symptoms *combined with* their work situation, allowed them to continue in paid employment, and directly and indirectly enjoy health benefits. Thus they were able to build balance into their life worlds; they described the ability to keep busy by undertaking a range of activities, and fulfilling social obligations which were familiar aspects of their lives, and their identities.

In contrast, and crucially, the frequent consulters were unable to draw on work as a resource in their attempts to live with illness. This had ramifications for their management strategies, as they were unable to enjoy the material, economic and social benefits which being employed offered the less frequent consulters. Employment, and its associated benefits did not cushion the impact of their chronic illness, neither did it aid them in their overall illness management. Moreover, as some participants explicitly stated, and others implicitly conveyed, their lack of material and economic resources had a negative influence on their ability to manage living with ongoing, severe and unpredictable symptoms. Nor did they have the opportunity to allude to work as a symbol of successfully containing symptoms in order to manage positive presentations of self. Again, for them paid work was a symbol of how illness had disrupted their lives, and identities.

Both groups also talked about the importance of social contact. The less frequent

consulters described a broader social network, and the importance of talking to others, in a general way, but also for more personal support from close friends. This was particularly clear in the women's accounts. But there were signs of tensions, as they spoke of their fears of illness behaviour slipping into their social lives. This was a more significant fear in the accounts of the frequent consulters, who described fewer opportunities to accommodate their symptoms, and more severe crises episodes and ongoing problems. They clearly articulated the importance of confiding in their friends but they also feared being seen in a negative light and suggested that they did not want their illness status to swamp their identities as friends, nor to stain their self-image.

The family was positioned as important, particularly for the frequent consulters who relied more heavily on their close family as a core support network, as they reported limited social interaction. The accounts reflected some traditional ideas about gender roles. The women described their gratitude for routine tasks around the house, whereas the men did not. The women were more likely to talk of support they received with ambivalence, articulating guilt and reluctance to burden their partners and children. The men described help with medications and either practical, or emotional support with symptom management, whereas the women were unlikely to do so.

Both the less frequent and frequent consulters described how they paced in order to manage living with chronic illness, attain normalisation, and prevent disruption. The less frequent consulters revealed that such strategies allowed them to continue in paid work, enjoy social life and maintain their familiar lives. In contrast, the frequent consulters gained fewer benefits which had symbolic as well as practical implications. Despite displaying ongoing stamina in the face of adversity, illness management strategies were tainted by ambivalence, tensions and risk. To pinpoint the difference between groups, the less frequent consulters described pacing in a busy life world, whereas the frequent consulters discussed pacing in a diminished world, which illustrated their stoicism, but an inability to contain symptoms and stave off the consequences of illness on their daily lives.

Participants also described their use of alternative therapies, treatments and equipment use which aided their quest to manage illness. This talk was characterised by uncertainty, experimentation and issues around cost. However the less frequent consulters described their ongoing use of such strategies, whilst the frequent consulters conveyed a sense of risk which they found unacceptable. This also revealed how they were likely to depend on their GP for medication and advice, positioning him or her as having a central role in illness management. Both groups of participants spoke of using equipment to ease illness. However, they voiced practical problems and often limited benefits, as well as significant gains. What distinguished the frequent consulters' accounts, was that the equipment symbolised; a sense of deterioration, premature old-age, feelings of difference, isolation and fundamental threats to identities. Again, there was a clear sense of ambivalence in such use, which permeated the accounts of the frequent consulters in particular.

As in Chapter Four, and identified above (3.3.2.1), I have tried to stay 'true' to the participants' accounts by systematic analysis, and illustrating my findings with a range of participant accounts. Through constant comparisons, I have also tried to check that the accounts are *credible*, in that they reflect the participants' experience of managing multiple chronic illnesses. I have also claimed that although the data generated are favoured accounts, they can also be said to relate, in some way, to an external reality, based on checks I have undertaken for consistency and coherence throughout the interpretive and analytic process. Detailed field-notes also help support any such claims in this chapter.

A major source of both relief, and added tensions, was medication use, thus the ambivalence that characterised the illness experience so far, stretches into this aspect of the participants' management strategies which I examine in the following chapter.

Chapter Six

Medication matters

6.1 Introduction

Most of the participants spontaneously described the importance of the use of medication as a core strategy to aid illness management. Medicines were a key resource on which participants drew in their attempts to: *ease* symptoms; *stabilise* conditions; prevent *disruption* and achieve *normalisation* in their daily lives. However, the accounts also illustrated tensions and ambivalence around medication use, thus emphasising the ambiguities integral to the participants' illness experiences revealed in Chapter Four.

This chapter addresses several major themes. First, I discuss both regular and flexible, *regimens* adopted by the participants and the associated *reasons* for medication use. This is followed by an analysis of how the participants talked about *tensions* around medication use, how *reliable* they perceived medication to be, and how they *sourced* it. Then I focus on how they discussed the GP *consultation* in conjunction with gaining a prescription. Finally, I engage with the dialogue as a moral discourse. As in Chapter Four, a sense of morality suffused participants' accounts. All were concerned to construct themselves as responsible consumers of medicines, and their talk around drug use revealed their stoicism in the face of suffering, and validated their illness status.

6.2 Regimens and reasons

Both less frequent and frequent consulters described taking medication flexibly: '*As required*' (Jim, FC), and regularly in a drill like manner: '*at night...I take the tablets for... high blood pressure... the diabetes, I take that in the morning. I take the tablets for my ulcer, after I've had my dinner*' (Derek, LFC). '*I've got a set amount... seventeen types of medication...*' (Ian, FC).

The regular drill like regimens, were commonly associated with particular conditions (such as diabetes, cancer, heart disease, and hypertension) and specific drug types (for example antihypertensives), and characterised by clear medication times throughout the day. The flexible regimens were commonly for symptom management (for instance, pain, anxiety, and diarrhoea). Due to the participants' illnesses, most of them described taking a range of medications that involved a combination of regimens. However, typically, the frequent consulters described more medication use than the less frequent consulters, in terms of dosage, range, strength and frequency.

6.2.1 Regular regimen, conditions and 'survival'

The less frequent consulters talked unquestioningly about drugs that they took regularly, for conditions such as cancer and hypertension. They communicated an implicit need to take them, for 'survival': '*... I have to take them you know, for the blood pressure ...*' (Martha, LFC); '*... breast cancer... I've been on the Tamoxifen five years...*' (Rita, LFC), '*... my blood pressure... I got tablets for it*' (Derek, LFC). However, they did not commonly articulate an explicit need for medication to 'survive'. One reason for this could be that they were able to *normalise* their conditions and had fewer complications than the frequent consulters did. Furthermore, as they took medication in the context of busy lives, it seems feasible to suggest that, up to a point, they were able to normalise their medication use. In this light it is understandable that they did not pinpoint how medicines aid their 'survival', as this aspect is not at the forefront of their experience.

In contrast to the less frequent consulters' accounts, the frequent consulters talked extensively of regular medication use for 'survival'. For instance, in the context of an account which mentions acute episodes and the threat of death Ian says:

'... it's mainly vascular coronary artery disease, you know it's thingamy, and it's all over, through my whole body, you know it's thingamy, stopping the circulation in my neck and all that. That's what he (GP) says to me, he says "You're going to end up having a massive stroke", he says, "So it's up to yourself". So I'm on quite a lot of medication' (Ian, FC).

The above extract is indicative of the frequent consulters' accounts around the need for life saving medication. In this example, its critical role is underlined by the threat of '*a massive stroke*' for Ian. His GP has specialised knowledge, which gives him authority, and Ian, shows that he is a responsible patient. The doctor has told Ian '*it's up to yourself*'. The role of the GP in the medication talk distinguished the accounts of the frequent consulters. Janet's words illustrate this recurring theme:

'... because of the strokes and the high blood pressure I have to, I know I have to take medication I couldn't survive without it. But I feel more secure in myself because I have a man (GP) that knows what he is doing' (Janet, FC).

This group talked about how it is important to consult a GP who is familiar with, and recognises the needs of, the patient as an individual. The following quote from Lesley underscores this. She expresses the potential risks involved when a GP fails to recognise the problems associated with her multiple conditions and medications. In this way, she reiterates the complications that the frequent consulters regularly relay. This highlights the importance of a GP who knows the patient, and is familiar with their medication:

'He (GP) said "You've got high blood pressure, you've got, you take palpitations". He says, "You could take a heart attack". And yet that first doctor says "Yeah, go ahead". I think that's where you should see your own doctor, comes into it, they don't know you...' (Lesley, FC).

The frequent consulters described the GP as having a crucial role in maximising stabilisation of their illness conditions. They presented a reciprocal relationship, highlighting their role as responsible patient. They placed a high level of trust and confidence in the GP when discussing their use of medication, and 'being known' by the GP was central. In contrast, the less frequent consulters neither discussed the pivotal role of medication, nor their GP in relation to survival. Comparing the two groups brings into sharp focus the reported important role of the GP in the medication management of the frequent consulters, magnified by the complications of their co-morbidities, and multiple and complex drug regimens.

6.2.2 Flexible regimen, symptom relief, and daily life

The participants also talked about taking medication to ease symptoms in order to function in daily life. For example, the less frequent consulters described how medication helped facilitate 'normal' life. More specifically, they noted how medication allowed particular activities: *'I have to take Imodium (sometimes) and that lets me get to work'* (Sarah, LFC). Paul notes:

'Sometimes I do things I know I'm going to suffer for. But it can be a difference of maybe sticking a set of brake pads on my car that takes me half an hour, so maybe it'll cost me twelve quid to do it myself. If I'd have not done it, sixty quid, so there's times when I say, "I'd better just take a couple of pain killers and do it" ...' (Paul, LFC).

This extract is part of an extensive account of the importance of work in Paul's life, and his reliance on high doses of pain-killers to function. Paul, a taxi-driver elects to take medication in order to undertake job-related tasks. The symptoms are contained and masked with the use of drugs. Other less frequent consulters described self-regulation of drugs, alongside other strategies, to control symptoms in order to facilitate particular tasks or social roles and obligations. Fulfilling roles such as employment, often aggravated symptoms, which could lead to taking more medicines, but this was 'justified' by the need to fulfil social obligations, for instance be 'responsible' workers. In this way, the less frequent consulters were able to *normalise* illness, and prevent *disruption* of their daily lives, and positive identities.

The frequent consulters' accounts were also characterised by references to the benefits of taking medication for specific activities. For instance, Janet described a particular incident when she was given painkillers by her GP:

'...I said (to the GP) "... these painkillers are doing nothing for me". He says "Right, try these ones, here you go". Absolutely fabulous, absolutely fantastic so they are... I've still got pain

but nothing to what it was, nothin. I went shopping yesterday with my daughter; my future daughter in law went to B&Q. I couldnae before, we went all round B&Q store, came out of there and went all round the shop, eh Tesco's, came out, went for a coffee. We sat with the babies and fed the babies, came out of there and went to my daughter's house, another coffee, walked round the garden with my other grandson and came back home. I felt absolutely great... I felt great and that's the first time I've done that in such a long, long time and I really felt good for it, I really felt good for it' (Janet, FC).

Janet's account suggests that medication has benefits beyond alleviation of symptoms; it contributes to her role and identity as a mother and grandmother. Janet describes medication use in the context of a disrupted and shrunken world. For example, she conveys a high degree of pleasure from being able to function in what might be considered a basic way. Such talk distinguished this group from the less frequent consulters. The form of the talk underlines the significance of her experience. Her repetition of how 'good' it was, and her comment: '*that's the first time I've done that in such a long, long time*' highlights what medication means to her. This was indicative of the accounts of the frequent consulters. Medication offers practical and symbolic respite, allowing them to do things which gives them a sense of 'being' who they 'are', lending coherence to their sense of self.

The participants spoke of the work involved in balancing activities and medicine regimens. The less frequent consulters commonly had fewer types of drug to manage, but still noted problems. A minority of the less frequent consulters described single drug use: '*I still just take Dihydrocodeine... on a daily basis*' (Peter, LFC). However, this phrase masks a reflexive regimen prompted by the need to contain fluctuating symptoms throughout a typical working day:

'If I didn't take the Codeine, I'd be in constant pain. Ehm, I take some Codeine in the morning when I get up and it's usually painful at that time, and probably about an hour later the pain subsides. I take some more Codeine sort of lunchtime, and I can feel the pain coming on. I know it's there maybe from about 11.00 o'clock and so I take more Codeine, then the middle of the afternoon. That's OK, and then I just sort of,

usually by not long after teatime the pain comes back, so like now I can feel that it's coming back and by the time I'm ready for bed kind of at 10.00 o'clock I'll be sort of very, very agitated. Just with the pain, it's annoying. It's not a, it's not an ache, it's not a throbbing pain, it's a raw pain. If you can imagine if you fell and grazed yourself and somebody poured disinfectant in it, you know that sort of really raw, nippy, burning sort of pain. That's the kind of pain it is. So, it's very uncomfortable. And I'm getting very sort of irate by about 10.00 o'clock so then I take more Codeine and I go to bed'

Anne: Okay. So, you take it about four times a day then?

Peter: Four times a day, uh hu, but only half the dose that I used to be taking because otherwise I couldn't work because I'd be falling asleep' (Peter, LFC).

Implicit in this extract, but integral to Peter's experience, is his need to monitor the amount of pain relief he takes alongside the pain he endures. He relays the severe and incessant nature of symptoms, which interweave with carefully timed consumption, and his ongoing reliance on medication. The detailed way in which Peter describes his daily routine offers the listener insight into how much emotional and practical work is entailed in managing symptom relief with drugs. He has to weigh up the amount of pain he can endure with the amount of drugs he is able to take and continue to function. His account mirrors the talk of other less frequent consulters who described their management of medication as a complex project, based on constant assessment and monitoring, which led them to vary their use of drugs to achieve maximum symptom control, and minimum drug use.

The frequent consulters also described taking medicines reflexively, although, in contrast to the less frequent consulters, the process was typically, part of a multiple regimen, and a disrupted life. Like Peter, Betty notes taking Dihydrocodeine as unproblematic, but suggests a difficult regimen:

Betty: 'It's routine... but I tend to the ones like the Dihydrocodeine I mark down on a diary when I am taking them so that I wouldn't go over the eight in a day. Because when I am really bad if I didn't, I've got so much pain that I can forget when I've taken it...'

Anne: 'So, the Dihydrocodeine you can be flexible with?'

Betty: *'No, not recently I've been taking eight a day'*.
Anne: *'Okay and all the other things you take it's not as and when it's just every day'*.
Betty: *'Everyday. Basically, I'm taking everything everyday...'*
(Betty, FC).

So, both Peter and Betty describe taking Dihydrocodeine reflexively in a bid to manage severe and incessant pain. Betty explicitly states what Peter has implied, neither of them must *'go over'* a certain amount. However, Peter takes medication as part of his working day, whilst Betty is no longer able to work, and consumes hers in a life clipped by illness, as she says on *'a good day...the pains bearable and I can move about'*. The significant difference is that Peter takes his medication in the course of his *'normal'* life, and Betty's account conveys her diminished world.

To compare the groups the frequent consulters described a *disrupted* world, characterised by fluctuating symptoms, which impacted on their daily lives, and expressed a fundamental need for drugs in both a practical and emotional sense. In contrast, the less frequent consulters noted how drugs contributed to their bid to *normalise* their illness, and achieve goals. Medication was a key resource, enabling them to undertake tasks, remain in employment and enjoy leisure activities and therefore fulfil roles and maintain identities.

The participants described particular events or episodes which prompted them to turn to medication *in extremis*. The less frequent consulters indicated episodes or incidents when symptoms that they typically managed to contain broke through personal boundaries:

'When my mum died they put, he (GP) gave me 5 mg of Diazepam... I can't cope with a crisis' (Rita, LFC).

'I took them (prescription pain killers) the time I crushed my foot, I had to (laughs)' (Johnny, LFC).

Peter: *'... it (pain) was ok for about, until about five years ago when I had an abscess in the abdomen...'*

Anne: *'Could you talk a bit more about that episode?'*

Peter: *'... So basically for a long, for possibly even for the rest of your life you suffer wee bouts of pain but they never really amount to very much and you get to expect them and you put up with them and so on, and so on. And, but this kept getting worse and worse and worse and worse and I went to the doctor and he gave me antibiotics...'* (Peter, LFC).

These accounts conveyed a need for specific medication as a result of isolated incidents. Typically, the less frequent consulters were able to manage symptoms with a combination of strategies, resources and self-regulated medications, and stabilise illness conditions with drug use. At times they were unable to achieve equilibrium and were forced to take types of medication that they normally avoided. Although they experienced occasional flare-ups or set backs, a sense of control was conveyed. However, such control was tempered by the knowledge that disruption of both the body and daily life was a possibility. These accounts suggested that GP consultations might often be averted unless crisis hits, and, as illustrated in Chapter Four, the less frequent consulters talked about their ability to avoid crises.

In contrast, the frequent consulters regularly described crisis points in their illness trajectory, which in turn prompted action. In the extract below, Janet describes her need for medication to ease severe symptoms:

Anne: *'Okay. So you phoned the doctor?'*

Janet: *'Mhmm (affirmative).'*

Anne: *'Why that day particularly rather than another day that you might have been suffering?'*

Janet: *'Because... these painkillers weren't even taking the edge off it, it was so severe.... I had so much swelling behind my legs, so much inflammation I says "The pain is unbelievable". And he said: "Yes, I can understand that"... Hydrocortisone injections, I got them, one in each knee. And em he gave me another injection in each knee, which really helped a great deal. He gave me steroids to reduce the inflammation to take every day. I finish them in two days time'* (Janet, FC).

Janet adds that her knees are *'crumbling'*, and she will have to use a wheelchair. Her account conveys a steady deterioration, characterised by acute episodes. This was a common feature of the frequent consulters' accounts and contrasts with the less frequent consulters' descriptions of crises which were depicted as rare. The following example highlights an inability to stabilise illness, and a need to contact the GP for medication at critical times:

'When my asthma is bad the first thing I do is I up my inhalers and I will give it a day or two.... But if I feel it's getting bad I'll up them, I'll double the dosage again and if it's not any better then I'll have to phone the doctor...' (Lesley, FC).

The crises described by the frequent consulters are persistent; the form of the talk (specifically the continuous tense), underlines the habitual, ongoingness of such crises. In contrast, the less frequent consulters revealed occasional and past crisis situations and so a lesser need for varied drug use. Such differences in experience have implications for GP consultations.

Another feature of the accounts was the possible costs involved in taking a combination of drugs; there was a risk of complications. A minority of the less frequent consulters indicated this:

Anne: *'Do you take anything for the nausea then?'*

Johnny: *'No. I don't see any point in taking anything for it. I've took, stuff for an upset stomach right enough but I'd rather just...'*

Johnny's wife: *'Yes 'cos sometimes his stomach's quite acidic. I've used a pill a sickness pill before now; it seems to settle his stomach. Again, you have to watch what you take because of all the other tablets. You're kind of wary'* (Johnny, LFC).

The contingency of the illness experience revealed in the previous chapter extends to wariness around drug use. Participants not only carefully monitored dosage due to the risk of side effects, but also had to watch what they take due to the potentially problematic consequences of mixing medications.

Like the less frequent, the frequent consulters referred to complications. For example, a drug for one condition may aggravate symptoms of another health problem: '*... antibiotics trigger it (colitis) off...*' (Lesley, FC). Others mentioned drugs reacting to each other:

'... they're (doctors) not wanting me to take this tablet because of the amount of steroids that I've taken...' (June, FC).

In contrast to the less frequent, the frequent consulters regularly talked about the combined problems of multiple medications, severe symptoms and uncontrolled illnesses. For example, in response to a question about self-regulation and pain, Ian's response relays a complicated situation:

'I'm on the top whack, same as the pain-killers; you know for this, for the stump, it's got phantom pains an' all that. That's what stops me as well, I cannae take the other tablets because they would interfere with the other tablets so they'd have to give me they ones which was an experimental thing' (Ian, FC).

The problems of multiple medications were heightened due to the strength of the drugs and the need to *experiment* with combinations, which led to more uncertainty and unpredictability.

In summary, medicines were a central part of participants' management strategies and were taken in both a drill-like manner to stabilise conditions, and flexibly, as a response to symptoms. However, the frequent consulters typically described more complex regimens, which were more likely to lead to complications. For them, medication is at the forefront of a shrunken world, whilst for the less frequent consulters the regimens are typically less onerous and taken in the context of their 'normal' daily lives. Nevertheless there was evidence in the less frequent consulters' accounts of the hard work of juggling medication, and daily life. Both groups' accounts of medication use revealed tensions as part of the illness experience. Overall, the accounts of the frequent consulters emphasised the importance of medication in helping them manage, and maintain some sense of

normalcy in an already disrupted life. For the less frequent consulters drugs were presented as playing a part in suppressing symptoms, allowing them to perform social roles central to their self-concept, and resist disruption of their familiar lives. Both groups alluded to using drugs to alleviate symptoms aggravated by doing more than they 'should' in fulfilling roles.

6.3 Tensions around '*pills and potions*'

Whilst all participants took some medication, some spoke of their concerns about taking too much, and some of not wanting to put '*pills and potions*' into their bodies (Betty, FC). An aversion to using medication was conveyed in a number of ways: '*I just hate tablets of any kind. I hate medication*' (Rita, LFC); '*I didnae want to end up back on these tablets again*' (Jim, FC). Janet notes she only takes particular medication '*... if it gets to the stage where I cannot cope with the pain any more*' (Janet, FC). Both the less frequent and frequent consulters described how they had no choice in taking some types of medication to stabilise illness conditions. '*I don't like taking pills but I have to take them you know, for the blood pressure and the thyroid...*' (Martha, LFC). Lesley notes: '*I'd rather do without (medication)*'. But she adds: '*... I was put on tablets right there and then... And, my, my blood pressure was stabilised again...*' (Lesley, FC)

Participants expressed concerns around types of medication that they felt they could avoid alongside medications that they felt they had to take:

'I take my high blood pressure (medication), but I try not to take anything else, I surely take enough... I don't take any other things' (Johnny, LFC).

Martha, Lesley and Johnny note that medication for hypertension cannot be avoided. This was a common theme throughout the accounts. Overall, the participants conveyed a dislike of medication in general, but a need to take some medicines such as *antihypertensive drugs*.

Some of the less frequent consulters described aversions to, and attempted to avoid, particular drugs, specifically anti-depressants. For example, Rita states: *'I used to be like hooked on Valium years and years ago'*. She continues:

'So I do think I'm a bit depressed the noo, but, I'll just need to get on with it, I'll just get over it... Cos I'm no gonnae take any more tablets (anti-depressants)...' (Rita, LFC).

The frequent consulters mirrored these concerns:

'... I didn't want to go back to the doctor, a didnae want to get to the stage where I had to go back to the doctor... end up back at the doctors, back on these tablets again... That (depression) I could control myself, okay my back and my leg, I'm very limited in what control I can exercise over that. But the other thing, the depression side of it, that to me is something that, that em as a say 90%, the solution to the problem is in my own hands' (Jim, FC).

'I don't want to be stuck on anti depressants... I want to live for myself not for tablets. I want to be able to control myself, not have tablets control me... and that's what they eventually do, control you. You don't control them, they control you' (Janet, FC).

It was notable that the participants aligned resisting medication to maintaining control. Jim says he has little control over his pain relief, but he is determined to avoid anti-depressants, and in this way is able to exercise some control over his symptoms. Similarly, Janet equates taking anti-depressants with relinquishing control. This seems particularly significant as expressed by the frequent consulters. In the context of a daily life that has been stemmed by illness due to an inability to contain particular symptoms, it is important for them to remain in control of others.

Both groups described attempts to reduce their symptomatic drugs. The less frequent consulters regularly relayed a desire, and demonstrated an ability, to cut down, or cut out medication:

'I thought it was about time that I maybe stopped taking so many and I tried to... it's down to a much, much lower dosage than it was ...' (Peter, LFC).

'I did take them (anti-depressants) for quite a long time, but managed to come off them...' (Marie, LFC).

The differences between the two groups were underlined by the frequent consulters' reported inability to reduce or stop medication. Below, Betty and Janet refer to a range of drugs including pain-killers, and for Betty anti-depressants:

'I would love to be able to turn round and come off all these things (medicines) but to be able to function half normally I've got to take them and if that's the way it's got to be that's the way it's got to be' (Betty, FC).

'Who wants to be on medication for the rest of your life, I certainly don't but I know I've got to...I have to, I know I have to take medication I couldn't survive without it ' (Janet, FC).

Thus, both less frequent and frequent consulters expressed the same desire – to cut down or cut out their medication, but this produced tensions around drug use that were more problematic for the frequent consulters. Their inability to control their symptoms without medication is a tangible reminder to them of their illness status, whereas the less frequent consulters were able to 'enjoy' a degree of drug control, which indicated bodily control.

Furthermore, the less frequent consulters described an ability to turn to other methods of symptom relief:

'You can do a lot without taking painkillers all the time. You can try to ease it by gentle exercising and no doing things that are bad for it...' (Paul, LFC).

In contrast, the frequent consulters described an inability to avoid medication. For example: *'I got down to one Prozac, but then the Doctor put me on two again'* (Betty,

FC); *'I'm back on the other tablets again for my anxiety, I'm not sleeping'* (Lesley, FC); *'I had to call the doctor and he upped my painkillers'* (Janet, FC); *'... sometimes I don't take the sleeping tablet to see if I can do without it, but I cannae...'* (Ian, FC).

In summary, both the less frequent and frequent consulters voiced aversions to medication, but a need for it. However, they demonstrated a 'responsible' attitude in the face of this disdain. Despite not wanting to take drugs, they described their use of medication regimens to stabilise conditions, displaying how, despite ambivalence, they were responsible patients. For symptomatic drugs, the less frequent consulters invoked moral fibre in their determination to stay off, reduce, or minimise consumption. In this way they were able to convey control of the body, and illness, and expressed few tensions around such use. However, the frequent consulters were less able to resist or reduce symptomatic drugs, and so were less able to demonstrate self-discipline and 'successful' symptom management. On the one hand they wanted to resist drugs; on the other hand they needed them to function *'half normally'* (Betty). Thus tensions around particularly symptomatic drugs permeated their illness experience.

6.4 The reliability of medication: *'keep taking the tablets'*

Although the less frequent consulters talked about medication as unhelpful for some complaints, and not needed for others, they also conveyed an overall sense of gain from the medication that they did use. They noted that conditions were controlled, and symptoms were contained: *'... its (hypertension) been controlled with the, the pills are fine ...'* (Martha, LFC). Peter comments:

'Well, I mean that's (painkillers) the one thing that works, it's the one thing that's a reliable option...' (Peter, LFC).

The less frequent consulters noted relying on regular drugs which stabilised their illnesses. However, they described a process of trial and error which had preceded this current stability and control. A certain vulnerability was expressed in their references to

past experiences. The process of finding the correct medication had not been straightforward, but an experimental stage, which had prompted GP consultations:

Anne: *'So, which of your conditions bothers you the most, do you think?'*

Martha: *'... blood pressure. But it's more or less settled, yea. Mmm. He's (the GP) given me umpteen different pills'* (Martha, LFC).

'I kept on going in (to the GP's surgery) every month hen, to see how ma tablets were doing... I had a few, I've been on them for quite a while the depression ones hen, you know that's going back quite a long while' (Derek, LFC).

These extracts indicate the fluid relationship between medication and the experience of symptoms, which was referred to by participants in this group. Their words illustrate a recurrent theme; typically, stability had been achieved, and the medication which they take on a regular, or a flexible basis, could be relied upon to help them maintain a normal life. The extract below highlights the central role of medicines:

Anne: *'So what's most important do you think in helping you manage?'*

Derek: *'To keep taking the tablets'* (Derek, LFC).

Derek's reply typifies the talk of the less frequent consulters. Despite difficulties with, and aversions to, medication, it is reliable. In this way, the less frequent consulters communicated how medication was a pivotal resource in certain circumstances, for particular conditions, and specific symptoms. Importantly, drug use, in the context of other management strategies and resources, contributed to a level of control and overall illness management.

In contrast, the frequent consulters commonly relayed frustrated attempts to stabilise their illness conditions and ease symptoms with medication. They too took drugs regularly, but talked about an inability to rely on drugs to ease their illness experience:

Anne: *'Do you take them (painkillers) more some days than others if your leg is playing you up?'*

Ian: 'Naw'.

Anne: 'You've got a set amount?'

Ian: 'Aye, I've got a set amount. It disnae, taking any more wouldn't make any difference...' (Ian, FC).

Ian describes what the frequent consulters commonly talked about. He takes his medication, but there are no guarantees that it will work. This highlights the severity of symptoms, the level of debility, and the extent of incapacity for people in this group. He continues, talking about medication for erectile dysfunction:

'So I've had two, I've had, it's a five milligram injection. Second time you go if it disnae do nothing you get a ten. I'll go in on Monday and it's for a fifteen one, and a fortnight again if I need it, depending how it goes on Monday. But it would be twenty milligrams. After the twenty milligrams you cannae go any further, so it either works or it doesnae work. So there's been a slight improvement in thingemy but not much, so that's what I'm going through the now...' (Ian, FC).

The medication dosage is increased in attempts to make his body 'work'. Ian articulates that the medication *'either works or it doesnae work'*, revealing the uncertainty which permeates his experience. His words, *'so that's what I'm going through the now'* suggests this is one aspect of an ongoing process, and indicates an added burden for those with multiple chronic illness. Importantly, there has been a *'slight improvement'*, there is hope, thus experimenting is worthwhile, and so, ongoing; the frustrations are worth it, because the drugs *may* work. Such a process was a recurring theme in this group:

Jim '... I don't know whether it's psychological or physical, but there are days you feel like you've taken maybe two or three and it's, you know, you've still got a bit of pain. And the next day you can take one, you know, and you don't need to take till maybe night time again, you know'.

Anne: 'So the effect varies then?'

Jim: 'Yeah'.

Anne: 'Sometimes they seem to work and sometimes they don't?'

Jim: 'I'm not saying they don't work, you know they work em at varying, varying degrees' (Jim, FC).

Jim highlights his feelings of uncertainty with his remark: *'I don't know if it's psychological or physical'*. He stresses that the medication does work however; conveying that he relies on it up to a point, but cannot estimate how much it will ease his pain. Thus, his drug use is characterised by uncertainty. Janet's words indicate how this uncertainty has ramifications beyond the symptoms. Unlike the less frequent consulters, this group of individuals describes how medication cannot be relied upon to facilitate activities:

'I just take it a day at a time. Take your medication, same routine, if it's a good day it's a bonus, if it's a bad day, that's it, that's part and parcel... of your health, this is it. You don't take your medication to make you feel better, you take it on a day to day basis... hoping everything is going to get better... You just go from day to day and hope that the wedding day you're going to have a good day in your body and your health and your pain is going to be at a minimum rather than a high but if it's a high, that's just tough you've just gotta go out and be able to get on with it...' (Janet, FC).

References to good and bad days imply a certain unpredictability with which the frequent consulters had to contend and medication could not promise to assuage. Janet takes painkillers routinely and hopes they will work. June provides a further example:

'I get up in the morning, on a good (day) if I'm getting up in the morning em, the emphysema might not restrict me that day, it might be, I'm always breathless, always, there's no ways that I'm not. I would love to get up and say "God I can breathe". I get up, take my medication, take my nebuliser, and if I feel my chest isn't too tight, "Oh this is good" I'll run the bath, can't wash my hair, 'cos I have to use my arms and that's too painful... But what I would love to do is to be able to get up, have a bath, have lunch, pick my grandson up from school, go shopping, and, no. No way. I do not make plans with anyone...' (June, FC).

June expresses the ramifications of being unable to rely on her medication. As a consequence of this, she cannot do what she would love to do - her daily routine, and straightforward activities are referred to as problematic; they may be possible, but they may not. It is notable that June describes waking up, taking her medication and *waiting*,

monitoring the degree of the tightness of her chest which 'sinks' her lifestyle. The combination of a 'good day' and drug use mean she can '*run the bath*'. Her words (*'I do not make plans with anyone'*) reveal how an inability to control her symptoms with medicines impacts on her life. She has to contend with unpredictable symptoms and uncertainty, which remain salient features of her daily life.

In summary, the reliability of medication was talked about in different ways by the frequent and less frequent consulters. The less frequent consulters conveyed stable conditions, predictable symptoms, and reliable medication, which influenced their GP contact. They took medication, alongside other strategies and resources, to help *normalise* their illness and maintain their familiar lives. In contrast, the frequent consulters relied on medication for 'survival', and referred to it as crucial in their attempts to ease symptoms, but were not confident about its efficacy. They used medication, often experimentally, alongside other strategies, but could not predict to what extent, or when, it would work. Consequently, their accounts of a lack of control around their illness conditions and symptoms as described in Chapter Four were paralleled in their descriptions of medication use.

6.5 Sourcing the medication

As the less frequent consulters typically described stable conditions, contained symptoms, and controlled illness it was perhaps unsurprising that they noted routinely collecting repeat prescriptions:

'Well, I've had to use my doctor quite a lot... But mostly just for the (repeat) prescriptions...' (Paul, LFC).

'I don't even think I went down to see him (GP), I just went up for my repeat prescription of Tamoxifen' (Rita, LFC).

In contrast, the frequent consulters' accounts of sourcing medication were characterised by uncertainty and risk and featured the role of GP consultations. For instance, Ian described how when he collected his prescriptions every two months, he selected to see the GP as well:

Anne: *'Do you see your doctor every two months?*

Ian: *'Aye, no, when I'm up there it's mainly for my tablets but I prefer to go up there and get my blood pressure taken, and if there's anything wrong, the likes of my chest, I've got a lot of bother the noo in my chest. She'll examine me and all that, make sure everything's alright'* (Ian, FC).

During the interview, Ian referred to a previous occasion when he ignored his symptoms; subsequently his GP had advised him to see her more often. Thus, for Ian, his repeat prescriptions work as a prompt to more, not fewer, consultations.

The less frequent consulters commonly provided examples of obtaining non-prescription drugs: *'... get them over the counter, Anadin...'* (Martha, LFC); *'I tend to em, go to the pharmacist, the local pharmacist'* (Sarah, LFC). Their experience of less severe symptoms and better stabilised conditions led to feelings of security and confidence in their own judgement, and subsequently a willingness to self-medicate. Having established that they responsibly monitored their illness, utilised resources and only used medication when absolutely necessary, the less frequent consulters continued their narrative of 'responsible patient' by identifying appropriate ways to source their medication for symptoms that they felt did not warrant a GP visit.

On the whole, the less frequent consulters described acquiring medication without a GP consultation, revealing that the illness is contained and by implication, *they* are in control. In this way they are able to continue to build a positive identity in the interviews. However, Peter's account is unusual, as he explicitly describes the potential risk and vulnerability linked to using the chemist:

'I'm sure that the patient should be in control, that the GP, or whoever it is, should just be there just to keep an eye on you so that you don't do anything silly. You know, so you don't walk into a chemist and start taking drugs that you shouldn't, you know, just because of an advert you saw in the paper. You know, I don't believe you should do things like that' (Peter, LFC).

Peter suggests a tension around maintaining control of one's health, and utilising the GP. He conveys responsibility and risk as components of illness management, indicating care should be taken to assess when, and what, appropriate action should be taken. His words add insight to the complex daily management project of self-medicating, particularly for multiple conditions. They also draw attention to the sense of contingency that has been evidenced in the data extracts so far. It is interesting to note that Peter refers to the generalised other as behaving inappropriately, in the context of an extensive account in which he positions his GP as on the sidelines of his care, as he self-medicates. This comparison underlines his responsible behaviour. He continues to build a positive impression of self, as he reports that although one *'should be in control'*, he recognises when medical knowledge *'should'* be sought, conveying a moral message that one must not *'do anything silly'*.

The frequent consulters, in contrast to the less frequent consulters, talked about wariness or a lack of purpose in going to the chemist:

Anne: *'What about the chemist or the Pharmacist?'*

Janet: *'No. I'd be a bit wary because of all the different conditions... I need to watch what I'm taking... no, I couldn't handle the stress...'* (Janet, FC).

Anne: *'Do you ever go the chemist?'*

Jim: *'No, I'm a bit, well I mean it's pretty, it's pretty powerful painkillers I get from the doctor you know, so I mean anything I buy over the counter I don't imagine would serve any purpose'* (Jim, FC).

However, unusually in this group, Dick talked about the important role of the chemist:

Anne: *'What about the chemist?'*

Dick: *'She's (the chemist) really good... one time I had to get a tablet for some reason, and the doctor gave me the prescription, took the prescription up and she wouldn't give us it because it interfered with the tablets I'm on the now. So she wouldn't give the prescription out, she phoned the GP up and told him, who rearranged a different tablet for me. Oh, she's good, she is good, you know...'* (Dick, FC).

In noting the role of the chemist as an important resource, Dick's account reveals the potential for a three-way relationship between patient, chemist and GP. In this instance, the chemist is indicated as a helpful resource, but to assist with prescribed, rather than provide medication. This atypical example underscores the theme that care needs to be taken with medication, particularly when tackling multiple, fluctuating and severe conditions.

The frequent consulters identified the pivotal role of the GP in their attempts to alleviate symptoms with the help of medication. Betty commented how the GP will '*normally try various pills and potions*' (Betty, FC) in a bid to ease her symptoms and Jim said: '*... and then, he (the GP) gave me tablets... Then he put me on to something else, then on to something else...*' (Jim, FC). Other examples are provided by Dick and Ian:

'My head starts, once something goes in my head it just goes round and round... and it all starts off again, you know... he (GP) actually stepped my tablet up. See there's ranges I can go up to. I'm no on the right top range yet, you know, just in the middle...' (Dick, FC).

However, increasing the strength is not always a solution:

'... it's just shooting pain and that was it... Gonnae give ye this new tablet that's out... that's what I'm on noo. But they (the doctors) started me aff at 100 and I'm used to it and eventually I went up to 600, and that done the trick' (Ian, FC).

These accounts relay a sense of ongoing 'trial and error', and an inability to ease the symptoms which leads to further consultations. Lesley's words shed light on the self-monitoring process involved, and the care taken prior to consulting her GP:

'When my asthma is bad the first thing I do is I up my inhalers and I will give it a day or two. Know, I take two like the blue and the brown both times and Ventolin. I take that in the morning and at night time. But if I feel its getting bad I'll up them, I'll double the dosage again and if its not any better then I'll have to phone the doctor... go down' (Lesley, FC).

In summary, the less frequent consulters described either reliance upon, or a lack of, useful medication. They were able to collect repeat prescriptions, indicating stable conditions, symptom control, and lack of crises, and as a consequence were able to avoid GP consultations. Also, when they did experience new or recurring symptoms they described buying over the counter relief, which was successful. In contrast, whilst the frequent consulters also had repeat prescriptions, their erratic conditions and unpredictable symptoms were more likely to lead to crises, and indicated that medicines were not controlling illness, and as a consequence they consulted the GP. Moreover, they did not feel able to use over the counter medicines, as the symptoms were too severe and they feared exacerbating their illness.

6.6 Medication and the GP consultation

The less frequent consulters established that whilst some medication ‘worked’ and there was no need for a GP consultation, this was in the context of a general dislike of drugs. These factors were linked to their help-seeking decisions. They discussed not making an appointment to see a GP because: they could collect a repeat prescription; they could obtain what they needed at the chemist; or they anticipated the GP would offer them medication that they did not want. Thus, the less frequent consulters' accounts that did link consultation and prescription were typically negative. GPs were criticised for ‘mechanically’ offering prescriptions in the place of an investigative approach and more personal interaction:

Anne: 'How could things improve with the GP?'

Marie: '... To investigate the cause of your symptoms. If someone's going in with constant headache or constant backache, you have to find the cause of the backache... to give them pain killers is no answer whatsoever' (Marie, LFC).

A recurring theme from the less frequent consulters' accounts was that they felt a consultation should offer more than medication. They often relayed a sense that they were not being recognised as individuals, and their specific needs were being neglected. In this

way a physical examination symbolised being attended to, and treated as an authentic patient, legitimately consulting with specific needs.

The frequent consulters' accounts also reflected these concerns. They too prioritised GP consultations which clearly offered more than a prescription. June, below, conveys the importance of a GP who is aware of her illness biography and examines her:

'Umm, yea, well, 2 or 3 doctors you see in the practice... know my history... so emm... they don't just say to me "Well take steroids or your inhaler". They sit, they examine me, they say: "Let's see what we can do here to make this a wee bit better". Without throwing you into hospital, or handing me a pack of steroids...' (June, FC).

Like the less frequent consulters, there is a sense that a prescription alone is perceived as a sign that the GP is failing to engage with the needs of the patient. However, in contrast to the less frequent consulters, June's words denote a sense of being recognised as an individual, and being attended to, by the GP. She uses direct speech and personal pronouns to indicate what she feels is a positive consulting experience: *"Let's see what we can do here to make this a wee bit better"*, is favourably compared to a more negative scenario with the use of words which portray a careless (or less caring), and impersonal approach: *'throwing you into hospital or handing me a pack of steroids'*. In this way, June draws on common sense notions of the 'right' and 'wrong' ways for the GP to interact with patients.

The participants also talked about time as an important factor. There was a sense that a prescription *given in a particular style of consultation*, rather than the prescription *per se* was the problem. Mary, a less frequent consulter, comments:

'... There's one doctor, I just don't like it 'cos she doesnae, she sits, you go in and she disnae even say "Right, yes". It's', you say "Right I've got a sore back" or something "Yes right". Get your prescription. "Cheerio". You are in there two seconds' (Mary, LFC).

The following extracts are examples that further illustrate this common theme, now from the alternative perspective of the frequent consulters:

'Because this doctor takes time to explain the procedures you are going through. He takes time to tell you what is wrong with you. He takes time to examine you... There's none of this, give you a prescription, and say, "Right try that, come back in two weeks"...' (Janet, FC).

'Taking time to sit and listen to me, none aw this carry on of writing ye oot a prescription, you're saying something and bang two minutes and you're oot.... It's no just idle chit chat... (checking) my blood pressure, and then I'll say to her, well I'm feeling, she'll look it up, and she'll say, or she'll look the book up, and then she thingme's aw the prescription through the computer...' (Ian, FC).

These accounts are notable because the speakers do not reject the prescription, but do detail a need for the GP to recognise that the consultation is about them both as patients, and as individuals with expressed needs. Moreover, as they relay positive consultation experiences with their GP who takes time to listen, to explain, and examine them, they are able to construct themselves as morally adequate and authentic patients. The reported consulting behaviour of the GPs, reflects their appropriate consulting behaviour as patients, and underlines their integrity.

In summary, both groups indicated that they wanted more than a prescription from a GP consultation. Although they often felt medication was needed, this was in the context of feeling attended to, and alongside, a physical examination, discussion, and at times, a referral. The experiences described by the less frequent consulters conveyed how they did not feel the GPs attended to them as individuals or as valid patients. These descriptions, suggested how the prescription-giving symbolised a careless attitude of the GP, which in turn reflected their moral worth. In these instances the prescription was seen as a poor substitute for examination, discussion of symptoms, or referrals. In contrast, the frequent consulters described their positive experiences of the consultation. They referred to the importance of the GP recognising and engaging with their needs as

individuals, and as patients. Moreover they were able to bolster their moral identity as worthy patients. Overall, the accounts suggested that the ways in which the prescription were given had two dimensions; the practical utility of the prescribed medication, and the symbolic function of the prescription.

6.7 Moral discourse

The participants conveyed a commitment to containing their symptoms, controlling their conditions, and managing illness and daily life, and medication use was one strategy employed in this process. However, participants also constructed medicines as a symbol of illness, their use was a sign of 'giving in' to particular symptoms, and so they could also be perceived as a source of stigma. Thus, drug use was characterised by ambiguities and ambivalence. As we have seen, the participants conveyed an aversion to medication in general, but a willingness to take particular types in particular circumstances. In so doing they were able to continue to build positive identities throughout the accounts, despite indicating shared assumptions about illness, self-discipline and medicines. For example, in a culture which imbues tranquilliser or anti-depressant use with negative connotations, taking them can be seen as a mark of moral inadequacy. This could explain these participants' aversion to anti-depressants. Other drugs have similar associations. For example, Peter notes: *'I must admit I still take codeine'* (Peter, LFC) illustrating the morality associated with painkillers, there is a sense one should face certain symptoms with stoic resolve, and if medicines are taken this challenges one's moral fibre. Overall, it was clear that accounts of medication were placed within a moral framework.

The accounts often relayed the sense of a rational and responsible patient, tackling a multiple medication regimen:

'... I take the tablets and that's me, it's brilliant so it is... Eh, I take one for the ulcer, one for the schizophrenia, one for the depression, eh. And that's about it hen. I think aye... I make sure I take them hen' (a slight laugh'). (Derek, LFC).

In a similar vein Janet notes:

'I've got thirteen tablets I take in the morning, I take four at lunch time and five going to bed it's a lot of tablets to be taking in a day.... It's become just a daily routine; I've to prepare the tablets before I go to my bed at night so they are ready to take in the morning.... Who wants to be on medication for the rest off your life? I certainly don't but I know I've got to' (Janet, FC).

Both groups described concerns around remembering and adhering to, the correct regimen. In the cultural context of the 'ideal' patient who works hard to manage illness, they present themselves as responsible patients, despite their negative references to medication. Derek has to '*make sure*' he takes his medication, Janet has to '*prepare the tablets*', despite her aversion to them. There is a moral imperative to use the medication appropriately combined with a shared understanding that medication should be avoided when possible. This 'common sense' knowledge is illustrated by Janet's rhetorical question: '*Who wants to be on medication for the rest of your life?*'

Dick was an exception to this. He spontaneously offered how he depends on his wife to organise his medication, and resists responsibility for this aspect of his illness management:

'They say that if my wife wasnae there I wouldn't be taking them. I wouldn't mind, I couldn't even tell you what tablets I'm on, you know. She does it all; she does everything for us' (Dick, FC).

None of the female participants described such help, in contrast they were prone to detail, and at times underlined their self-reliance. For instance, Janet stressed emphatically during the course of her account: '*I manage to take ma tablets, I manage to take ma medication, I manage fine...*' (Janet, FC). It is interesting to note, that one dimension of medication use in the accounts was to illustrate careful and reflexive self-management, and thus build a positive identity. Dick may not have felt compelled to do so, as a result of drawing on cultural assumptions about gender roles in the family. Indeed, his ability to refer to almost total reliance could be seen to underline his illness status; in such description, is the implication that he is worthy of such encompassing support.

Another common theme that emerged in the analysis was the way in which the participants looked to their inner resources in a bid to reduce or cease medication. In this way medication talk can be seen to express agency, control, responsibility and moral competence. Marie recounted how she managed to 'come off' her anti-depressants: *'I just did it, willpower. I had to put up with it'* (Marie, LFC). Rita's account also stressed her self-discipline:

'...when I was first put on them (Diazepam), I was told (by GP) to take them three times a day, so I done it, took them three times a day and I got hooked on them. But em, I came off of them maself, I didnae get help fae anybody, I just thought this has got to stop... I just got maself off them but I cannae go without them in ma bag. I got maself off them' (Rita, LFC).

It is notable that this extract is divided into a passive first half, when Rita *'was first put on them'* (Diazepam), *'was told to take them three times a day'*, and then *'got hooked'*. However, she goes on to compose an image of herself as an active patient and responsible individual. She uses repetition to underline how: *'I came off of them maself'* alerting the listener to her agency. Her integrity is re-emphasised when she uses a rhetorical device to 'close' and sum up her main moral point: *'I got maself off them'*.

However, a moral hierarchy was suggested, as participants described taking medication as a last resort, to fulfil social roles:

'I couldn't bear watching my three young children coming in every day and seeing me in bed. I had to do something, I knew I had to do something, and I was very loath to take these anti-depressants. I only took them because I began to feel almost suicidal. At one point, my husband begged me to take them, and I only took them for a short period. I couldn't bear them coming in from school and seeing me still there unable to function really' (Marie, LFC).

Marie's account illustrates that she is committed to getting well, but medication, specifically anti-depressants are shunned, at first. Her words are suffused with morality, and are informed by shared cultural assumptions about such drugs. The image of Marie's

husband 'begging' her to take her medication and her three small daughters coming in from school to see their mother still in bed captures some of the emotion work of medication use. She succumbs 'at the eleventh hour'. Marie's aversion to the medication is swamped by her familial duties and she is portrayed as a loving and caring wife and mother as well as a stoical patient. Her moral adequacy is assured.

Such a moral discourse weaved through the data. Peter '*admits*' he still takes some medication. Marie indicates she took anti-depressants as a last resort, her reference to '*almost suicidal*' underlining this point. The spontaneous ways in which participants and particularly the less frequent consulters described how they 'managed' to come off medication indicates a shared value system. As illustrated in section 6.3 the frequent consulters tended to talk about their attempts to reduce their drug consumption, but described how such attempts were often thwarted, and so could not build their moral character in the same way.

The moral backdrop indicated by the extracts above is highlighted by references to others, and underlines the moral judgements associated with certain types of symptomatic medication:

'Other people are always on to you- "Oh you're taking too many of these pain killers, blah, blah, blah" - but they've no' got the back ache I have' (Paul, LFC).

The moral dimension was reinforced by participants who simultaneously identified, and distanced themselves from, a particular type of person, in a bid, I would suggest, to present themselves as morally adequate: '*... You know, I don't take, I mean I'm not a pill freak, great pill taker...*' (Jane, LFC). '*I've got a friend who would just go down to the doctors and get strong pain killers at the drop of a hat, I'm the other extreme*' (Jim, FC).

However, as illustrated, typically the frequent consulters described consuming high levels of medication but were still able to construct themselves as stoic and morally adequate in their accounts. For example, Ian spoke of medication to describe the extent

of his suffering; he avoids being seen as a complainer, which has been identified as a key concern in the accounts. He quotes a conversation between a nurse and his wife:

'She (nurse) done that at the start. When I wisnae, well, before I lost my leg wi this carry on, she was coming out. Keep upping the morphine, 160 milligrams I was on then. But when I was in hospital they took my leg off, it went up fae I think 200 to about 340 milligrams. And then I was on the tablet stuff and that was Thermadoll I think you called that or that was 80 milligrams ye know, that was plus the 320 or 40. The wee nurse says to the wife she says "If ye were to get one drop of that, that he's getting the noo, it would kill ye". But it was different for me because of the pain I was in. It was really high doses you know. Nothing worse than getting yer leg aff' (Ian FC).

In this extract Ian manages to communicate his suffering, and in so doing conveys his stoic approach and his moral fibre which threads through his narrative. He is unable to rely on a shared reality; there is no common understanding of what *'getting yer leg off'* feels like. Ian employs other rhetorical devices to communicate his experience. He uses medication as a vehicle to transmit knowledge. In his account he employs 'scientific' precise language when he describes his increasing dosage, which adds weight to what he says. His use of a supporting cast, direct speech, and the emotional warmth suggested by his words the *'wee nurse'* draws us closer to his experience, as he recounts how the nurse alerts his wife to the severe pain he experiences; just a drop of his medication would kill her. This underlines his message, as he employs the notion of difference not shared experience to communicate his experience. He then uses a common rhetorical device to maximum effect, and ends his talk with a short effective phrase, 'wrapping-up' his talk, with the main message: *'Nothing worse than getting yer leg aff'*.

Jim refers to his medication use as a way of identifying his illness status. In so doing he legitimates his status and maintains his moral character. On our first meeting at the interview outset, I ask Jim about his conditions:

Anne: *'Can you tell me in as much detail as you can, in your own words what conditions you have'.*

Jim: *'I take medication for high blood pressure, which is due to a what I was told at the (hospital) was that it's a non-specific*

kidney disorder. Also water tablet to help control the blood pressure as well, aspirin, and I take pain relief for my back and my leg, which I injured in work two years ago. Well, more than two years ago now. That's basically all the medication I'm on now' (Jim FC).

This reply serves to validate Jim as an authentic patient. His closing phrase sums up and reinforces how medication indicates his illness status. Jim mentions that he is on prescription pain killers as the result of an accident at work, the listener is aware that Jim has experienced an acute episode, not by being careless or foolhardy but while doing his job (he was a Fireman). This further legitimates him as morally adequate and deserving. This is particularly important in a culture which treats back pain with suspicion, even derision. People are at risk of being described as malingerers (Jim describes vividly, and with emotion, how he experiences this problem later in the interview).

Overall, the frequent consulters did not talk of their ability to reduce or come off medication 'successfully', but nevertheless as these extracts indicate, did draw on drug use to underline their moral character as they conveyed their stoic attitude in the face of severe suffering, and authentic illness. Thus medication talk was part of a moral discourse, about coherent identities, in accounts which so often were characterised by disruption and a lack of control which challenged their sense of a familiar and morally adequate self.

6.8 Summary

In this chapter, I have presented data on the nature and extent of medication use as the participants talked about living with illness. The fact that I did not identify medication as an area of interest on the interview guide, but it emerged as a major topic of the interview and analysis, underlines its pivotal place in the illness experience. It was clear from the accounts that medication was used in different ways, with varying degrees of success and difficulty.

The analysis revealed that both groups of participants practised drill-like regimens for prophylactic drugs, and described taking medication for 'survival'. However, the less frequent consulters did not elaborate on this theme, which suggested that such use was routine, a sign that their conditions were stable, and not at the forefront of their experience, whilst the frequent consulters were more apt to detail such use. Moreover, they spoke of the crucial role of the GP in a life which was characterised by illness, uncertainty, and their lack of control. They communicated their need for a doctor who knew them, and who had knowledge of their illness biography and was familiar with often complex and changing medication regimens.

The accounts also featured flexible drug regimens for symptomatic medicines, and often a combination of both regimens. This reflexive process was particularly complex for the frequent consulters, who described a greater range, higher doses, and more frequent drug use, typically for severe and unpredictable symptoms. Such regimens often involved experimenting with drug combinations that exacerbated participants' feelings of uncertainty and lack of control. Whilst the less frequent consulters noted similar, but less extensive problems, what distinguished their accounts was how they discussed balancing activities and drug taking to 'successfully' relieve symptoms. The crucial difference was that the less frequent consulters took symptomatic drugs as part of an overall management strategy, to maintain their '*normal lives*', and described their ability to maintain social roles in terms of paid work, leisure, and family responsibilities. In contrast, the frequent consulters did so in a daily life that had been *disrupted* by illness and placed medication at the forefront of their daily experience, in a diminishing world. As such it was a tangible reminder of the 'failure' of their bodies, and their inability to control illness.

Both groups conveyed tensions around medication use. They voiced aversions to drugs in general, and relayed a dislike of symptomatic drugs in particular, for example antidepressants, whilst describing a need to take particular medication such as *antihypertensives*. The less frequent consulters described an ability to cut down or cut out their medication, whilst the frequent consulters revealed an inability to do so. In this way

the frequent consulters displayed more tensions around drug use, and underlined the severe nature and extent of their symptoms and the impact they had on their daily lives, as well as their often futile attempts to gain control of their illness, their bodies, and their lives.

There were clear differences between the frequent and less frequent consulters, in terms of how far they could rely on the medication. The less frequent consulters described relying on drugs to control symptoms which enabled them to maintain their normal day to day lives, for example to remain in paid employment. In contrast, the frequent consulters referred to changes of dosage, strength and drug type, in talk around experimentation, exacerbated by the combinations of drugs they took. This magnified the frequent consulters' feelings of loss of control of their bodies and lives. This also had implications for sourcing drugs and consulting. The frequent consulters rarely spoke of obtaining medicines over-the-counter from a chemist or with repeat prescriptions; instead they referred to GP contact to gain drugs, positioning the GP as central in their management strategies. In contrast, the less frequent consulters were likely to note the reverse; purchasing medicines or processing repeat prescriptions rather than discussing medication and illness situation at length with their GP.

Both groups expressed concerns around 'prescription based' consultations. They were keen to prioritise other aspects of the interaction, and viewed gaining a prescription as only one part of a multi-dimensional process which properly involved investigations and discussions and being recognised as individuals with specific biographies and problems. Both the less frequent and frequent consulters highlighted the importance of these factors as they juxtaposed 'ideal' consultations with more negative scenarios. The less frequent consulters typically described the medical encounter as insufficient, and suggested they not only felt neglected as patients, but devalued as individuals. In contrast, the frequent consulters conveyed a sense of being attended to as patients, but more fundamentally as morally adequate individuals. Being attended to by the GP in the consultation illustrated their authentic status, and positioned them as appropriate users of the GP services. In this way time spent in the consultation, investigations, referrals, and discussions, had

symbolic as well as practical values. Thus, the frequent consulters, whose accounts were so often permeated with loss and disruption, conveyed how the prescription-based consultation, offered them practical benefits, moral standing, and relief from symptoms and worry, as well as hope of improvement. Throughout the accounts medication use was placed against a moral backdrop.

I make the same claims to validity here as I have above (3.3.2.1), and in the previous 2 chapters. By using a range of participants to illustrate my findings, and constantly comparing and contrasting the transcripts as part of a systematic analysis, I hope to have represented the experiences of the participants. Again, although I see the interviews as favoured accounts, based on a systematic analysis, I also regard them as relating to an external reality. Detailed field-notes help support any such claims in this chapter. However, as I explain more fully below (7.5), I cannot make reality claims about the accounts of the doctor/patient relationship, as my analysis and field-notes do not allow for consistency checks regarding the medical encounter.

The practical and symbolic dimensions of chronic illness have been identified and I will explore these aspects further in my examination of the ways in which participants talked about the GP consultation, and how, and what, they gained from the consultation in their bid to manage illness in the context of their daily lives.

Chapter Seven

Consulting the General Practitioner

7.1 Introduction

This chapter concerns the place of the GP consultation in the overall management strategies of the participants. The data presented emerged from open questions about why and when participants consulted, and how helpful they perceived the GP to be in managing their illnesses. All of the participants voiced clear-cut reasons around when it was appropriate to consult. Further, whilst a broad range of advantages were attributed to the consultation, there were also less positive accounts in which the GP was positioned as unhelpful.

First, I relate how participants linked symptoms and illnesses to GP consultations and explained why they consulted, or not. This section includes aspects of self-treatment and consultations for ongoing monitoring. Second, I address how the participants talked about their experiences of consultations which included both the perceived medical outcomes and the anticipated interactional process, and the degree to which these could be seen to act as a barrier or a prompt to further consultation. Third, I examine the ways in which symptoms combine with daily life to influence decisions to consult. One striking similarity in the participants' accounts was the ways in which they portrayed themselves as 'appropriate' users of GPs' resources, and so the ways in which they continue to construct themselves as morally adequate is also addressed in each of these sections.

7.2 Reasons to consult the GP

7.2.1 The last resort

Consulting a general practitioner, like the use of medication, was described as a 'last resort'. Participants commonly gave general reasons as to why, and when, they consulted, but said they used the GP services only when they felt it was absolutely necessary. For instance: *'I only go if I really need to go'* (Sarah, LFC); *'...I try not to go unless it's something that's really annoying me'* (Mary, LFC); *'I would only go if I was in real bad pain or very, very sick...'* (Betty, FC).

These sentiments were expressed in all accounts, but such explicit statements were commonly made by the women participants. However, all indicated an underlying assumption that GP services should be used sparingly, and that the speakers behaved accordingly. In conveying such views, they drew on commonsense knowledge about acceptable behaviour, as they described a range of symptom-based reasons for consulting:

'I had pain in my stomach hen so I went down to see him...Two or three times I was caught short of breath and the wife got a fright... I couldn't get a breath, eh I was like choking you know and the wife got me to the doctor' (Derek, LFC).

'I just felt really washed out you know and I really thought nothing of it... and I felt a bit of pain in my lower back... but this kept getting worse and worse and worse and worse and I went to the... doctor...' (Peter, LFC).

'I had reached the end a my tether with the pain in my hand...' (Jim, FC).

Janet: *'... I was in such severe pain I couldn't cope with it any longer, " I really can't cope with this" like that, I'll have to phone him... never had pain like this, ever...'* (Janet, FC).

These extracts demonstrate that the 'consulting symptom' is interpreted in specific ways. Participants described how they judged when to contact the GP as being when they could no longer contain their symptoms. This often included unexplained, ongoing, severe, or resistant symptoms, which indicated a lack of control and feelings of uncertainty. The language used denotes feelings of anxiety and distress, engendered by *crisis*,

abnormality, severity, and longevity. Derek describes a critical event. He *'had pain'*, but elaborates on his shortness of breath which induced *'fright'*, and *'choking'*. The phrase *'you know'* and his economical use of words, noting his wife *'got me to the doctor'*, leaves no rhetorical gap for any other action, and underlines the common-sense based decision to consult, and an inter-subjective reality. Thus, he builds a logical justification for the consultation into his account of a very personal experience rooted in shared cultural assumptions. Similarly, Peter and Janet offered accounts that are anchored in commonly held notions about symptoms and consulting. Peter's repetition of *'worse'* indicates ongoing, severe pain, illustrating the decision to consult is a rational response to his symptoms. Also, in noting she had *'never had pain like this, ever'* Janet underlines the extremity of her symptoms and the severity of her pain, and communicates her distress and anxiety, and so justifies GP contact.

Despite this similarity, there was a marked difference between the accounts of the less frequent and frequent consulters. As illustrated in Chapter Four, the frequent consulters referred to severity of symptom, and illness crises as integral to their ongoing illness experiences, whereas the less frequent consulters did not. For example, they identified severe episodes as rare, and often in the more distant past:

Anne: *'What about those conditions, which ones would you say bothers you the most?'*

Sarah: *'The bowel complaint. Yeah, that affects my life more than any of the rest of them'* (Sarah, LFC).

Sarah continues:

'... I had a spell of diarrhoea for a long, long time... I don't know it was a long time ago. I think it was about twenty years ago now. And then some years back, I think it was about nine or ten years ago I was having a lot of pain and... that was when the doctor (GP) said about the, to take the Imodium...' (Sarah, LFC).

Sarah describes past episodes, which led to GP contact, but details current stability. She says of her bowel condition: *'I've got that under control yeah'* (Sarah, LFC). This

illustrates a common theme in the less frequent consulters' accounts; severe episodes *in the past* were connected to GP consultations, but were not conveyed as a core characteristic of their illness experiences.

The participants were clear about what constituted inappropriate GP contact. Having established that consulting the GP should only take place when absolutely necessary, they provided examples of 'trivial complaints' unfit for professional scrutiny. For example, Jane suggests symptoms have to be suitably severe, thus she does not consult about an ongoing problem because she is '*not in agony*' (Jane, LFC). In a similar vein Marie stated: '*What do you say to the doctor, "I'm terribly tired and I've got a sore neck?" You know, hard*' (Marie, LFC). These words draw on a shared lay and professional understanding about use of the GP. Marie's use of the term '*you know*' points to a commonsense knowledge shared between interviewer and interviewee, which reaches beyond the scope of the interview. Similarly, the frequent consulters described symptoms they perceive as unsuitable for consultation. Lesley describes her menstrual cycle in the context of deciding whether or not to consult her GP:

'...in the last two month it's been, I'm taking a full, really flooding and then stops for a couple of days, I finished up last Thursday, and that's me back on this morning again.... No, it depends how bad it is. Em, I'll leave this, if its, gets real bad I'll go but if it dosnae I'll just leave it, cos it must be a change of life thing' (Lesley, FC).

Lesley articulates a strategy of 'wait and see'. Her words indicate the need for the consulting symptom to be an observed abnormality, which is also severe and ongoing. Initially, she is able to make sense of the abnormality by interpreting it as part of the life course. In *normalising* the symptom, a GP visit is not justified. However, symptoms and decisions are fluid. She may re-interpret the symptom as warranting professional advice. This indicates the ongoing surveillance that is part of the illness experience, and suggests the care with which decisions around consulting are made, drawing on both personal biography, and broader cultural concerns about responsible consulting.

Both groups described such instances, when symptoms were interpreted as not warranting the GP's attention. However, as noted, whilst the less frequent consulters commonly referred to such incidents, the frequent consulters regularly reported fluctuating symptoms and deteriorating illness conditions, which they conveyed as *'real bad'*. It is notable then that the frequent consulters were apt to describe symptoms as minor and inappropriate for GP consultation in the same ways as the less frequent consulters.

Having established in the previous chapters that the participants commonly voiced concerns around functional ability, it is unsurprising that they also talked about an inability to function as a reason to contact the GP:

'It (pain) was stopping me going out because I couldnae stand and it was stopping me... I couldnae stand up every time I stood I'd to sit down. And it meant I couldnae... stand in the kitchen and peel my potatoes 'cos my feet were that sore... "I'll just go to the Doctors and get it sorted out"... ' (Mary, LFC).

'It's difficult. It's very, very painful some days; the past couple of days have been really bad. The past couple of days I couldn't walk at all. I went to get the doctor this morning...' (Janet, FC).

Both groups, as illustrated in the examples above, explicitly linked debilitating symptoms with a GP consultation. Unsurprisingly, the less frequent consulters were less likely to do this than the frequent consulters. For instance, Mary's description of how she lost the ability to perform routine tasks refers to a dysfunction she suffered in the past, rather than a current episode. In contrast, Janet, indicative of the frequent consulters, describes a situation that is both ongoing and has a fundamental functional impact on her current life.

7.2.2 Self-treatment

The accounts revealed that for particular symptoms, self-treatment, as a form of self-care, was considered appropriate prior to, alongside, or instead of, consultation. Chapters Four and Five illustrated how the participants utilised strategies and resources to aid their

symptoms in the context of their daily lives, and showed that the less frequent consulters were more likely to utilise a chemist (prior to, or instead of, consulting the GP) than the frequent consulters:

'...the local pharmacist if I have maybe like a, say I had a cough, something like that... I would go there before I'd go to the doctor. I only go to the doctor if I feel I need to, need to go' (Sarah, LFC).

'There's got to be something. I went to my doctor a couple of months ago because I took a reaction to, I must have been using some chemical in the kitchen and my hand broke out. And I got every cream imaginable and I got things, the chemist made me up some things and it wisnae working, so I had to go to the doctor. So it was an antibiotic cream I needed or I widnae have went' (Rita, LFC).

Both Sarah and Rita re-emphasised the point that they only use the GP when other attempts at relief are unsuccessful. Rita's language underlines judicious GP use: *'There's got to be something... or I widnae have went'*. These examples form part of an extensive narrative that was addressed in Chapters Four and Five, on the use of strategies and resources to manage symptoms.

However, the frequent consulters said they did not make use of chemists. In contrast, they were more likely to describe gaining advice from others prior to contacting the GP. For instance, as part of a discussion about how his wife provides him with both emotional and practical help Dick comments: *'(I) talk to my wife and she said if it continues she'll phone the doctor'* (Dick, FC). Janet describes how sometimes she gains professional advice prior to consulting the GP:

'If it's something not too bad, I'll say to her (the Practice nurse). "Look, what do you think? What will I do?" and she says, "Well, I think you should speak to the doctor" or "Wait I'll just see what's been done". And that sort of thing, if it's not too urgent, I'll speak to the nurse herself, if it is urgent I'll go direct to the doctor...' (Janet, FC).

There is a recurrent theme in the accounts of both groups, that other strategies 'should' be used before consulting the GP. This underlines the shared assumption that the GPs' resources are to be used only when absolutely necessary. Betty's words bring this into sharp focus:

Anne: *'How long did you have that then before you went to the doctor?'*

Betty: *'I must have had it for a good few, maybe even six months'.*

Anne: *'When did it get to the stage when you made up your mind to go to the doctor?'*

Betty: *'What I would normally do is, if I feel sick or have a pain, I'll try the normal remedies, I'll maybe leave it for a week or two and if it doesn't move, I'll go to the doctor then...because some people would just go at the drop of a hat and other people would leave it for years, I'd try the obvious things first and if that's not clearing it up, I'll go to the doctor unless of course it's something that you know you've definitely got an infection or something and you go straightaway' (Betty, FC).*

Betty describes the reflexive decision-making process that underscores the shared understanding that GP consultations are to be undertaken selectively. She would *'try the obvious things first'*; this accords with the common cultural understanding that when symptoms emerge one takes particular actions prior to turning to one's GP. However, there are exceptions; as the threat of an infection, was mentioned by several participants as a reason for consulting swiftly. Therefore, a 'responsible' patient is aware of the need to refrain from consulting for minor symptoms, whilst concerned to maintain a wary watch on symptoms which may herald infection. Betty highlights 'appropriate' consulting, by positioning herself next to, and distinguishing herself from, those who *'would just go at the drop of a hat and other people would leave it for years'*. These words underline the delicate balance between 'over' and 'under' consulting and reveal the ongoing 'work' around consulting as integral to the overall experience of chronic illness. They suggest an extra burden; alongside unpredictable symptoms, and the uncertainties of medication regimens (as illustrated in Chapter Five), are dilemmas around decisions to consult, all inextricably linked to being a 'responsible' patient.

7.2.3 Monitoring

7.2.3.1 GP-monitoring

The need to have a condition monitored was given as a reason to consult. A recurring theme in the accounts was how often 'monitoring' consultations were GP-led. Derek for instance noted that his GP wanted to see him: *'Just to keep a wee check on us hen, you know'* (Derek, LFC). Ian commented that he is invited back to the surgery for a check-up as part of a frequent monitoring process to *'make sure everything's alright'* (Ian, FC). On the whole, the less frequent consulters described occasional monitoring:

'I saw him (GP) a couple of times 'cos I had to go back and see him because they altered my, they were testing my sugar' (Johnny, LFC).

'I very, very rarely go (to the GP). I only go, when, because of the blood pressure. Because I've had to get it checked...' (Martha, LFC).

Johnny relays an episode in the past, whilst Martha notes regular but rare 'checks'. For the less frequent consulters, the seldom monitored condition indicates stability and a level of control, which mirror the findings in Chapters Four and Five. As illustrated above, there were references to being re-called, but these underlined the typically less frequent need for repeated visits to the GP.

However, a clear feature of the frequent consulters' accounts was that GP-led monitoring was typical. This highlighted unpredictable illness conditions, uncontrolled symptoms, and experimental medication regimens. It was notable that the frequent consulters' talk featured concerns to validate such GP contact:

Betty: *'...it's a routine thing. He (GP) just likes to see me every four weeks'*.

Anne: *'And what is that for then?'*

Betty: *'To ask me how I am. To check how I am because of the ongoing things not only the MS, my husband and all that, he just likes to keep an eye on me.'*

Anne: *'And if he hadn't said that to you, do you think you would go?'*

Betty: *'I would go on my own? Not as much, but I do feel secure that he is saying that to me... don't like to waste the doctor's time'* (Betty, FC).

Betty's account is a good illustration of this common theme. She describes how she is required to go for regular check-ups, and thus feels *'secure'* about seeing her GP, as she doesn't *'like to waste the doctor's time'*. This indicates a further distinction between the groups. Having established that GPs should be used sparingly, the less frequent consulters cite rare GP consultations, adhering to the *'ideal'* pattern, whereas the frequent consulters revealed concerns to legitimate, frequent consultations.

7.2.3.2 Self-monitoring

When answering questions about when they would go to the GP, the participants also talked about the importance of self-monitoring, to pre-empt health crises. They described how particular symptoms prompted a swift consultation, to prevent deterioration, or facilitate a speedy recovery. For example, Sarah described a problem with her inner ear, which causes dizziness and is potentially debilitating. However, she recognises a symptom that alerts her to the onset of the problem. She comments: *'...if I have a sore throat I am just very careful to go to the doctor and get something for that'* (Sarah, LFC). So, Sarah notes how she may go to the GP for a sore throat, because it indicates something more serious. Thus, she recognises medical attention is required. Her words convey a sense of responsibility and reflexivity, she is *'very careful'* to go when she recognises particular symptoms. Along similar lines, Derek relays the importance of speedy consultation before the illness condition deteriorates:

Anne: *'Can you think of any advice to give to other people who might have the conditions that you have that are having problems?'*

Derek: *'Well go down and see the doctor right away and don't delay cause if you delay it makes it worse. You know, specially'*

depression, the longer you put it off the harder it gets, you know because you become introverted, if you don't bother you know' (Derek, LFC).

Derek's words underscore the notion that in particular circumstances 'appropriate' action is reversed and the GP's help should not be a last resort, but rather sought without '*delay*'. In this way, the less frequent consulters are clear that they consult rarely, but with care. His phrase '*if you don't bother*' highlights the moral aspect of the action, hinting at an alternative sloppy surveillance, which is to be avoided.

The frequent consulters, like the less frequent consulters, described visiting the GP as a result of recognising particular symptoms that herald deterioration. For example, June described how she interprets particular signs:

Anne: 'So what occasions might you make an appointment then?'

June: 'Just... when, I always get a wee sign that things are not all, or my medicine my nebulisers are not working and I'm heading for trouble. I get to know because I get like emm, not so much a tightness in my chest, but like the cough, and, and the phlegm becomes dirty and, so I know I'm heading for trouble maybe an infection or something so that will cause me to go (to the GP)' (June, FC).

June's words reiterate the theme of reflexive action which was characteristic of consultation behaviour in both groups. She recognises when she is '*heading for trouble*', and has got '*to know*' which symptoms herald deterioration, and implicitly, warrant her GP's time and resources. June interprets the interplay between specific bodily signs, inefficient medication, diminishing control and the role of the GP as prompting a consultation. Notable in this account, which exemplifies the talk of the frequent consulters is the continuous nature of medicine '*not working*', and the constant fluctuation of symptoms.

The form of the language underlines the problems this group persistently face. The unconscious choice of words denotes regularity, as well as severity. This parallels the

analysis in Chapter Four. The frequent consulters' accounts were more likely to feature unpredictability around their symptoms and medication, which engendered feelings of uncertainty, and lack of control, which led to GP consultations. The extract below illustrates this further. Betty outlines a previous episode of depression, which informs her ongoing situation. She is now able to recognise signs that indicate a recurrence of depression, and thus takes appropriate consulting action in order to 'nip the flow' of her symptoms. This illustrates the ongoing process of interpretation of symptoms around decisions to consult. Betty compares 'normal' feelings to those that point to illness and consulting action:

Betty: *'I thought I'd lost it, I'd gone gaga, I screamed the place down, it was horrible'*.

Anne: *'You didn't recognise the signs?'*

Betty: *'Mmm-mm (negative). But any time after that, I did and as soon as I start feeling iffy, I know the difference between feeling a wee bit uptight, a wee bit agitated and the difference of when I'm going down the long dark tunnel and I go straight to the doctor'*.

(Betty, FC).

The use of metaphor communicates a lack of control. Betty, like June, conveys a sense of movement, towards 'trouble'. Betty refers to '*going down the long dark tunnel*'. In order to prevent movement in this direction, or deterioration, she contacts the GP. The implication is that symptoms are contained, and disruption minimised through successful monitoring and appropriate consultation. The metaphor of the journey resonates with the language used by this group in Chapter Four, as they described their illness experience and conveyed a lack of control.

Such reflexivity suggested a complex process based on interconnecting features of a range of symptoms, conditions and medications as part of the multiple chronic illness experience. Both groups expressed an important link between careful monitoring and consulting.

The following extracts reveal the symbolic dimensions of consulting, illustrating the ways in which identity is implicated against a moral backdrop:

'You know, I suffered from ulcerative colitis when I was in my early twenties and I was really, really, I mean I almost died a couple of times. So I had quite radical surgery for it, and this is one of these things that you have to, you just have to manage it yourself. You know, otherwise you become, you almost become somebody else's patient, and you're always looking for somebody else to do things for you, rather than to be self-sufficient. And, as long as you can see, you know there are boundaries where things that can go, you know so far in one direction you should speak, you should seek expert advice, rather than just rely, you know, you shouldn't be arrogant about it' (Peter, LFC).

Peter illustrates that maintaining the balance between self-management and becoming *'somebody else's patient'* is ongoing, complex and fluid. There are accepted behaviour patterns that should be adhered to. He recognises that there are boundaries that should not be crossed, and notes that one should not be *'arrogant'* about consulting the GP. Crises can be averted if one is careful to consult, but equally, one must be careful not to consult too readily. This highlights the importance of the individuals' knowledge of their bodies, and their ability and need to recognise when symptoms are *'moving towards trouble'*. As Peter comments, expert advice should be sought when symptoms move *'so far in one direction'*. Again, his words go some way to bring into focus the sense of *contingent normalisation* that the less frequent consulters have evidenced so far in the analysis. Peter's words illuminate the role of control and the risk of vulnerability. However, this extract also indicates the possibility of 'successful' self-management. In this way, the less frequent consulters were able to construct themselves as competent patients, displaying their moral adequacy as they contained symptoms, managed illness, and avoided GP contact.

Likewise, the frequent consulters talked extensively of the ongoing and complex nature of self-monitoring multiple symptoms and medications. However, in contrast to the less frequent consulters, GP consultations could not be avoided:

'I know it's turning into a chest infection and because I cough cough cough all the time with my asthma... I know to build up (medication)... And then my colitis is the same thing; I take, when my colitis is bad, I get the steroids again... I know, I know how long my colitis will go, and it's maybe a week I'll have constant diarrhea... I can work out how severe it is, whether it's gonna be a six month shot or three month or whatever and I go to the doctors and say right I need... But then nearly all people with these type of illnesses, they know what to do. It's... when your asthma is (bad), you cannae just phone the doctor and say, constant. You do that first...'
(Lesley, FC).

Lesley's account is a good example of how the frequent consulters conveyed how 'competent' individuals are sensitive to the length of time they have a symptom prior to consulting the GP. Lesley takes action based on specific guidelines. She alerts the listener to the need for self-surveillance when she refers to symptoms, which signal infection and need prompt action. She positions herself as one of a distinct 'community' of people with chronic illness who recognise symptoms and '*know what to do*'. This commonsense knowledge of appropriate behaviour involves not going to the GP '*constant*'.

In summary, careful monitoring and consulting featured in the accounts of both consulting groups. However, the analysis revealed a greater degree of complex monitoring for the frequent consulters, which engendered more emotion work, and symbolic risk. Despite striving to contain their symptoms, they indicated an inability to do so, and a need for a GP consultation. Both groups rationalised consultations and symptoms in the same way; they only consulted as a last resort, if symptoms were severe, ongoing, abnormal or resistant. However, the accounts conveyed different experiences of symptoms, which were associated with contrasting consulting patterns.

7.3 Experience of GPs

7.3.1 My doctor: 'no keen' or 'absolutely fabulous'?

The participants also talked about their experiences of GPs. Initial analysis suggested striking differences between the two groups' accounts. For example, the less frequent consulters regularly made negative comments about their GPs: *'He's awright. I'm no keen on him'* (Rita, LFC); *'I've got no confidence in her'* (Sarah, LFC); (He) *'wasnae helpful'* (Johnny, LFC). Others intimated that they felt unsupported by their GPs, for example: *'I felt that he was sceptical, rather sceptical'* (Marie, LFC); *'... she's very, very, bad attitude... you feel, (pause) intimidated'* (Martha, LFC). In contrast, the frequent consulters typically responded in positive ways: *'... He is absolutely fabulous, great. A great doctor...'* (Janet, FC); *'My GP is fantastic...'* (Lesley, FC); *'Absolutely first class'* (June, FC).

Nevertheless, it would be misleading to say that the accounts were so opposed. Both groups relayed both positive and negative experiences with GPs although the sentiments were weighted differently. The less frequent consulters tended to criticise 'their GPs', and offered positive reports of consultations with other GPs and health-workers. Typically, the criticisms included a range of both interactional and more medically based factors. Sarah, for example, noted problems with her GP ranging from mis-diagnosis to mix-ups with referrals, and overall felt that her doctor was *'not supportive'*. She elaborates:

'Sometimes I have been known to comment that I think she (GP) is stuck to the chair. Even like for a sore throat and things like that she is very reluctant to examine your throat or anything but, it's the way she is. I have got used to her now. I get quite anxious when I go to see her because I feel as if I'm wasting her time and I don't go very often but I just get this feeling that she thinks I'm wasting her time' (Sarah, LFC).

However, Sarah adds: *'I try not to go to this doctor, I go to a different doctor in the practice now'* (Sarah, LFC). Johnny gives a further example:

Anne: *'So you said one wasn't bad - how was the other one different then?'*

Johnny: *'Well he listened to me and he gave us tablets and things like that, whereas the other one wasnae really interested'* (Johnny, LFC).

Johnny and Sarah's accounts featured several interconnecting themes. They indicated favouring the GP who they felt engaged with their needs. This involved both medical outcomes and interactional aspects of the consultation. Johnny's words encapsulate the common view: *'I didn't feel he was on the right wavelength'* (Johnny, LFC). Notably, they also revealed turning to another GP in the practice, rather than not contacting a GP.

The frequent consulters noted similar factors, but linked such negative characteristics to either a previous GP, a locum, or another GP in the same Practice. Again, they expressed the importance of medical and interactional dimensions. Lesley commented that she doesn't like seeing other GPs in the Practice: *'Cos they don't understand'* (Lesley, FC). Ian gives a good example of this common theme, in response to being asked how helpful he finds his GP:

Ian: *'Brilliant doctor I've got. Best doctor in the world as far as I'm concerned. The other ones that's up there, don't get me wrang I just don't like them. For the simple reason is, if I go in, I could sit and talk to my doctor and everything else and thingamy. Gets it done, hospital thingamy... The other doctors, ye can go up there and get in there and that's it. Doctor, I don't want to mention any names up there, but they're thingamy, they're no, well I wouldnae say. They've nae time to thingamy'* (Ian, FC).

It is clear that both groups agree about what makes a 'good' or a 'bad' doctor. However, interestingly the frequent consulters refer to their 'own GPs' in positive terms, whereas typically, the less frequent consulters describe 'their GPs' in more negative tones. This could be due to the role of the GP in the frequent consulters' lives. If they are occupied by their illness, and management strategies are at the forefront of a disrupted life and diminished world, as illustrated in Chapter Four and Five, it is unsurprising that the GP is often perceived as pivotal. Furthermore, just as the less frequent consulters negotiate who

they see as a result of their negative experiences, the frequent consulters may be more adept at selecting 'their own GP'. They may have moved through the process of changing doctors at their surgery. There was some evidence of this. As part of an extensive negative account of her previous GP, Janet noted '*That (third diagnostic error) was enough, I changed my doctor*' (Janet, FC). Typically then, there was no explicit indication that negative or positive consultation experiences influenced how often the participants contacted a GP. This was not surprising. Set in the moral framework of appropriate consulting behaviour, the participants were very clear about why and when they consulted, and relayed this was due to severe, ongoing or abnormal symptoms which impinged on daily life, resulting in careful monitoring of conditions and symptoms, and judicious use of the GP.

7.3.2 Being heard

The participants emphasised the importance of 'being heard' by their GPs, but the frequent and less frequent consulters articulated contrasting experiences. The less frequent consulters overwhelmingly gave critical accounts. For instance, Paul described his GP's responses to his conditions, and, by extension to him. He noted how his GP failed to recognise his alcoholism as an illness: '*...doctor doesn't believe in it. He doesn't think, he thinks it's, you're weak willed...*' (Paul, LFC). Thus, according to Paul, the GP offers no practical help or symbolic support: he invalidates his illness status, and challenges Paul's integrity. The two extracts below underline this common theme. Jane and Martha describe why they no longer consult about ongoing health problems:

'...according to the doctor there's nothing I can do... basically... for six years I had internals and even asked for a hysterectomy, "No, no, no, no, you don't want that". ...So I still seem to have the things that I had years ago when, and, em, I, I feel as if nothing's really, you know...' (Jane, LFC).

'I said can you [check my] thyroids, maybe you know it's not right yet. He said: "Oh no don't be silly"... And I said well, I find it difficult to walk very far and he said: "Tut, don't talk nonsense". You know (Slight laugh). I get so back this leg, you

know, it is, when you're walking it's really difficult. I can walk so far and it starts in the front it's all sore. And he said: "That's because you're not doing enough (slight laugh). Okay, he's got an answer for everything (laughs). So, so in the end I just gave up' (Martha, LFC).

Based on such descriptions, the reported decision not to consult is rational. The GP is presented as unhelpful in easing symptoms and controlling illness, and posed as one who questions the patient's authenticity. Thus, the consultation is deemed useless, even damaging. There are no benefits medically, and it is detrimental symbolically. The accounts feature GPs positioning the less frequent consulters as inappropriate users, and as such their identities are questioned.

However, two of the less frequent consulters gave positive accounts of their GPs. Derek communicated how he values the medical outcome of consultations and highlighted the symbolic role of the GP. What distinguishes his account is how he identifies a network of health professionals, including practice nurses and his hospital psychiatrist. He says of his GP: *'He's very helpful ...'* (Derek, LFC). Derek discusses what he values about the medical team:

Derek: 'I think they're really brilliant people to look after us in the way they do you know, I think the world of them'.

Anne: 'What makes them particularly good do you think?'

Derek: 'The attention you get hen'.

Anne: 'The attention?'

Derek: 'You know, everything's all done for us an that and everything's looked at and investigated and it's absolutely marvellous...As soon as I go down, they want to know everything that's went on an that an' if they're anything you need done, they do it' (Derek, LFC).

Peter emphasises the interpersonal aspects of the consultation. He elaborates on his relationship with his GP:

'Well he listens to you. He listens to what you say. He gives you a bit of eh, he gives you credit for being intelligent.... So he gives you credit for, for knowing what you know, understanding what you understand... it's difficult to put into

words, but you just feel that the man is reasonable and he's realistic and he accepts you for what you are...' (Peter, LFC).

The extracts above relay the importance placed on the interactional aspects of the consultation. Both Derek and Peter stress the significance of being treated as individuals, and of 'being heard'. When probed as to what makes the health-professionals 'good', Derek replies it's *'the attention'* he gets which includes both the medical and the interpersonal aspects of treatment. Peter finds it hard to elaborate on what is 'good' about his GP, suggesting more than a medical dimension. He also conveys a sense that he gains moral worth from the consultation, in that, as an individual, he is being attended to; as he notes *'the man is reasonable and he's realistic and he accepts you for what you are'*. This constructs the GP as someone who engages with Peter and his experiences of illness and management. It contrasts with the negative comments made by the majority of this group, who communicated that their GP does not listen, fails to attend to their needs, and crucially, does not give them credit for *'knowing what they know'*.

In contrast to the less frequent consulters, the frequent consulters described more positive interaction between themselves and their GPs. For example, regarding appointments, they were able to validate their status as patients by describing how they have preferential treatment over others:

Anne: 'And how practical is it to get to see your doctor?'

Dick: 'Eh, well, no for like say my children's experience, trying to get to see the doctor, they'll maybe need to wait a week or so because he's busy. But I'm no, when I phone up, well I don't phone up, my wife phones up, they fit me in either that day or the very next day, no problem. I definitely don't find any problem with that whatsoever ...' (Dick, FC).

Dick underlines his point by positioning himself alongside his children, who *'need to wait'* to see the GP, in contrast to him; his use of words like *'definitely'* and *'whatsoever'* emphasise the difference. In so doing, he highlights his authentic status as patient. The frequent consulters' accounts extended to an overall picture of a positive relationship with the GP, who they identified as having specific attributes. Importantly, this also sustained their positive identities in the accounts; it illustrated their authenticity as patients, and

underlined their 'appropriate' consulting behaviour. In contrast to the less frequent consulters, their accounts commonly referred to how their GPs attended to their needs, and gave them time, information and examinations. To illustrate this point Janet detailed what she means by a '*really good GP*'. Similarly, Ian provided a typical example of the importance of being attended to by his GP:

Anne: '*And why is he really good, what makes him really good?*'

Janet: '*Because this doctor takes time to explain the procedures you are going through, he takes time to tell you what is wrong with you, he takes time to examine you and he gets to the bottom of what's wrong with you. He doesn't leave you in limbo. There's none of this, give you a prescription and say right try that, come back in two weeks... Somebody to be straight with me... just get right down to the nitty gritty tell me what's wrong with me and give me something to help me along the way... I'm not there a lot so when I do go he knows there's something really wrong. It's the only time I do go and this doctor knows that and he sits down, "Right what's the problem"? And he'll discuss it... and that's what I like about him'* (Janet, FC).

'...it's all about the things that's wrong with me.... And her checking it up, and, my blood pressure... and it's all talk. It's not just sitting talking about the weather or thingamy or anything like that, it's all about me. But she takes time to sit and listen to you and it's, and if there's anything that she's concerned about it's referred to the hospital. Really brilliant doctor...' (Ian, FC).

These accounts illustrate a common theme present in the frequent consulter accounts. Both descriptions form part of positive narratives on GP interaction, and intertwine the medical gains and the interpersonal experience. The concept of '*time*' is important, both stress that the GP has time for them. In selecting this aspect of the relationship, they build positive identities of their GPs, and themselves; the doctor who spends extensive time with a patient validates him or her.

But it also matters *how* the time is spent. Janet comments that the GP gets '*to the bottom of what's wrong*'; she wants him '*to be straight*' with her and '*get right down to the nitty*

gritty'. Similarly, Ian comments that the talk is not just *'idle chit-chat'*. He feels *he* is being engaged with; *'it's all about me'*. There is also a sense of things being done, and so hope is offered in the consultations. The talking is to actively gain, and give, information for medical purposes. Both Janet and Ian articulate a need for treatment, and an ability to communicate with the GP at a fundamental level. Furthermore, in the context of the interview, both gain status as authentic and active patients. They position themselves as accomplished individuals who deal with their GPs 'successfully'. This is underlined in both accounts, as a negative scenario is juxtaposed with their own experience, highlighting the qualities of their own GPs and their positive relationship. Reciprocity is illuminated by Janet's use of direct speech, drawing the listener closer to her experience. Throughout, Janet and Ian interweave positive images of their GPs with favourable presentations of themselves. Overall, exemplifying the frequent consulter accounts, both re-affirm their identities as 'genuine' patients, and therefore, as individuals with integrity.

However, an exception in the group of frequent consulters was Betty. She noted that her GP offered limited help. This was in the context of a body of support agencies with which she constantly negotiated in her bid to manage her multiple morbidities. She described her past experience of the GP consultation as favourable but of limited practical use:

'It's erm, I do I mean I think the Government has very bad constraints on the doctors and they do feel I can tell by looking at Doctor Butterfield. When I walk in and if I'm in a bad state and I sit and bubble the poor guy just doesnae know what to do with me, if you know what I mean. Erm, he knows what he'd like to do, but he, he doesn't have the where-for-all, or the authority' (Betty, FC).

Betty linked her personal experiences in the surgery to more structural concerns and refers to a number of constraints which she feels impact on her treatment. She also continues to construct herself as a positive and appropriate user of her GP's services as she comments that he is embarrassed that he can't do more for her. At one point, she describes her GP as *'the poor guy'*. This phrase challenges the normal boundaries between doctor and patient and positions the GP as relatively powerless to help Betty. Notable, is

unlike the less frequent consulters, Betty does not *criticise* her GP for being unhelpful, rather, she implicates the Government, and external constraints over personal agency when identifying his limited usefulness.

In summary, most of the less frequent consulters were critical of their own GPs' whilst the frequent consulters praised theirs. However, this was not explicitly stated as influencing decisions to contact a GP at the Practice. Both groups emphasised the value of the 'ideal' consultation in terms of medical and symbolic outcomes. But the less frequent consulters commonly consultations with no medical benefits, and discussed how their GPs questioned their views, challenging their illness status, and implicitly their integrity. In contrast, the frequent consulters' accounts were distinguished by their references to positive outcomes of the consultation, medically and morally; their status as responsible patients and appropriate consulters was validated.

7.4 The GP, symptoms, and daily life

Although the accounts centred on participants' ability to control symptoms and maintain daily life with the minimum of disruption, *it became clear that the social and cultural location of individuals impacted on their ability to accommodate symptoms, prevent disruption, and normalise illness.* As Chapter Four, illustrated cultural and material factors impacted on the ways in which disruption of daily life could be avoided. For example, paid work influenced the impact of illness, whilst material benefits could cushion its effects. These issues were also apparent in decisions about consulting and it is to these issues I now turn.

7.4.1 The consultation and paid work

As the analysis progressed it became clear that the structural organisation of paid employment also influenced decisions to consult. Regarding the less frequent consulters, for instance, Johnny described how he does not consult his GP currently despite experiencing ongoing symptoms of nausea, sleeplessness, and depression. Based on his

experience he anticipates being offered unhelpful and unrealistic options; medication and a sick-note. He feels that the drugs do not work, and he is unwilling to have any time off work: *'I've had a lot of accidents at work and I've used up all my (paid) days'* (Johnny, LFC). He adds that his wife drives him to work, *'Well luckily enough we work together'* and says that his work-mates also help his diabetes from impacting at work, *'Well I'm lucky enough, the boys I work beside will say to me you want to eat something'* (Johnny, LFC). The structural constraints of his employment mitigate against a consultation, whilst situational factors allow him to continue to work. Likewise, Jane explains that taking time off is unhelpful as there is so much 'catching up to do when she returns, yet working full-time makes her tired and stressed. But she has been able to re-organise her working day: *'I've been job-shared and ...haven't seen, haven't seen, the doctor for months'* (Jane, LFC). Similarly, Sarah explains that the nature of her symptoms, interactional factors at work, and the way that sick leave is organised, combine to negate a consultation:

Anne: *'Would you have had to go to the doctor then for a sick line?'*

Sarah: *'No that would just be self-certificate, just three days. But I was having to have interviews in work because of this. We have a new system where you have to, if you are off two days in six months or something, you have to have interviews. It was an awful official and everything. But luckily, my head teacher's daughter suffered from migraine so she knew what it was like. Some people are not very sympathetic, they think it's a headache'* (Sarah, LFC).

Location in the employment structure, at both a macro and a micro level informs help seeking. Pragmatic decisions are made, based on the interplay of personal circumstances and external constraints. The less frequent consulters typically neither need the GP for treatment, to validate their illness status, or for economic resources (a sick line). A consultation offers them nothing. In this way, the symptoms and cultural and structural contingencies are inextricably linked. It is the interconnection of the symptoms, *together with* a combination of the personal arrangements at home or at work, and the organisation of sick pay, which combine to influence the consulting decision.

In contrast, although most of the frequent consulters had been unemployed for some time, a minority described a need to consult the GP due to their (un)employment position. Betty describes seeing her GP for a range of reasons including advice, support and help with receiving Benefits, and validating her illness status. Jim describes rarely seeing his GP for treatment, as he collects a repeat prescription. However, due to his social location and broader structural concerns, he sees his GP frequently. Unlike Johnny, Jim is unable to continue in paid work (as a firefighter). When I asked him why he consults his GP he responded: *'Med Certs, yi know incapacity benefit, panel lines'* (Jim, FC).

Comparing Johnny (LFC) and Jim's (FC) situation is helpful in bringing into focus exactly how consulting can be explicitly linked to broader structural factors. Neither see the GP for symptom relief. Jim consults for both practical and symbolic reasons, linked to his social location. The GP offers economic support as well as moral support, the two are intertwined; Jim needs his GP to validate his status as authentically unemployed and receive sick pay. On the other hand, Johnny decides not to consult along similar lines; the nature of his employment means he not only can, but also *needs*, to continue at work, with no sick leave. It is important for him to retain his employment and economic status. The decision to consult for Johnny and Jim hinges on the interplay of their paid work situation and their symptoms. So, the social context of the symptoms needs to be taken into account when assessing consulting behaviour.

7.4.2 Reasons to consult

As illustrated in Chapter Four, functional ability, levels of control and degrees of loss were prioritised in the accounts. Whilst the less frequent consulters noted contingent *normalisation* in their daily lives, the frequent consulters talked about having significantly *disrupted* lives. Thus, the personal constraints on the body, for example the inability to fulfil 'normal' culturally accepted roles and social obligations became a reason to consult the GP. For example, commonsense ideas about 'normal' functioning, in this case 'being busy', informed Dick's decision to consult his GP. Dick notes that he has been referred to a carer by his GP:

'I'm going out this Wednesday with a carer... Hopefully through doing this, I'm hoping and they're hoping too, it'll help me go out myself. Even just go into the shop, go to the shop myself, you know. That would be definitely a good day for me, if I could just even go up to the shop myself, you know' (Dick, FC).

Dick wants to go out on his own. This is a basic requirement for a functional adult in our society. In this way, the GP has an instrumental value in that he has offered Dick an opportunity through a referral, to simply 'go out'. Dick is 'hopeful', and so are 'they'. This implies an ongoing project in which 'they' are working together towards this aim. It indicates a basic status gain and sense of achievement, and shows Dick is making attempts to improve. The words 'even', 'just', 'you know' point to the commonsense assumptions about appropriate behaviour. In this case, Dick describes inaction and an inability to go out alone as a tangible sign of illness. The ability to go out on his own, 'Even just go into the shop' will also offer Dick benefits in two ways. First, it will demonstrate that he has gained some measure of control over his symptoms, and second, he will be able to function more normally and take part in routine activities, and thus on both counts demonstrate moral adequacy. The significance of being able to go out is highlighted by his repetition of the term 'hope'. This is what the carer, who Dick has access to through his GP, offers Dick.

Ian also describes the importance of GP referrals when he discusses the Occupational Therapist who organises equipment that will reduce his incapacity, and help him retain his independence in the home, and his identity in the local community. He says he has been asked by the Occupational Therapist to 'get your doctor to write doon everything that's wrang wi ye and send us a letter in' (Ian, FC). He adds: 'I'm still waiting to see about the shower in the (bed) room, and the ramp'. Ian describes his current functional problems in the bathroom:

'So what I've got to dae is noo is just if I don't use that chair, I just sit on the thingamy, haud on to the handrail and the thingamy, and swirl around on my feet, my bath which is a pit, takes ages an aw. But I prefer to dae it that way sometimes for the sake of getting right doon into the bath and lying back,

you've got the seat in ye cannae, but if you've got the shower with the seat built in to it, ye just sit in it and shut the door o'er, and Bob's your uncle' (Ian, FC).

The above words indicate the importance of the Occupational Therapist for Ian. He compares what 'is' with what *will* be, 'if' he has the equipment. The difference is clear, and underlined by Ian's detailed problematic account, ending with the closing phrase '*Bob's your uncle*' (Ian, FC), mirroring the hoped for contrasting experiences of struggling with the bath, and simply having a shower. Ian also sees his GP to help him maintain some sense of coherent identity in his daily life. When asked how he copes with his illness in general, he replies: '*Doon to the bingo and roon about*' (Ian, FC). Ian continues:

...I just cannae stop talking, I've gotta talk all the time and as I say it's maybe to take my mind off the other things. I can always have a conversation with anybody. To gie you an example there, last week I was going oer in the wheelchair into the bingo... But that's just ma nature' (Ian, FC).

The first extract refers to practical elements with which his GP assists, the second to the outcome of the GP consultation. Due to his electric wheelchair, Ian is able to take his mind off his symptoms, and, in the context of a more extensive account around the value he places on social contact, he is able to maintain his identity by mixing with, and talking to others. As he notes that is '*just ma nature*'.

Ian has other symptoms that debilitate him for which he sees his GP. For instance, he notes he has consulted for Viagra. He comments that he is '*only fifty*,' and it is for his wife's '*sake*' as much as his. These words convey the disruption he feels. It is 'normal' for somebody of his age to be sexually active. Furthermore, by mentioning his wife, he brings into focus not only the threat impotence holds for his masculine identity, but also how it prevents him from fulfilling his role as sexual partner. In this way, the GP consultation again offers both practical and symbolic help. With Viagra, Ian hopefully will be able to have sex, and re-gain his sexually active status. Overall, both Dick and Ian

illustrate that their GP has a pivotal role in potentially easing their debilities and aiding their identities, both in the family, and in the wider community.

The frequent consulters expressed desires to fill social roles and fulfil social obligations, which overrode the fear of symptom 'flare-ups'. They discussed how 'doing things' exacerbated conditions and led to GP consultations. Betty described how her GP gives her a 'row' for doing too much. But she communicates her dilemma; she does not want her sons doing things for her: *'I don't want to burden them'* (Betty, FC). Similarly, Janet describes how her role as mother swamps her role as responsible patient; she will 'overdo' things. Having described how she has helped her daughter move house, which has exacerbated her symptoms and put her in great pain she says she will continue to help in such ways because *'When you've got a family you just can't lie down you know what I mean. I mean I've got grandchildren as well. I've got a daughter about to have another baby. I am not going to lie down to it; I keep going on and on'* (Janet, FC). But she explains how helping her daughter led directly to a GP consultation:

Janet: *'You think "Oh it's nothing". It's after it, (helping her daughter move house) the pain, I'll never forget it. He (GP) says it was there to start with but me doing that, it was there to start with but I just made it worse actually, made it worse.'*

Anne: *'Do you think you would think twice again? Think "Oh I better not do that because"?''*

Janet: *'No, I'll be honest, no, I would do it again. No point in lying to you'* (Janet, FC).

Janet needs to fulfil her role as mother in the family. This formed part of an extensive account of how important this is for her identity. She is unwilling to pace to such an extent that her sense of self is threatened. In this instance the GP is consulted, not to facilitate or help functional ability and status attainment, but as a result of attempts to function in social roles, which exacerbate symptoms, and which Janet cannot ameliorate. Again, it is the combination of the nature and extent of the symptom with the social location of the individual, which prompts the consultation. Furthermore, Janet states *'I would do it again'* (Janet, FC); the GP offers her respite from her suffering, and a way of being a mother and grandmother.

Some of the frequent consulters described a combination of disruptive life events which they attempted to deal with alongside their illnesses, and said this combination *added to* an inability to manage. For example, Jim describes going to the GP more often: *'jist at that time when, it jist seemed everythin wis aw jist pilin in. Am an unlucky bloke, everythin that could go wrong wis goin wrong'* (Jim, FC). He describes a point in time when his marriage broke up, he became unemployed because of an accident at work, and he moved from the family home into a bed-sit. Unsurprisingly, having established very clear reasons for consulting the GP, Jim falls short of saying he consulted for these reasons. Lesley notes a time when her consultations had been more frequent, when her husband had lost his job and they had moved home. Again this was alongside symptoms and she felt *'it was always something'* (Lesley, FC). Illustrating this further, Betty noted that her GPs had always been helpful in stressful periods of her life, which she noted exacerbated her symptoms of Multiple Sclerosis:

'...they (GPs) have actually all been very good. There's a lot of things happen like my brother dying young and my mother dying and I had a miscarriage between my mother and my brother dying, and then my husband went off the rails, and then we lost the business, and then we lost the house; all these sort of things. So I found that the GPs really been very supportive. And although he doesn't know really that much about MS he is supportive. And he will try his best' (Betty, FC).

These extracts suggest that participants with multiple problems seek the help of their GPs. Although they do not explicitly consult for social reasons, it seems feasible to suggest that medical and social problems mingle to form complex conditions that may require a consultation. Both Lesley and Betty conveyed that during stressful periods, as they attempted to manage their symptoms, they consulted their GPs, whilst Jim noted his GP contact had been more frequent in troubled times, though for medical problems (depression and back-pain).

None of the less frequent consulters described such episodes. They were inclined to talk about a lack of stress, and a sense of well-being which they felt helped them manage their

illness in general (5.2; 5.3). At times they explicitly associated a lack of worries with avoiding GP consultations. When Martha was explaining why she rarely went to the GP she gave a number of reasons to do with her symptoms and self-management techniques, *combined with her family situation (she was a single parent with four young adult sons), which she said made her 'happy':*

'They (sons) never have (given her cause to worry) and every one of them works, there's none of them unemployed, and they've always, I mean, no great jobs or anything like that, but, they work, and I think that gives you a wee sense of pride in your, happy, makes you happy. So I think that's really the reason why I keep on top of it, I don't really let it get me down. Because I'm quite happy as I am. That's it you know I can't really think of anything else...not go to the doctor (Martha, LFC).

Others in this group spoke of their material circumstances as aiding illness management. They noted fewer worries, and more material resources, which they felt helped them (5.2, 5.3). Overall, *daily life, structural and cultural factors, as well as symptoms coalesced to inform consulting behaviour.*

7.5 Summary

The interviews demonstrated how participants steered a delicate path through their various symptoms and management strategies in daily life, and conveyed a common knowledge about appropriate consulting behaviour. They constructed GP use as a 'last resort', but also noted how in particular circumstances help-seeking should be swift. The interplay of the functional and moral concerns around consulting became clear. Inaction may invite prolonged illness and further treatment and, therefore, ultimately, more GP time and resources. Avoiding consultation mitigates against being seen as a responsible user; sloppy surveillance may undermine one's moral adequacy. Having established that they should only visit the GP for carefully delineated reasons, the participants positioned themselves as judicious consumers of scarce resources. As they did so, they presented themselves in positive ways, conveying that illness and consulting is a complex and reflexive process, involving constant monitoring, interpreting and re-interpreting

circumstances in a moral framework. The accounts revealed the accomplishment of moral identity was a core part of the illness experience, as the participants showed concerns to display physical and moral stoicism in the face of suffering.

This chapter has identified a number of reasons which go some way to explaining the opposing consulting patterns of the less frequent and frequent consulters. All participants spoke of consulting as a last resort in the context of their daily lives, based on common sense knowledge of illness, and shared notions of appropriate use of the GP. They discussed visiting the GP for condition and symptom specific reasons involving: *abnormality, severity, longevity, crisis* and *dysfunction*. As Chapter Four revealed, the frequent consulters tended to describe disruptive illness episodes which featured such characteristics, whilst the less frequent consulters noted *normalising* ongoing, less severe symptoms and dysfunction, and referred to occasional crises. The analysis demonstrates that both the frequent and less frequent consulters interpreted illness and GP resources in the same commonsense ways, but crucially, the frequent consulters described more severe symptoms, erratic conditions and crises. As a consequence they described more dysfunction, and less ability to control both illness and their daily lives. This then was conveyed as one reason for the contrasting patterns of consultation. Overall, the frequent consulters described more illness, which impacted significantly on their functional capacity, which in turn disrupted and diminished their daily lives, and reportedly, prompted a GP consultation.

Although severity of symptom was a clear indicator of consulting behaviour, the analysis revealed a multi-dimensional process, and illustrated how interconnected factors combined to influence illness and consulting behaviour. It was clear from the accounts that both groups tried other strategies and resources prior to, or instead of a consultation. Often, the less frequent consulters mentioned using over-the-counter treatments, whilst the frequent consulters were unlikely to do so; they felt that the medicines would be ineffective or may aggravate their routine regimen, and conditions further. They talked about gaining both formal and informal advice, for instance from a practice nurse, or family member. This suggested added uncertainties for the frequent consulters. They

relied on prescribed drugs only, due to their complex set of conditions, symptoms and medications. Typically then the combination of severe, ongoing and unpredictable illness combined with the fear or unwillingness to use over the counter medicines, was communicated as leading to more GP consultations for the frequent consulters.

Both less frequent and frequent consulters talked about consulting their GP for monitoring. These were either GP led (check-ups) or (reflexively) instigated by participants. These were more likely to be part of the frequent, rather than the less frequent consulters' accounts. This was unsurprising as they were more likely to describe unpredictable and fluctuating conditions and symptoms, low degrees of control, and high and unstable medication regimens, which often led to further complications. All of this, reportedly, combined to influence their consultation behaviour.

Regarding accounts of the consultation, the less frequent consulters were often critical of their GPs, and preferred to see another GP at the same practice. They discussed medical and symbolic outcomes of the consultation; they commented that often no viable treatment was offered; their patient status was questioned, and their integrity challenged. In such accounts, GPs were constructed as failing to engage with, or attend to, the less frequent consulters' individual needs, and as invalidating their patient status. However, importantly, they noted seeing other GPs at their surgery, if they felt an appointment was necessary. Accounts in this group underlined the importance of being heard by GPs, and having their needs attended to. Being accepted as an authentic patient, was identified as pivotal to a successful medical encounter, and inseparable from the medical outcome. A minority of the less frequent consulters reported gaining such benefits from their own doctors. Typically for this group, the GP consultation whether spoken about in positive or negative terms, was not positioned as crucial.

In contrast, the frequent consulters spoke positively about their typical consultation experiences, which reflected a close alignment between themselves and 'their GP'. They described how, as a consequence of the consultation, they felt 'something was being done' to control, limit, prevent, arrest, or even reverse symptoms and conditions. This was even

though the treatment offered no permanent respite, and sometimes no medical improvement; however they relayed how the GP offered hope and support and validated them as authentic patients, facing illness with stoicism. In this way accounts of the consultation, contributed to the construction of positive moral identities for the frequent consulters.

This was of particular importance to the frequent consulters, who described few cultural resources on which to draw to manage a positive presentation of self throughout their accounts of a daily life disrupted by illness. As the accounts revealed in Chapter Four, Five, and Six, all of the participants wanted to 'get better'; they strove to limit the impact their symptoms had on their daily life. To this end, the frequent consulters located the GP as crucial in their management of illness, and central in authenticating their patient status, and validating their consulting behaviour. Notably, they were able to position themselves as 'distinct' from less 'deserving' cases, suggesting that they felt concerned to justify their use of the GPs' scarce resources. Typically, they conveyed an ongoing and valuable relationship with their GP, who was positioned at the forefront of their illness experience in the context of a diminished world, and a sinking self. They were able to construct positive identities, through their descriptions of illness and careful consulting.

The participants conveyed how their social position or 'relational setting', *combined with* their symptoms to directly and indirectly influence consulting. For instance, alongside symptoms, they described structural factors at work and cultural factors in the family, as affecting consulting. The frequent consulters also reported disruptive life events, alongside symptoms as coinciding with particularly frequent consulting periods, whereas the frequent consulters noted how positive aspects in their lives (for instance being 'happy' with family-life: Martha, LFC) contributed to rarely seeing the doctor. This evidence builds on the findings in Chapter Five (in particular 5.2 and 5.3) illuminating the complex consulting process as one in which *symptoms coalesce with personal situation, cultural expectations, structural factors and biographical characteristics to influence the consulting process.*

Regarding the status of accounts, I have attempted to represent what the participants said by using a range of illustrative examples and deviant cases. I have also attempted to reflect the experiences of the participants by undertaking a systematic analysis of the data, looking for consistencies. Again, although I see the interviews as favoured accounts, I also claim they relate to an external reality beyond the interview, regarding reasons to consult the GP. Field notes have helped build confidence in these findings. However, it is important to identify that no such claims can be made about the reports of the consultation itself. I have no way of checking, either with the use of field notes, or looking for consistencies in the data, as to whether or not the reported interactions happened, or to what extent they mirror medical encounters. As identified in the literature review, (2.3.1.2) research strategies have revealed some discrepancies between what people report, and what happens in practice (Stimson & Webb, 1975).

As I reported earlier, I suggest two possible reasons for the positive accounts of the frequent consulters regarding 'their' GPs. First, to a certain extent it may reflect how the participants actively manage relationships with GPs. The less frequent consulters relayed they negotiate who they see as a result of their negative experiences. The frequent consulters, based on their experiences, may have moved through this process, and selected a GP who meets their requirements. As illustrated there was some evidence of this (Janet, FC).

Second, the frequent consulters described a world diminished by illness, in such a context, the role of the GP is magnified, and they have more invested in their relationship with him/her. In such a context, they may be less likely to continue a negative relationship, or perceive their relationship as negative, whereas the less frequent consulters may feel free to do so.

In terms of the accounts being used as vehicles to build moral identities, the less frequent consulters typically discussed how their GPs questioned their views, challenging their illness status, and implicitly their integrity. In contrast, the frequent consulters' accounts were distinguished by their references to positive outcomes of the consultation, medically

and morally; their status as responsible patients and appropriate consultants was validated. One reason for this may have been because in the context of the interview the frequent consultants had fewer cultural resources on which to draw than the less frequent consultants; they were less able to build positive identities, and in the interview as in daily life, the role of the GP was pivotal as they managed positive impressions of themselves.

With the benefit of sociological theory, these findings will be discussed further in the final chapter.

Chapter Eight

Discussion

8.1 Introduction

My aim in this thesis has been to investigate how people with chronic multiple illness, but contrasting consulting rates, manage their illnesses and make use of the general practitioner consultation in primary care. In order to do this, I have analysed participants' accounts of the impact of illness, the resources available to them, and the place of medicines, and the GP consultation in their overall management strategies, and attempted to answer three questions:

1. How do the participants experience the *impact* of multiple chronic illness in their daily lives, and what are the similarities and differences between people with contrasting consulting rates?
2. How do the participants perceive and use resources and strategies in their attempts to *manage* multiple chronic illness in daily life, and what are the similarities and differences between people with contrasting consulting rates?
3. How do the participants perceive and use *the GP consultation* in the context of living with multiple chronic illness, and what are the similarities and differences between people with contrasting consulting rates?

In this chapter, first, I provide answers to these questions by summarising my findings and relating them to empirical studies referred to in Chapter Two. Second, I attempt to expand these analyses by relating them to broader social theory. Finally, in the context of concerns around an increasing prevalence of chronic illness, and associated policies around self-care, the concept of concordance and notions of the 'expert patient', I relate my research to policy and practice development.

8.2 Summary of findings and previous research

8.2.1 Chapter Four: The impact of chronic illness

Chapter Four tackled the first research question and showed how participants talked about the impact of illness, describing symptoms and interlocking concerns around function, control and loss in daily life. These findings support the analyses of Herzlich (1973), and Williams (1990), who suggested that an inability to function had both practical and existential dimensions for respondents.

In line with previous analyses (Anderson & Bury, 1988; Frank, 1995; Kelly, 1992; Pinder, 1990; Radley, 1993), participants articulated concerns around an ability to control illness, their bodies and lives. An associated dilemma, which has been well documented, is the notion of loss as an integral part of the chronic illness experience (Bury, 1991; Charmaz, 1990; Gerhardt, 1990), and this was echoed by participants in my study. The participants conveyed how lost functional abilities posed core challenges to their identities. In this way, the association between the practical and symbolic dimensions of the body was a salient feature of my analysis, and concords with previous research (Bury, 2001; Charmaz, 1983; Kelly & Field, 1996). Further reflecting the work of others, the participants revealed how, depending on their ability to control symptoms, they attained normalisation, or experienced disrupted worlds. This indicated the significance, as well as the consequences of illness on them and their daily lives (Bury, 2001; Charmaz, 2000b; Riessman, 2003; Robinson, 1990).

I have highlighted how both the less frequent and frequent consulters shared the same concerns about symptoms, functional debilities, and attempts to live a 'normal life'. Overall, the less frequent consulters described their ability to contain symptoms, relayed few challenges to their identities, and conveyed a sense of contingent normalisation. In contrast, the frequent consulters described severe, ongoing and unpredictable symptoms and illness. They discussed significant functional debility, a lack of control of their bodies and a deep sense of loss of familiar lives and former selves. Their self-image was

often based on particular behaviours they were no longer able to perform with impunity, or in some cases, at all. Their accounts featured illness experience as fraught with *loss*. In comparison to the less frequent consulters, the frequent consulters discussed high levels of illness, which had a significant impact on them and their lives.

By explicitly comparing and contrasting the multiple chronic illness experiences of frequent and less frequent consulters aged around 50 years, I am contributing new knowledge to medical sociology. My analysis suggests that attempting to live a 'normal' life, and 'hang on to' a coherent moral identity are particular burdens for those who have high levels of chronic illness at a relatively young age. The following section summarises how the participants strove to fulfil their social obligations, manage their familiar roles, maintain normal daily life and stave off disruption.

8.2.2 Chapter Five: Living with chronic illness

Chapter Five addressed the second research question. Participants described their quest to have 'normal' lives. They discussed how they attempted to contain symptoms, and control illness, adding to the body of evidence in this area (Charmaz, 2000b, Herzlich, 1973; Locker, 1981, Williams, 1990). They prioritised activity as a management strategy. For example, 'keeping busy' was not only a distraction from their symptoms; the benefits extended to a symbolic dimension; being active demonstrated the participants' moral fibre. Mirroring other empirical findings (e.g. Radley & Green, 1987), the accounts revealed concerns to undertake 'normal' activities, and fulfil social roles and obligations.

Employment was perceived as a positive resource in a number of ways. Being employed offered participants economic, material, social, and symbolic resources on which to draw. In this way, individuals' structural location offered them ways to manage illness. This supports the analyses of Radley (1989) who showed that people have access to different resources, which in turn influences their *styles of adjustment* to illness. As I discussed in more detail in Chapter Two, Radley (1989), drawing on the theory of Bourdieu (1984),

brings into sharp focus the importance of understanding the structure/agency interface when investigating illness experience.

The participants conveyed the importance of, and tensions and ambiguities around, social contact. For instance, practical and emotional support was valued, but the benefits of confiding in others were set against the risk of damaging their coherent identities; they did not want to be seen as 'complainers'. Further, seeing friends was a tangible reminder of the participants' difference in terms of functional problems, and associated limited lives. This was a particular problem for these participants, who were relatively young (around 50 years) to have such high levels of illness.

The family was positioned as a core resource. Consistent with previous analyses (Blaxter, 1976; Charmaz, 2002, 2004; Radley & Green, 1987; Radley, 1989; Reisine, 1987; Riessman, 2003), the accounts were gendered. Women and men perceived the availability of support in the family in different ways. The women's descriptions of 'help' with housework, cooking and shopping, were expressed against a backdrop of guilt and gratitude. This indicated that personal interpretations of the availability of resources in the home were influenced by common sense assumptions about idealised behaviour. In this way, deep-seated cultural structures were present in the most personal of accounts, as the women strived to manage illness alongside familiar lives and identities. This interpretation of the accounts is underlined by the male participants' lack of references to concerns around routine domestic tasks. Moreover, the men described how their female partners helped with medications, and organising professional help, whereas the women did not. Both men and women spoke of practical and emotional help in the family, but crucially, the women were likely to talk of family support with ambivalence, as they communicated a reluctance to burden their partners and children with their illness. This finding resonates with the empirical and theoretical work of Bourdieu (1984) who emphasised the ways in which women actively interpret their personal situation in the family informed by broader cultural constraints. In my study ideas about traditional domestic roles, informed the women's personal interpretations of the availability of support in the family, and challenged their coherent sense of self.

The participants described practical and emotional strategies in their quest to 'carry on'. Reflecting previous analyses they described pacing (Charmaz, 2000; Herzlich, 1973), alternative treatments, and equipment use (Charmaz, 2000; Verbrugge, 1997) as helpful, but problematic in a variety of ways. For example, pacing could be misjudged and risky; alternative treatments could be expensive, ineffective or have deleterious effects, and equipment use could be onerous and a tangible reminder of debility and difference. A major theme and mirroring other evidence (Baruch, 1981; Blaxter, 1983; Pollock, 1993; Radley, 1993; Williams, 1993), the participants talked about the importance of keeping a positive attitude. They described facing their illness dilemmas with stoicism. Reflecting the work of others (Goffman, 1969; Robinson, 1990; Riessman, 1990) this featured as an integral part of the accounts and underlines the ways in which the participants felt concerned to construct their moral identities and manage positive impressions of self throughout their accounts. This illustrates further the added burden of maintaining one's moral identity when experiencing chronic illness and I would suggest this is particularly salient for those who are relatively young to have such high levels of illness, often leading to significant debility, and in turn, isolating difference.

Explicitly comparing the less frequent and frequent consulters highlighted the similarities and differences between them. Importantly, *both groups worked hard at reflexively controlling their symptoms, and managing their illnesses as they relayed how their decisions to mobilise resources were contingent on a combination of interconnecting personal factors and broader structural issues*. The less frequent consulters conveyed 'success' at managing illness alongside daily life. The frequent consulters' accounts were characterised by tensions and ambivalence in a disrupted life and a diminished world. Both groups perceived ways to manage illness in similar ways. But crucially, the frequent consulters did not have access to the same resources. For instance, due to their functional incapacities they were less able to 'keep busy', and be active. All were unemployed and noted this was due to their illness. Associated with their unemployment they had fewer material, economic and social resources on which to draw. They were also less likely to use alternative therapies, and faced more significant risk if they misjudged their pacing. Moreover, existential problems mirrored their practical dilemmas. They were unable to

display their ability to control their illness and maintain normal life; thus their moral identity was challenged.

8.2.3 Chapter Six: Medication matters

Chapter Six dealt with part of the second research question, and highlighted aspects of medication use, which has been identified, in the literature (See Appendix A, also Britten, 1994; Faircloth, 1999; Pinder, 1988; West, 1976). The participants reported both drill-like (using prophylactic drugs) and flexible regimens (using symptomatic drugs). They described how drugs stabilised conditions, eased symptoms, and helped them function in daily life, yet whenever possible they would resist taking them. Analysis showed that the aversion to drugs in general could be organised around two concepts; the 'responsible patient' and the 'stoic patient'. The participants showed how they were careful to take medicines to stabilise and control particular conditions such as high blood pressure, whilst medication purely to relieve symptoms was avoided as far as possible, and was conveyed as a matter of self-discipline. However, the participants relayed how such drug use was warranted to enable fulfilment of social roles and obligations. Therefore, ambivalence and tensions continued to characterise the accounts. Medication had both practical and symbolic properties; it facilitated activity, helped the maintenance of social roles, and thus helped build positive identities and sense of self, but it could also be seen to symbolise illness or an inability to self-manage and control symptoms. A reflexive process was highlighted in the complex regimens, underlining the agency of the participants, who continued to construct themselves as competent, responsible and moral individuals.

Both groups described the same concerns, benefits and processes regarding medication use as outlined above. However, again there were marked differences between the experiences of the frequent and less frequent consulters. Due to their conditions and symptoms, the frequent consulters were more likely to describe problematic and wide-ranging medication regimens than the less frequent consulters were. They articulated an inability to rely on medication and a fear of aggravating symptoms if they took drugs

flexibly, or independent of professional advice. All of this culminated in more GP contact for: monitoring purposes and relief of unpredictable and resistant symptoms, which involved changing drug regimens, as well as referrals to a range of health practitioners. Overall, the accounts indicated a range of reasons around drug use which go some way to understanding the contrasting consulting patterns between the two groups.

8.2.4 Chapter Seven: Consulting the general practitioner

As the participants spoke of the role of the GP in their overall management strategies, they appealed to common-sense understandings about ideal behaviour to explain their consulting. The importance of being recognised as a valid individual continued to be a salient theme of the accounts as participants demonstrated a moral obligation to use the GP judiciously; typically as 'a last resort', but in certain circumstances, swiftly. Thus help-seeking was constructed as reflexive and skilful and articulated as a moral response, mirroring previous research discussed in more detail in Chapter Two (e.g. Locker, 1981).

The participants described how decisions to consult were contingent upon conditions, symptoms and personal situation, in the context of broader structural and cultural factors. This supports other research (Blaxter, 1983; Cornwell, 1984; Radley, 1994; Robinson, 1971; Locker, 1981), and builds on the previous findings chapters where I reported how participants' interpretations of symptoms and use of resources, needs to be understood by addressing both micro and macro factors.

In a similar vein, the less frequent and frequent consulters shared views about the characteristics of a successful consultation. However, it should be noted that, as was identified in the literature review, accounts of the consultation cannot be said to concord with what happens in practice (Stimson & Webb, 1975). The participants discussed the need to be recognised both as patients and individuals by their GPs. They intimated that the GP consultation was unsuccessful when they felt that *they* were not being attended to, and not 'being heard'. But it was 'successful', for both the frequent and less frequent consulters when they were being given '*credit for knowing what they know*'. This reflects

previous research on accounts of the consultation which has revealed how people feel their integrity is challenged in medical encounters (Johansson, 1996; Radley, 1994; Werner and Malterud, 2003; Ong et al., 2004). These concerns resonate with recent policy and practice priorities on the changing nature of the patient-practitioner relationship and contribute to the body of empirical and theoretical work on the concept of concordance (Campbell & McGauley, 2005).

As noted above, the frequent and less frequent consulters valued the same characteristics of the GP consultation. But they reported contrasting experiences. For instance, the less frequent consulters constructed their GP consultations as typically unhelpful. They discussed how their GP neither offered them symptom relief (medicines or treatment), knowledge (information which eased their symptoms) hope (referrals or different treatments) or moral support (empathic understanding). Moreover, they conveyed how their GP threatened their integrity, and failed to help them in their ongoing struggle to live a normal life, and maintain positive and coherent selves. Overall, they were likely to criticise 'their GPs' in terms of treatment, knowledge, and support, and stressed negative interactional factors. They reportedly gained little or no physical relief, or moral support from such contact. However, typically, they made no claims to this influencing their decisions to consult a GP, rather they would consult a different doctor in the same practice, emphasising throughout their accounts that they would use the GP judiciously, but would be careful to consult if the occasion required it.

In contrast, the frequent consulters positioned their GP as central to their overall management strategies. They described how the GP consultation offered them, above all hope and empathy. They were hopeful of being offered *some* relief. In the context of severe and unpredictable symptoms they described how drug regimens could be altered, new treatments, exploratory work, referrals, and monitoring could be offered. Thus their GP was positioned as one who offered knowledge, hope and symptom relief. Furthermore, in the context of the interview their doctor offered ways of bolstering their moral identity. As one who took account of them as individuals, thus positioning them as authentic patients, and

consulting appropriately. Overall, the accounts of the frequent consulters' conveyed how their own GPs verified their moral competence, in the face of challenges to it.

Overall, the GP consultation was conveyed as a practical and symbolic resource for the frequent consulters in a life diminished and disrupted by multiple chronic illnesses, in which their identities were challenged. In contrast, the less frequent consulters' accounts did not feature the consultation to the same extent. Rather, they spoke of gaining practical and symbolic benefits from their familiar lives, building positive identities and managing their illness using a bank of cultural, material and social resources. In this way, the role of the GP consultation was magnified in a diminished world, whereas the less frequent consulters related a 'normal' life, in which the GP played a 'background' role.

Having summarised the main findings with the benefit of relevant literature I will now discuss the analysis in more detail applying sociological theory.

8.3 Theoretical framework

As reported in Chapter Two, I have found it helpful to use two conceptual lenses in the discussion of my findings. First, in an attempt to gain an understanding of the illness experience and, because of the participants' salient concerns to establish their moral adequacy, I have applied a narrative analysis which focuses on the temporal, the episodic, and action which has a moral purpose (Hyden, 1997). I have also examined how the participants have built positive identities and coherent selves throughout their accounts. My interpretation of this approach is that it is essentially informed by the work of Goffman who wrote about 'impression management' (Goffman 1969). For Goffman, social actors 'show' their positive selves, and save face, when faced with situations which may threaten their identity, such as chronic illness. I have illustrated how participants constructed themselves as 'active moral agents' as they conveyed stoic suffering, reflexive management, and 'responsible' consulting.

However, as I wrote in Chapter Three, my analytical approach allows for a 'real' world beyond the narrative turn and the interviews have been treated as 'situated narratives'.

That is, as self-stories told in both micro and macro contexts (the interview, daily life, and structural and cultural environments). My second analytical approach, as identified in Chapter Two rests on my interpretation of Bourdieu's theory of practice. Locating the personal narratives in a broader structural framework reveals how social structures inform personal experience and action. In the following discussion, I use theory, in order to shed light on why the participants were concerned to construct moral identities, as they spoke of stoicism; gendered accounts of illness experience in the family; 'being a worker', and the place of the GP consultation in their overall management strategies. Such theory will add external validity to my findings and underscore the usefulness of my conclusions.

My qualitative approach has been informed by a narrative analysis of the data as described in the methodology chapter, and illustrated in the findings chapters. Particularly relevant here is how such an analytic approach has been helpful in exploring theories of the body, and the accomplishment of identity. For example, Sparkes (1995) sees the performing body as a sign system, a way of representing ourselves to others; when problems arise, telling stories about ourselves is a way of placing order on disrupted lives:

'As individuals construct past events and actions in personal narratives, they engage in a dynamic process claiming identities and constructing lives... an obvious example is provided by the identity dilemmas faced when individuals experience chronic illness...' (Sparkes 1995: 104)

According to Sparkes, the focus on personal experience that characterises the narrative provides powerful insights into the subjective reality of individuals and the ways that they interpret their own lives and the world around them. This is in line with symbolic interaction theory; the *'self no longer references an experientially constant entity, a central presence or presences, but, rather, stands as a practical accomplishment'* (Holstein 2002: 4). Seeing narratives as performances builds on recent work in the UK (Bury 2001: 273), and specifically draws on the work of Goffman (1969).

Narratives in social science research have also, in part, emerged as a response *to* aspects of symbolic interactionism and those who are '*dissatisfied with the neglect of the broader structural character of the world*' (Silverman, 2004: ix). This approach shows how the active construction of self through talk is tempered by the cultural context on which one draws. In Chapter Two I outlined how others (e.g. Riessman, 2003; Charmaz, 1990) have identified the usefulness of an analytic approach which involves interpretive and more structural traditions. As Somers notes:

'sociologists have attempted to recast social analysis along the central axes of the interaction between agency and structure, that is, to develop a social theory that allows for human action that is nonetheless bounded and constrained by structural restraints (Somers, 1994: 614).

Somers adds that narrative analysis allows this double focus. '*People's*' experiences are *inextricably interconnected with the larger matrix of relations that shape their lives... (and) Can only be understood according to their relational setting what Bourdieu would call habitus* (Somers, 1994: 626). Charmaz too, (1990) investigates chronic illness from theory which derives from a symbolic interactionist perspective, sensitised by the work of Mead and Schutz to explore themes and issues around 'the self' tempered by a more structural approach (Charmaz, 1990 : 1161-1162). Thus tackling how 'society *'impinges upon the individual and how individuals reproduce dominant ideas within society'* (Charmaz, 1990: 1161).

Like Riessman (2003), to whom I referred in some detail in Chapter Two, I apply Bourdieu's theory to my analysis, to demonstrate how the participants' accounts, are contextually based, and constrained by cultural and structural factors. In this way symbolic interactionist priorities blend with Bourdieu's theory as the narratives unfold. According to Bourdieu, narratives of the most personal troubles often reveal fundamental structural features of the social world. For instance, illness narratives feature common sense assumptions about behaviour drawing on a collective and historical stock of knowledge and experience (Schutz, 1971). Depending on our social positions we are pre-disposed to take certain actions. Such dispositions include the way we speak, use our

bodies, and spend our social lives. This is what Bourdieu terms the habitus, an '*acquired system of generative dispositions*' (Bourdieu 1977: 95). The habitus structures different social spheres or *fields*. For Bourdieu, society is a network of fields, for instance, the family, employment, and medicine, which have guiding principles of action associated with an individual's position. In the family gender roles are linked to particular social obligations, likewise in the field of medicine the status of doctor and patient are associated with behavioural norms. Fields are hierarchical, and positioning is based on an individual's ownership of volume and type of resources or assets, or what Bourdieu terms *capital*. Capital can mean any of the following: *economic capital* (money, or the means to accumulate money), *cultural capital* (relevant knowledge), *social capital* (relations with others which can be utilised in a range of ways) and *symbolic capital* (prestige and social honour). The body too can be a form of *physical capital* (the ability 'to do'). It is important to note that these are transferable.

Here I want to focus on Bourdieu's conceptualisation of the body as a form of *physical capital*; a possessor of power, status and distinctive symbolic forms which is integral to the accumulation of various resources, or capital, and contributes towards people's attempts to position themselves favourably in any given field, and be *distinct* from others. For the purposes of this discussion, I will focus on how ultimately the participants have revealed their concerns to position themselves favourably, and gain moral standing (*symbolic capital*) in their illness narratives as they attempt to construct positive images of self. Importantly, Bourdieu claims it is this need to construct oneself as different to, or to be distinct from others, which drives action.

The *production* of physical capital refers to the development of bodies in ways which are recognised as possessing value in social fields, while the *conversion* of physical capital refers to the translation of bodily participation in work, leisure and other fields into different forms of capital. Physical capital is most usually converted into economic capital (money, goods and services), and both of these can lead to the accumulation of cultural capital (for example, education and knowledge) and social capital (social networks which enable reciprocal calls to be made on the goods and services of its

members). Bourdieu views the management of the body as central to the acquisition of capital, status and distinction; '*Bourdieu is concerned with the body as a bearer of value*' in contemporary society (Shilling 2003:111). This is significant if bodies are sick, there is a loss of physical capital, and fewer opportunities to accumulate other types of capital.

From this perspective, we learn to do things with our bodies, which are seen as natural so in this sense the habitus is embodied. If people cannot manage their bodies 'appropriately', a core aspect of their identities is challenged (Shilling 2003:111). When people are no longer able to function in particular social spaces, or 'fields', they cannot adhere to shared values, or what Bourdieu calls '*doxic beliefs*', because of their bodies' inability to take part in activities, fulfil tasks and social obligations. This is particularly significant if, as Bourdieu claims, the need to distinguish oneself from others, and position oneself favourably, in the social hierarchy, is an essential part of the human condition: '*To exist within a social space, to occupy a point or to be an individual within a social space, is to differ, to be different...*' (Bourdieu, 1998: 9). He goes on to say that '*Difference becomes a sign and a sign of distinction (or vulgarity) only when others recognise the underlying principles of such difference*' (Bourdieu, 1998: 9). In this sense, there is a '*dominant aesthetic*', or idealised way of behaving based on shared assumptions. This encourages people to aspire to particular types of action and works as *symbolic violence*. People are induced to act in appropriate ways which offer them status, or symbolic value.

In the next section I will focus on how the participants talked about their personal experiences and constructed positive identities as: stoic individuals; self-managers; responsible patients and masculine and feminine identities in a range of social spaces, or fields, structured by the habitus. This illustrates how the deepest structures of the social world are present in the most personal narratives.

8.4 Constructing moral identities through illness narratives and the voice of the habitus

8.4.1 *'You just have to grin and bear it'*

My analysis revealed how the participants guided positive impressions of themselves through their accounts whilst relaying their 'sick bodies', often conveying disruption, loss, a diminished world and fractured selves. As a group of relatively young people with high levels of chronic illness they were concerned to display stoicism as they strove to overcome their illnesses and manage their 'normal' lives. Commonly, they noted how their attempts to '*carry on*' involved the risk of exacerbating symptoms and aggravating conditions.

These accounts of a determination to be positive in the face of illness drew on taken-for-granted notions about appropriate self-disciplined behaviour, and such talk was a way of avoiding being regarded as a 'malingerer' or a 'moaner'. This positive attitude was not openly contested, but reported as a 'natural' response, and positioned as the *dominant aesthetic*. This is an example of the *symbolic violence* which permeated the participants' accounts as they managed positive impressions of self. The form of the language underlines the common sense understandings. As Janet noted: *'You just can't lie down to it'; 'I have to keep on top of it'*. Such statements leave no rhetorical gap. The use of the impersonal second person and the imperative, illustrates the falsely 'natural' positive response to illness and the assumption that you have to just '*carry on*' (Betty). Applying a fine-grained analysis of the accounts pin-points how far such talk reaches beyond the personal experience and reveals core cultural structures. Informed by symbolic interactionism, the work of Goffman, and Bourdieu, the micro and macro are linked.

The participants used a range of rhetorical devices to draw the listener into their experiences and convince of their moral worth. For instance, they used a supporting cast, and direct speech. Ian described how people in his local community ask "*How can you have good spirits an' all when you've lost you' leg?*" He replies "*What do you want me to*

do... sit and mope?” This is a rhetorical question, allowing Ian to reveal and explain his stoic response to illness, as *‘just ma nature’*. Drawing on shared notions of idealised behaviour, Ian is able to manage a positive impression of self, but my analysis moves beyond Goffman and the interview. Ian conveys his personal troubles, but in so doing both reveals, and perpetuates the deep and generative structure of the habitus.

The participants described ‘talking’ as a management strategy, but noted a disinclination to disclose the extent of their problems to others; they conveyed their fears of projecting a negative image, and were anxious to resist the label of ‘moaner’. For example, Ian talks of how important it is to *‘keep cheery’*, whilst Betty has a *‘big cheesy grin’* in company, whilst inside she is *‘crying’*. Striving to be positively regarded by others drives such behaviour. As Jim notes *‘the last thing you want to hear is about somebody else’s aches and pains and depression’*. Common-sense assumptions about facing illness with stoicism, work as symbolic violence, and are another burden to face for those with multiple chronic illness.

Participants also discussed their resistance to taking symptomatic medications, particularly for pain and depression, to illustrate their moral fibre. They described taking such medicines as a last resort. This was not raised as a subject for discussion, but rather referenced as an obvious course of action, indicated in the form of the language used. For instance, Janet says *‘Who wants to be on medication for the rest of their life? I don’t’*. Again, the rhetorical question underscores the taken-for-granted ideas and attitudes which structure illness behaviour. Similarly, the form of Rita’s language reifies the moral thread suffusing the accounts. The use of the active voice juxtaposed with the passive voice works as part of her identity construction, whilst illustrating the negative connotations of certain drug use. She stresses how her doctor *‘put her on’* anti-depressants, but she *‘came off them’* herself. She emphasises her main point, using repetition and closes with *‘I got maself off them’*. Such unconscious and spontaneous use of language underpins, and underlines the deep seated cultural structures which inform the personal accounts.

The narratives of personal difficulties, contradictions and tensions also articulated deep seated values and shared notions of what the 50 year old body is 'fit' for in terms of activity and deportment. The participants revealed concerns about not 'being in their bodies' in 'appropriate' ways which led to ambivalence about management techniques. For instance, the practical utility of particular equipment was set against its symbolic significance. In a culture which places little value on ill and ageing bodies, for this group of relatively young participants, certain equipment or pacing strategies were a potent reminder of their inability to control their bodies and a sign of disruption, both in daily life and the 'natural' course of their lives.

In such a light the tensions of illness are magnified, the contradictions, and ambivalence voiced understandable. Using particular strategies was a tangible reminder of a lack of physical capital, and a flawed bodily habitus. For instance, June reports how despite her disability and her severe symptoms which mean she '*dreads going up the stairs*' she resists a stair lift because '*I mean it's ridiculous I'm only 52... do you know what I mean?*' This demonstrates that the habitus swamps the cognitive; June chooses being in the body in a familiar way and would rather 'struggle' up the stairs, than use a stair lift despite knowing that daily life could be less arduous and less painful. This is an important point, and has implications when attempting to understand self-management strategies for those with chronic illness.

8.4.2 '*Illness comes second to your family, you'll know being a mother yourself*'

As mentioned, according to Bourdieu, social groups tend to develop distinct orientations to their bodies which predispose them for particular activities and actions (but do not determine behaviour). People are 'in' their bodies differently, for example the notion of a *tom-boy* encapsulates how the habitus is embodied; expectations are placed on bodies to behave in particular ways, but there is always room for strategic manoeuvre, that is at times, 'girls will be boys'.

Bourdieu (1984) outlines how women use their bodies in relation to the habitus and field, maintaining that there are typical ways in which females (and males) develop orientations to their bodies in the family. In his research he found that wives undertook domestic responsibilities, and mothers sacrificed their own bodily needs (for rest, recreation and food) in order to fulfil those of their husbands and children. Such value based behaviour is, he claims, strongly marked by the need to be regarded as morally adequate and distinct. Furthermore, as narrative analysis has shown, the symbolic values attached to particular bodily actions become particularly important to many people's sense of self (Riessman, 2003).

There were clear examples of such gendered family behaviour in my study. For instance, as women discussed the meanings they applied to their symptoms, and how they perceived their position in the family, they conveyed frustration and guilt about their inability to undertake domestic obligations, and fulfil traditional domestic roles, and were likely to mention their partners' and children's needs as barriers to gaining practical and emotional support in the family. Their need to be cared for by family members was portrayed as a tangible reminder of their illness and conveyed as a challenge to their moral competence. They also discussed anxieties around how they felt they were neglecting, and being a burden to, their families as a result of their illness. This led to them perceiving the availability of resources in the family with ambivalence. For example, some noted how, when illness was pitted against being a mother, common-sense notions of a 'natural instinct' swamped their illness orientated needs and directed action.

The women who were frequent consulters in particular described how they were distressed and frustrated due to their inability to fulfil their caring roles. For example, they described struggling against the pain and distress of their symptoms in order to fulfil their mothering responsibilities. They talked about undertaking actions and activities despite the knowledge that they would exacerbate their symptoms, invite further suffering and risk long term damage. Rest may be a suitable strategy, but perceived as

inappropriate, due to taken-for-granted ideas about behaviour and a desire to maintain coherent identities.

For instance, Janet says *'Illness comes secondary to your family... as you'll probably know being a mother yourself'*. Such words highlight the inter-subjectivity of shared cultural assumptions. Similarly, Marie relates how her familial role trumped her aversion to anti-depressants. She could not bear her children seeing her unable to function, so took her medication. Later she adds how she recovered from her depression due to her children stating *'motherhood is naturism'*. Betty draws on aspects of her familiar self to fulfil her familial role as mother to explain how she manages domestic chores. She will do (housework) herself as she has *'always been a fighter'*; she adds *'I think it's a mum thing'*. In this way the women's personal struggles, frustrations and anxieties were tied to their perceptions of what it means to be a mother, and draws on deep-seated, taken-for-granted and shared notions about gendered behaviour in the family.

From this perspective, the close match between social position and disposition exerts pressure on women to function in certain ways in the family. This is an example of the falsely natural, or *'symbolic violence'* which exerts pressure on women to 'choose' to act in this way. For the women the inability to carry out their 'domestic duties', and the need to be cared for, was an added burden, which 'went against the grain' of the habitus.

In contrast, the men commonly described ways in which their wives cared for them. Their spouses helped with medication, arranged GP appointments, and took part in the consultations, as well as organising diets, and monitoring their illness related behaviour, such as pacing and consumption of medicines. It was interesting to note that such talk formed part of the men's positive identity construction, and was conveyed as illustrating how they were authentic and responsible patients. Moreover, typically the men spoke about this type of care in routine ways, noting that their wives supported and helped them, but they fell short of articulating guilt, or anxieties of being a burden.

However, there were particular family behaviours which were deemed as 'natural' for men. Peter says of maintenance *'Obviously when you've got a family to look after there are always things that you do... I would never get somebody in to decorate the house'*. Again the form of the language, for example the use of *'obviously'* and the use of the impersonal *'you'*, reveals the *'falsely obvious'* structuring organising principles of the habitus in the field of the family. The crux is that the male *'sick body'* and the female *'sick body'* are positioned differently in the family, and this is an added burden for women in both practical and symbolic ways.

8.4.3 *'If I didnae have work what would I be?'*

An important way in which the participants composed positive identities was how they made claims about being responsible workers. Being at work symbolised one's ability to control illness and the body, and was a tangible way of displaying a stoic attitude. The less frequent consulters were able to draw on their current employment as part of their narratives of self, whilst the frequent consulters were not. Yet they were able to resolve such a contradiction. They described how they *had been* keen and ambitious workers, but forced out of work by illness. In this way they drew on the past to manage a positive presentation of self. Therefore, a particular work ethic ran through the accounts. Whilst the less frequent consulters said how they were *'lucky'* to work, and *'it (work) keeps me going'* (Martha), the frequent consulters noted *'It's 'very hard', 'if I could work I would work full time'* (Betty). In this way close analysis of the interviews revealed shifting identities, alongside coherent selves. Fundamentally, those who talked about their changed employment status still presented themselves, paradoxically, as responsible workers revealing that personal accounts are embedded in role obligations.

Before moving on, it is interesting to note the lack of the male participants' talk around unemployment. As accounts emerge from social contexts, we need to ask why people say some things, and remain silent about others. Only one of the male frequent consulters (Jim. 4.2.3), talked extensively about how illness impacted on his unemployment status (they were all unemployed). This could have been because it lacked significance. Or it

could have been because male accounts of unemployment make it difficult to draw on shared assumptions about the masculine family role, and build positive identities. What makes this particularly interesting is that the women who were frequent consulters elaborated about the sense of loss they felt as a result of being unemployed due to illness. I would suggest that one reason for this could be that the women did not feel that being unemployed was a fundamental threat to their feminine identities. However, it was clear from Jim's account that his work status was an important feature of his masculine identity. Jim talked extensively about not working, and his longest uninterrupted 'talk' in the interview was about authenticating his unemployment status, explicitly relating it to an accident at work. I would suggest that this is an example of accounts being historically, socially, and culturally specific. Silences have meaning too. Any consideration of what is spoken, invites consideration of what remains unsaid.

The accounts around illness and employment were clearly informed by the broader objective structures of the social world, for example, participants' location in the job market. Radley (1989) describes how individuals respond to illness in different ways, and stresses how structural organisation impacts on how one adjusts to illness. To reiterate what Radley says: *'becoming chronically ill does not remove one from society; if anything it amplifies one's position in it, so that what people adjust with is as important a matter as what people adjust to'* (Radley, 1989: 243). The significance and meaning of symptoms can vary depending on the context, and the ways one is able to respond. To link Radley's point to the study data, those who described experiencing debilitating pain, relayed how their 'styles of adjustment' varied according to their positions in the employment market.

My analysis showed that the social location of the consulters impacted on their ability to continue in paid employment in a range of ways. For example, depending on the type of work, and how it was structured, symptoms had more or less impact. The less frequent consulters described their employment situation as running alongside their illness. They described how particular arrangements at work, and in the home, meant that they could remain at work. For instance, there was talk of practical and emotional help and support

at home, and work which, combined with other resources and strategies, made paid employment possible (Johnnie, LFC). Others said they juggled their illness around part-time and flexible hours (Marie, LFC). Some noted the nature of their employment was pivotal, in that it enabled them to balance work tasks and days alongside coping and management strategies, as well as complex medication regimens (Peter, LFC). Others described their employment as *'the only job'* they could do (Paul, LFC), whilst commenting more manual work would render them unemployed. As such, the less frequent consulters conveyed how their bodies had value - physical capital - which could be exchanged for economic capital, which afforded them a range of gains which they noted both implicitly and explicitly as aiding illness management.

Specifically the less frequent consulters described some of the material and economic benefits of being in employment which they noted had both practical and emotional benefits. Overall, they claimed a comfortable material and economic situation cushioned the impact of their symptoms. They communicated how enjoying leisure activities, owning a 'nice home', having dinner with friends, playing sport, and having disposable cash all added to feelings of well-being, which they felt equipped them with the means to face illness with more equanimity. They could manage the wearing, ongoing pain and other debilitating symptoms; they could work hard at juggling daily life around management strategies, when they had areas of their life which they could enjoy, and things they could afford that offered them respite from their illnesses. In other words, to use Radley's conceptualisation, their social location offered them different 'styles of adjusting' to illness; the personal experience of managing similar types of symptoms was mediated through broader organisational concerns. In this way, people in paid work were able to *'do illness differently'*. As Riessman points out: *'Important social structures are deeply embedded in the illness narratives, an interpretation that moves beyond Goffman's idea of the performative'* (Riessman, 2003: 22).

Furthermore, the less frequent consulters were able to exchange physical capital for economic capital, which in turn could be reinvested in the body. They could also exchange it for social capital. By this I mean, they had access to a wider social circle in

two main ways. First, they were working, which meant they mixed with work colleagues, some of whom helped with symptoms, and some of whom were a source of company outside of work. They were also likely to socialise and undertake a range of activities, and described a wider circle of friends to whom they might chat, or close friends in whom they could confide. Fundamentally, their bodies allowed them to mix with others. This led to accumulating cultural capital, for instance gaining knowledge about illness and treatments. They were also able to share their experience with others; ‘everyone has something wrong with them’. All of this combined to form symbolic capital. They *are* part of the adult community, with aches and pains like anybody else, working, socialising and coping. In a society which places value on work, activity, having friends, staying healthy, and managing illness when one experiences it, all of these aspects combined to bolster self-worth. Thus the less frequent consulters were able to display an accumulation of capital, based in the physical, extending to the social, the cultural and the symbolic. In the narratives they were able to open up a gap between themselves and (sick) others, and in so doing gain moral standing.

In contrast, the frequent consulters had lost the ability to function in the workplace. Their ‘sick bodies’ had lost value, their physical capital had waned; they lacked the ability for capital exchange, most obviously economic, but also social, cultural and symbolic (status and prestige). Social networks were limited, and this had consequences for cultural capital; they had fewer people to talk to, confide in, and gain information from in order to help them manage their symptoms. They had few people to ask advice informally, and expressed an aversion to taking advice from more formal sources, for example alternative practitioners, or chemists. They had few opportunities to gain support from a range of people as their movements outside of the home were constrained. Because of their diminished lives they were unable to convert capital from one field to another. So, the frequent consulters had fewer practical and symbolic resources on which to draw.

As mentioned in the Introduction, this thesis emerged from an analysis of survey data which revealed a substantial amount of variation in consulting rates beyond the burden of morbidity (Wyke et al., 2003). I noted how quantitative studies revealed consulting as a

complex process, primarily linked to levels of morbidity, but associated with variables such as socio-economic status and gender. I also reported how 'frequent consulters' have been identified as having multi-dimensional health needs; they suffer from a disproportionate level of illness alongside other social problems (Gill and Sharpe, 1999). This qualitative investigation aimed to illuminate the role of the GP consultation in the context of the lived experience of multiple chronic illness and so gain a fuller understanding of the consulting process.

Following the quantitative evidence, this thesis underscores burden of morbidity as a major reason for consulting, in the context of other factors. Throughout the analysis and interpretation, the frequent consulters conveyed more illness than the less frequent consulters, and showed that severity of condition(s) *combined with*, the participant's 'relational setting' (personal, biographical, structural, social and cultural position) influenced decisions to consult. Such qualitative findings sit comfortably with the quantitative results (Wyke et al., 2003; Gill and Sharpe, 1999). Beyond this, the substantial amount of variation in consulting behaviour identified by Wyke and colleagues remains unexplained, as dimensions which I was unable to explore with this study design; although participants were selected based on number of self-reported conditions, level of severity and impairment was not part of the selection criteria. It is possible that, the frequent consulting group experienced such extreme conditions that 'relational setting' although indicated, was not as significant as it may be for those with less severe illness.

However, this qualitative study has illuminated the lived experience of chronic illness and consulting. With the benefit of in-depth analyses and Bourdieu's theory, it has offered a fuller understanding of the consulting complexities which the quantitative evidence revealed. The ways in which cultural and structural factors interweave with one's personal situation to influence consulting behaviour has been delineated and explored. By applying Bourdieu's concepts (capital, habitus, field and symbolic violence) alongside a narrative approach, the range of variables identified by quantitative analyses are conceptualised as a dynamic matrix which influences (consulting) experience and action.

Beyond this, by seeing individuals as embedded in social spaces rather than as stable categories, this thesis has illustrated, that, for example, to term people 'renters' or 'owners' does not allow for multi-dimensional experiences of multiple positionings. Thus, it is unsurprising that socio-economic status as a variable (measured by housing status) was not an indicator of action. Likewise, gender *in itself* as a categorical classification does not determine action. However, as one strand of identity worked out in multiple social spaces it places one '*in a matrix of narratives and relationships*' (Somers, 1994: 632), or what Bourdieu would term 'habitus', and, interweaves with the physical, biographical, social, cultural and situational position to affect consulting action.

So, severity of condition can be seen as part of a dynamic matrix, in which consulting action is worked out, actively by individuals as they attempt to maintain a normal life, and their moral identity. The participants conveyed the GP consultation as having a pivotal (frequent consulters) or peripheral (less frequent consulters) role respectively. Although no data were generated from the GPs' perspective, the active role of the GP must be considered when assessing how experiences of the GP consultation might affect consultation frequency. For example, the reported accounts of what happens in the surgery (the frequent consulters more positive, the less frequent consulters more critical) might reflect an external reality, and could implicitly influence decisions to consult. In turn, this could be linked to the frequent consulters' GPs managing patient needs 'appropriately'. In the context of an over-burdened and under-resourced welfare state, the physicians may position the less frequent consulters as less 'worthy' of their time, perceiving their physical needs as less, and their access to resources as greater than the frequent consulters. The GPs may also recognise their inability to help with particular sorts of diffuse symptoms, which the less frequent consulters often described. However, perhaps making this explanation less plausible, the less frequent consulters described how negative experiences of 'their GP', led them to consult another doctor in the surgery, rather than resist the medical meeting.

The accounts of the frequent consulters positioned the GP consultation as a crucial resource in their overall management strategies. In the context of severe illness, and a

diminishing life-world, and limited resources, the role of the GP is magnified for this group. In their attempts to control illness, limit loss and avoid disruption, the GP consultation offers practical and moral benefits. Following this, I now apply Bourdieu's theory and discuss how the GP can be conceptualised as a dispenser of capital.

8.5 'I could sit and talk to my doctor... (he) gets it done':

The GP as dispenser of capital

The participants continued to build their positive identities as they described their consultation behaviour. They discussed seeing their GP as a last resort. Having established that they only go to the GP when they really have to, they then offered very specific guidelines to consulting behaviour. Thus, their coherent moral identities remained unchallenged. Using supporting casts they distinguished themselves from other less discriminating users of the GP. For instance, Betty referred to generalised others; people who *'go at the drop of a hat...and others would leave it for years'*. Again, the personal experience of illness is informed by broader structural constraints. As Lesley remarks *'you cannae just phone the doctor...constant'*. In terms of moral adequacy they construct themselves as skilled, reflexively monitoring and knowing when to consult. This illustrates symbolic violence; there is a shared assumption of ideal behaviour; 'it goes without saying' that people use the GP judiciously; in building moral identity, idealised behaviours are invoked.

Much of this thesis has been characterised by participants' building positive identities and legitimating action. Participants' accounts featured concerns to be seen as legitimate patients, individuals who make an authentic claim on the GP whom they are careful to construct as a 'last resort' in the project of their illness management. The GP has been positioned as someone who offers symptom relief and condition control, but who also can validate the participant's claims to be ill, and by extension legitimate their inactivity. Indeed the frequent consulters spoke of the close relationship with their GP which positioned them as responsible and valid patients, whilst the less frequent consulters were more likely to note that their integrity was challenged by their GPs who often failed to

legitimate their illness claims, or offer relief. With this in mind, and using Bourdieu's concepts, the GP consultation has been constructed as a site in which physical and symbolic capital can be offered (or not), and exchanged for other forms of capital.

According to Bourdieu, doctors are amongst those with particular power in specific fields to administer statements about the body (Shilling, 2003: 126). As 'authorities on the body' they are well placed to label as deviant, or legitimate, ways of managing and experiencing bodies. This theory adds credence to the findings in the sense that it underscores the narrative analysis themes. The participants were eager to construct themselves as morally adequate and the GP had a significant role because of the power of the 'medical voice'. Furthermore, talk described in Chapter Six around seeing the GP invokes the subjective, moral agent. Not only did the participants share a view that the GP should be used sparingly (a measure of the force of the habitus in the medical field) but also they went to the GP for very particular reasons. Those who were frequent consulters were experiencing a deficit of capital, and consulted the GP if they anticipated a positive outcome. Such contact was conveyed as a crucial resource on which to draw in order to maximise their opportunities to live a 'normal' life. To this end the participants described how the GP consultation offered benefits, or in Bourdieu's terms, ways of bolstering *capital (physical, economic, social, cultural and symbolic)*.

First, the participants described consulting to help maintain or regain bodily control, typically, to gain access to treatment to ease symptoms, stabilise conditions and aid functional ability (physical capital). For example, participants described consulting the GP in order to gain control of conditions such as high blood pressure, and ease symptoms such as pain. The GP was consulted if the participant anticipated they would gain treatment in the way of medication, examinations and referrals that would enable them to gain tangible *physical* benefits.

Second, the accounts revealed that people strove to manage illness in order to continue to function 'normally', and live their familiar daily lives. For the less frequent consulters, paid employment was central, and they noted times in the past when they had consulted,

due to a crisis, when their functional incapacity was such that they felt they might no longer be able to work. This induced them to consult the GP. The frequent consulters though, were no longer in paid employment. However, one of this group noted consulting the GP, not for treatment, but purely for sick lines, whilst another was in the process of gaining long term disability status and benefits via her GP. For both groups then the GP was positioned as one who could either give them treatment and enable them to return to *economic* activity, or gain economic benefits in terms of validating illness status. The women frequent consulters also discussed consulting the GP to enable them to continue to offer *services* in the household, such as caring and other domestic roles, which can be regarded as economic activity.

Third, benefits offered by the GP consultation extended to the *social*. If one's body worked, then it was possible to go out, to mix, and to 'do things'. The frequent consulters, who could no longer work due to illness, who had time to spare, wanted to do such things. They described GP consultations, both implicitly and explicitly as offering them the opportunity to be a member of the local community, or a functioning member of social networks. Moreover, they also noted how GP consultations were sometimes needed as a result of them 'overdoing things', as they attempted to fulfil social roles and obligations. In this sense then, in a restricted world, with a limited network, the GP offered the 'hope' of an improved social life, and the possibility of fulfilling social roles.

Fourth, the participants described gaining information, knowledge, and advice from their GPs, and saw this as an important part of their illness management project. They also valued investigations, examinations and referrals in order to get to the '*nitty gritty*' of what was wrong, in order that they might know how to put things 'right'. They wanted discussions. The frequent consulters' accounts featured such consultations. In the light of them being apprehensive about using over the counter medications and alternative therapies, as well as living limited social lives and having less access to lay information about self-management, the GP played a crucial role in furnishing them with (*cultural*) knowledge.

Fifth, the frequent consulter accounts conveyed how the GP not only offered them tangible benefits, but how the consultation also had *symbolic* significance. The GP was referred to as attending to their needs as individuals, not simply as patients with 'diseases'. He/she provided emotional support, offered hope, eased frustration and distress, and sometimes an ability to function more 'normally' in society, in their family, and amongst their friends. The consultation also worked as a way to legitimate them as deserving, responsible patients who faced their illness with stoicism. The accounts showed how their integrity was reaffirmed in the consultation, particularly important when, in so many other areas of their life, they faced challenges to their moral identities and sense of self. Thus, for the frequent consulters who faced particular disruptions to their lives and identities, the GP offered a way of limiting the effects of illness and maintaining a coherent self.

Furthermore, the frequent consulters described the GP as legitimising the ways in which they used their bodies. In this way their accounts yielded them as authentic; bodily practices were legitimised, that is, inactivity in a number of spheres (for example paid employment and the domestic sphere) was presented as valid. Participants described GPs advising them to rest, to resist their domestic responsibilities, and conserve their energy. They also relayed how GPs offered sick notes which again validated their inactivity in the field of employment. In this way the GP was located in the accounts as one who legitimised their ill status, with its accompanying limited behaviour.

If, as Bourdieu claims, difference becomes a sign of distinction or vulgarity, then it is not surprising, in a world which devalues sick bodies, that the GP plays an important role in the lives of the frequent consulters. Neither is it surprising, that the GP is pivotal in their illness narratives as they construct their distinct, coherent moral selves. In this case then, the GP can be seen as a *dispenser of capital*.

Overall, the ability to control the body, and function in social roles, gives one status. The body is bearer of a shared set of values, as Martha remarked: *'I don't let my illness get me down, I'm better than that'* (LFC). This is literally the embodiment of distinction. If

ability to remain active in the face of illness is an important structuring principle in the competition between groups, this sheds light on why the talk was suffused with a desire to construct oneself as stoic, and responsibly managing illness, displaying a difference to, and distinction from, others, who may *'give in'*, or consult the GP *'at the drop of a hat'*. It explains why the participants were so concerned to legitimate their use of medication and the GP services so clearly. This was a way of building their moral identities in the face of threats to it. This is a particularly salient point for this group of consulters who are relatively young to have such high levels of multiple illness. Narrative analysis, informed by symbolic interactionist concerns of 'the self', combined with the structural approach of Bourdieu, illuminated participant use of the GP consultation. It was revealed as part of a reflexive project of the body, the site of 'distinction', or moral adequacy, rather than a passive response to symptoms and medical power; an interpretive, active strategy which is informed by the habitus. From this perspective, for the frequent consulters, the GP consultation offers one way, in a diminished world to gain practical and symbolic benefits.

8.6 Policy and practice implications

In the introductory chapter, I made reference to the policy context of this thesis. I noted how, due to the shift from acute to chronic illness, concerns have been raised about the efficiency of health care, and there is a need for knowledge about how people with chronic and multiple illness use the health service, particularly primary care. Although there are wide ranging concerns, and this thesis could be related in a number of ways to policy implications, I will identify four main points of interest in relation to recent policy concerns: the doctor/patient relationship and the concept of concordance; the practical burden of work involved for those who have chronic illness; the symbolic burden of bearing such illness; and the broader structural contingencies which inform the illness experience.

To recap, I noted two initiatives in the Introduction. First, the 'Innovative Care for Chronic Conditions' document (World Health Organisation, 2001) highlights problems

which require multi-dimensional solutions. This paper looks beyond the medical model, to solutions which attempt to sustain quality of life in the face of ongoing illness. Its focus is two-fold: *'appropriate policies and programmes can vastly reduce the weight of burden in terms of human suffering and economic loss'* (World Health Organisation, 2001: iv). A major strand is patient adherence to innovations, and the ways in which patient education for self-care simultaneously reduces use of health services, and health service expenditure. It offers some solutions, for example improved support for self-management, and more effective delivery of health services to those with chronic illness.

I also identified the Expert Patient programme introduced by the Department of Health in England (2001) (an idea which developed in the Government's 1999 White Paper, *Saving Lives: Our Healthier Nation*), which advocated that the health service provides care in which the patient will be actively involved. The underpinning philosophy is that this innovation will increase skills, confidence, and motivation of patients and enable them to take greater responsibility for their illness management, based on a reciprocal relationship with health professionals, who need to be sensitive to the social, as well as the medical profile of the patient. The paper is informed by user-led self-management programmes, which move beyond the medical view, and appreciate how illness impacts on daily life (Lorig and Holman 1989). This programme aims to develop the patient's knowledge of his or her condition to a level whereby *'self-management, within the boundaries of a medical regime'*, becomes a real option (DH, 2001: 6).

More recently, *'Self Care – A Real Choice'* (DH, 2005) highlights the importance of supporting those with long term conditions, its underpinning philosophy to *'empower patients to take more control of their lives'* (DH, 2005: 1). Distinguishing between different types of self-care, this paper reports that a priority for the NHS over the next 5 years will be the *'care of long-term conditions, improved access and patient experience together with greater choice and personalisation of care'* (DH, 2005: 4). It argues that with the right support people can learn to be active participants in improving existing symptoms, avoiding flare-ups, slowing deterioration and preventing development of complications and other conditions. This paper notes that self-care is consistent with the

policy of patient first in health delivery, and reports that *'Individual involvement and empowerment are now key to NHS and social care delivery'* (DH, 2005: 4). Again, it notes the increased incidence of long-term conditions presents a major challenge to the NHS, and reports that improved self-care can have a significant impact on demand for professional services.

Two core messages are pin-pointed in concerns around care of chronic illness in these recent policy documents. Fundamentally, more patient involvement leads to a better quality of life for the individual and simultaneously eases the burden of care on an already under-resourced NHS. The nub is, how far is it feasible to suggest that practitioners and users can have a reciprocal relationship which values the decisions of both equally, taking account of daily life, within a National Health framework, based on informative, non-judgemental, discussions and decisions, about the conditions and symptoms, and how people live their lives and manage chronic illness.

The concept of concordance underpins a relationship between professionals and lay people, characterised by discussion based on shared knowledge, experience and information of equal status. So, concordance can be seen as a way to give power to the patient. However, it has been criticised as a potential strategy to induce compliant behaviour under the guise of a balanced relationship. As Armstrong points out, the title from the UK House of commons All-party Pharmacy Group, *'Concordance and wasted medicines'* illustrates the key message; another route to adherence (Armstrong, 2005). So, it is important to at least recognise the possibility of concordance as being a rhetorical rather than a practical device.

It is hard to imagine a scenario in which the voice of the professional and that of the lay person have equal standing, in the context of conflicting knowledge, experience and limited resources. Health policy is designed to support self-management, but individuals need access to care as is appropriate to them in the context of their daily lives. This may mean professionals recognising, in a non-judgemental and supportive way, seemingly irrational and irresponsible actions, which are logical and appropriate for the individual in

the context of their daily lives. A problem is that although a lay person may welcome discussion and advice from medical practitioners, their input may be coloured by personal preferred views, and knowledge of budgetary constraints. Furthermore, whilst the consultation may ostensibly be based on shared decision-making, and more patient involvement, it may in practice invite less frank discussion (Stevenson and Scambler, 2005). Also there needs to be an acknowledgement of the limits of medicine, which may more usually be manifested as an implicit criticism of the individual who has diffuse symptoms, and undiagnosed conditions.

People need to be able to feel that their views are taken seriously; to not feel judged but genuinely supported. This was apparent in the participants' accounts in my study. Health policy is designed to support self-management, but individuals need access to care as is appropriate to them in the context of their daily lives. This means practitioners recognising patients as active agents, taking responsibility for their health, and, as Peter commented, *'giving them credit for what they know'*. This is particularly relevant to Bourdieu's theory of the habitus. In this case the habitus speaks louder than words. The structural position of health workers means they may well have different interests and views which are equally correct from their point of view. The problem is that, offering discussion will not automatically accomplish genuine shared decision-making. Furthermore, some individuals may be more adept at presenting their views than others, they might be privy to a greater range of information, and be able to articulate their needs and wants successfully. Others may not enjoy such resourcefulness. Patient choice and responsibility may perpetuate and accentuate current inequalities, and the most disadvantaged may become more disenfranchised than they are at present. Furthermore, shifting the 'frontline of care' to the family, may move the burden of care and responsibility onto women.

One problem which potentially stands in the way of a genuine concordant relationship is that the impact of illness and the management of illness interweave. As was revealed in my analysis, doing things more slowly or not doing them at all, are both impacts of illness, whilst pacing and changing lifestyles are management strategies. Further,

maintaining coherent identities may involve actions and activities which exacerbate symptoms and conditions. Tackling such contradictions will be hard indeed, contradictions are likely to characterise such information sharing between people who may at times have competing goals and perspectives. My findings revealed that individuals experienced tensions, ambivalence and contradictions when deciding what actions to take as they attempted to live with chronic illness manage their symptoms and maintain salient identities. Health workers may feel that some decisions made by patients as they attempt to live with chronic illness 'go against the grain' of medical knowledge. Whilst for the patient, the habitus (of for example the family), might speak louder than the words of not only the practitioner, but their own cognition. Such inherent contradictions in, and barriers to concordance, need to be addressed.

Further, the language used in the recent policy is inclined towards an adherence or a compliance model, if we take concordance to mean a discussion between people, rather than whether or not the patient agrees with the advice of the professional. For example whilst offering empowerment, the language used in the Self-care policy fails to address the hard work people already do to manage chronic illness. Also, at times the paper implies the passive patient, who is given advice about behaviour and medicines (DH, 2005: 4), rather than an active individual contributing to discussions and offering valued knowledge; such positioning suggests the models of adherence and compliance, not concordance.

It is important to note the difficulties and struggles that are part of the reflexive chronic illness experience, and part of the practical and emotional work involved with juggling daily life around multiple chronic illness. Decisions about taking routine actions, undertaking activities, fulfilling social obligations, and functional roles, all combine with decisions around complex medication regimens, what strategies to take, such as pacing, and which resources to use, such as the GP. Integral to the whole experience is trying to maintain 'a sense of normality', resist disruption, and sustain a coherent moral identity in the face of challenges to it. Managing illness is a moral responsibility being careful to project a positive image and avoiding becoming a burden to others are also part of the

ongoing and complex chronic illness experience. All of this needs to be addressed by policy initiatives, which currently offer promises of professional intervention which can help *'With the right support people can be empowered and learn to be active participants in improving existing symptoms, avoiding flare-ups, slowing deterioration & preventing development of complications and other developments'* (DH, 2005: 4). Crucially, what my findings show is that people are working hard at active self-management already, and convey that whilst they recognise *sensible* behaviour, there are times when they get ground down, and lose the will to be careful, as Betty says, she knows she's *'being daft'* when she wants to *'carry on'*, but sometimes she just wants *'to rebel'*, she wants *'to shout'*, she wants *'to scream'*. In such words are revealed the ongoing emotional work associated with the self-management of chronic illness, with which policy needs to engage, and practice must allow for, not in a condescending and patronising way, but as a feature of a truly concordant relationship between health worker and lay person.

The problem with not always being sensible is that there is a risk of exacerbating illness. 'Responsible' patients need to avoid risky behaviours, to not risk deterioration, or invite negative labels. Brandt notes that illness has become defined *'as a failure to take appropriate precautions against publicly specified risks, a failure of individual control, a lack of self-discipline, an intrinsic moral failing'* (Brandt, 1997: 57). As Galvin points out behaviours, attitudes and lifestyles become the focus of professional attention, and self-monitoring part of the reflexive process: *'Monitoring magnifies the sense of responsibility that people feel when they do 'succumb' to illness'* (2002: 122). This was borne out in the participants' accounts, which revealed an important characteristic of being an 'appropriate' patient was careful and constant monitoring, not only to prevent deterioration, but to practice appropriate consulting behaviour, and judicious use of the health services. Participants conveyed concerns to legitimate their use of the GP, despite having high levels of illness. Failure to be seen as independent, hard-working, autonomous and self-reliant was tantamount to admitting a moral failure.

For policy makers it is important to be aware that chronic illness and its management carries with it the burden of culpability and moral responsibility in the face of ongoing

problems, and often medical knowledge and expertise offers no solution and little respite. In this context it is important to move away from the notion that those with chronic illness can select a healthier option and improved quality of life by simply following professional advice. The implication is that if people cannot self-manage, then they are largely to be responsible for the consequences.

Such policy is in danger of suggesting that people can take medication, change lifestyles, and monitor behaviour with appropriate support from professionals, whilst neglecting to address fully how the social location of individuals combines with the nature and severity of symptoms and conditions, to impact on 'successful' self-management and use of health services in general and the general practitioner in particular. As Radley (1989) noted it's not so much what or how you manage, but what you manage with, or what he terms 'styles of adjustment' which needs to be engaged with. As my findings revealed, people who have multiple chronic illness are often unemployed and have limited economic and material resources as well as depleted social lives, so have fewer resources on which to draw to manage their illness.

Overall, burdens of being seen as an inappropriate, and irresponsible user, should not be underestimated. The idea that health and illness are matters of personal responsibility is not a new one. With the increasing prevalence of chronic illness, the culture of individual responsibility and the policy context of an already overburdened and under-resourced National Health Service, the pressures on those with chronic illness to be seen to manage are clear. A narrative informed analysis, using the theory of Bourdieu, offers three things. First, it highlights the ways in which illness is a moral and emotional burden, as well as physically and socially debilitating. Second, it shows how active individuals who work hard at managing their illness are constrained by cultural and structural factors. Third it aids an understanding of the role of the GP consultation in the overall management strategies of those with chronic illness.

8.7 Conclusions

In this thesis I have investigated how people with multiple chronic illness, and contrasting consulting rates, manage their illnesses and make use of the general practitioner consultation in primary care. I addressed this aim by examining three key research questions on which I reported at the start of this chapter. I then applied broader theory to my analysis to aid conceptual clarity, and external validity. I make six main conclusions.

First, the analysis revealed that the frequent consulters described more illness; they described more severe symptoms, greater functional impairment, less control over their bodies and lives, and faced more disruption and loss than the less frequent consulters. Linked to their bodily impairment, they enjoyed fewer resources, and were less able to mobilise a variety of strategies to help them manage. Fundamentally, and on a number of interconnecting levels, they were 'worse off' than the less frequent consulters. In such a context, the severity of their conditions *combined with* their 'relational setting' placed the GP consultation as a central resource on which they could draw, to gain practical and symbolic support. It is crucial to point out that, this group of frequent consulters have severe levels of illness which *may* not reflect other frequent consulting groups. The degree of severity which they describe may confound the influence of other factors which were identified and investigated as contributing to the consulting experience in both direct and indirect ways.

Second, this thesis highlights the importance of recognising people often experience multiple health problems in daily life; a situation which engenders particular problems including for example, managing complex medication regimens, and dealing with a range of symptoms. However, the participants described varied experiences of living with multiple chronic illness. Beyond the different levels of severity between groups, there were also differences within groups; some identified one main condition with debilitating symptoms alongside a number of unrelated less troublesome health problems; some described one main condition with related and problematic co-morbidities; some had a

combination of conditions and associated symptoms which combined equally to complicate their overall situation. Thus, whilst it is appropriate to try to gain a fuller understanding of living with chronic illness by exploring multiple morbidities, and considering individuals' shared core experiences, it is also important not to categorise 'multiple chronic illness' in a one dimensional way which misses the complex interplay of a combination of different types, and varying levels of illness, and the dilemmas of associated management strategies in daily life.

Third, the accounts of the consultation process illustrated the frequent and less frequent consulters shared the same notions of an ideal medical encounter. However, the frequent consulters indicated a positive relationship with 'their GP', whilst the less frequent consulters were more critical of 'their GP', and reported negotiating appointments to see favoured physicians. How far this evaluation directly affected their consulting behaviour is uncertain, but it gives a clear indication of valued aspects of the patient-doctor relationship, which concords with recent policy innovations.

Fourth, using stable categorical classifications to understand consulting experience is unhelpful. Instead, individuals should be seen as occupying multiple positions in a dynamic matrix where illness is experienced and actions taken. In this thesis, using housing status as a proxy for class was a crude way of investigating the influence of social class characteristics on illness and consulting experience, and produced no findings. A more robust measure of class might have generated different results, but would have still been inadequate. However, gendered experiences were revealed. Gender was conceptualised, not as a stable category but as an aspect of identity which, combined with other structural, cultural, biographical, social and personal factors, positioned men and women in a 'relational setting', (Somers, 1994) or in Bourdieu's terms a 'habitus'. For example, the women, participants, tended to talk about their familial roles and identities in ways which influenced their consulting actions, in ways which the men did not. Overall, Bourdieu's theory allowed an analysis which highlights the ways in which habitus may swamp cognition. In other words, Bourdieu's theory reveals how personal

experiences are informed by deep-seated cultural and structural contingencies, and illustrates the link between personal troubles and public matters.

Fifth, the accounts relayed that the experience of living with multiple chronic illness involves hard practical and moral work. Throughout the interviews, the participants felt compelled to build their positive identities, and construct themselves as stoic, appropriate users of scarce medical services, hard workers and good parents; overall they were compelled to display their moral competence, illustrating the burden of morbidity extends beyond the physical to the symbolic.

Finally, although a study based on a sample of 23 is limited in terms of making general statements, I would argue that it does have implications for policy. Recognising *the hard practical and moral work* that this group of frequent and less frequent consulters undertake, and informed by broader sociological theory, there is no reason to believe that such a group is an anomaly, in this respect. Policies which fail to acknowledge the hard work which people do to manage illness, *irrespective of their consulting patterns*, may hinder a close working relationship between patient and practitioner. Further, the patient-practitioner relationship needs to engage with the importance of managing 'normal' life *over and above* managing chronic illness. If policy to promote self-management fails to recognise the lived experience of chronic illness then practitioners may undermine rather than support lay people, which could be detrimental for both individuals, and ultimately for the healthcare system.

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Appendices

Appendix A Paper: Managing multiple morbidity in mid-life: a qualitative study

Managing multiple morbidity in mid-life: a qualitative study of attitudes to drug use

Anne Townsend, Kate Hunt, Sally Wyke

Abstract

Objective To examine attitudes towards drug use among middle aged respondents with high levels of chronic morbidity.

Design Qualitative study with detailed interviews.
Setting West of Scotland.

Participants 23 men and women aged about 50 years with four or more chronic illnesses.

Main outcome measure Participants' feelings about long term use of drugs to manage chronic multiple morbidity.

Results Drugs occupied a central place in the way people managed their comorbidities. Respondents expressed an aversion to taking drugs, despite acknowledging that they depended on drugs to live as "normal" a life as possible. Respondents expressed ambivalence to their drugs in various ways. Firstly, they adopted both regular and more flexible regimens and might adhere to a regular regimen in treating one condition (such as hypertension) while adopting a flexible regimen in relation to others, in response to their experience of symptoms or varying demands of their daily life. Secondly, they expressed reluctance to take drugs, but an inability to be free of them. Thirdly, drugs both facilitated performance of social roles and served as evidence of an inability to perform such roles.
Conclusions Insight into the considerable tension experienced by people managing complex drug regimens to manage multiple chronic illness may help medical carers to support self care practices among patients and to optimise concordance in their use of prescribed drugs.

Introduction

About half of the drugs prescribed for patients with long term conditions are not taken as prescribed.¹ However, few studies of users' views of drugs have been published. Those that have, focus on people with specific conditions, or on samples recruited through general practice. What is missing is the perspective of people with long term multiple morbidity. This is important given that such patients receive a battery of different drugs to manage their conditions, account for a substantial amount of health service use, and can present general practitioners with particular problems in the management of comorbidity.² We report on attitudes to drug use among middle aged patients with multiple chronic conditions.

Participants and methods

This research formed part of a wider study on the experience and management of illness among people with multiple morbidity. Our study sample comprised respondents purposively selected from the west of Scotland twenty-07 study.^{3,4} This is an ongoing longitudinal study in which respondents have completed interviews

at five-yearly intervals since 1987-8. Analysis of data collected in 1995-6 showed that, although reported morbidity and symptoms accounted for about a third of the variation in general practitioner consultations, much remained unexplained even after taking account of other factors.^{5,6} In order to explore this further we conducted a qualitative study with people (born in the early 1950s) who reported high morbidity (four or more chronic conditions) in the interviews in 2000-2.

Data collection

Forty one respondents who fulfilled our morbidity and consultation criteria were invited to take part in this additional qualitative study. We explained that this would involve two interviews, about three weeks apart, and the completion of a symptom diary for two weeks between the interviews. Twenty three people (13 women, 10 men) participated, 20 of whom took part in two interviews. AT conducted the interviews between October 2001 and July 2002.

Interviews were semi-structured. The first interview consisted of three overlapping sections—conditions and symptoms, the impact of conditions on daily life, and the use of formal services. The second interview allowed greater focus on management of symptoms (which had been recorded on a daily basis in a symptom diary for 15 of the respondents).

Data analysis

The recorded interviews were transcribed in full. We used a constant comparative method for our analysis.⁷ The data gathered from the interviews were wide ranging; here we focus only on how respondents spoke about their use of drugs.

We analysed the transcripts in stages (see bmj.com). Some themes related to drug use (such as people's aversion to drug use) were immediately obvious. Others (such as the higher order theme of "ambivalence") only emerged with further analysis. Once such a theme had emerged explicitly from some interviews, we re-analysed the data to establish whether others referred to the theme explicitly or implicitly and to look for deviant cases to develop and refine the findings.

Results

Drugs occupied a central place in the lives of all participants, and, as they all had multiple chronic conditions, most drug regimens were complex and sometimes demanding and restricting. For some participants, a complex drug regimen was the only means through which they could gain equilibrium, relief from distressing symptoms, or a sense of having a "normal" life (though this varied in degree of success and setbacks) (see box 1). Although drug use seemed to have little impact on the lives of a few respondents, most accounts revealed several tensions and ambivalence in relation to drug use.



This is an abridged version; the full version is on bmj.com

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A table giving details of participants' characteristics appears on bmj.com

Box 1: Example of complex drug regimen to facilitate "normal" life

"I can vary the dosage ... like during the summer holiday, I take a low dose morning, lunchtime, and a big dose at night, you know. But some days I'll maybe vary that and will maybe take slightly more in the morning when I'm not really good because I know that I'm not going to work and so on. But I still try to keep to the same daily dosage. You know, if I add something on here I try and take it off there. ... But it's quite difficult, though, especially if you're trying to lead, if you're trying to be as normal as possible at the same time, you know, that's very difficult.

"I cut myself right down before I went back to work because I knew that, the dosage I was on, I wouldn't be able to do the job. ... I just had to get it down. So about two to three weeks before going back to work, I just got it down to three and a half tablets a day, and it was hell for six months, you know, the pain."—Respondent 16, with a pelvic abscess, asthma, eczema, and having had an ileostomy and proctectomy

"Regular" regimen v "flexible" regimen

One tension was between the use of drugs taken routinely at regular intervals in a "drill-like" way (as some respondents described their use of antihypertensive drugs) and a more flexible regimen. Failure to keep to a set routine was often perceived to pose risks to the successful eradication, management, or containment of current symptoms or undesired future outcomes. However, almost all respondents were taking several different drugs, and they often referred to complex strategies that they had adopted so that they could remember to take the various drugs at the prescribed times. Only one respondent (with schizophrenia, depression, a peptic ulcer, diabetes, hiatus hernia, and hypertension) spoke unproblematically of his combined drug regimen (saying "keep[ing] taking the tablets" was the most important part of the management of his illnesses).

For most respondents, the experience of multiple morbidity was characterised by fluctuating symptoms, fear, uncertainty, and lack of control. In the face of uncertainties about the exact manifestation of their morbidity at a given time, the management of medication was a reflexive activity based on constant self assessment and monitoring. This sometimes led respondents to vary their use of drugs to gain maximum symptom control, or to seek further consultations with their general practitioner to request new drugs or higher doses.

"Flexible" use of painkillers was common (see box 1) and the subject of lengthy descriptions of variations in intensity of pain and drug use, although drugs for many conditions (such as colitis, emphysema, anxiety) were also described in this way (see box 2). Variations to "fixed" regimens included increasing the dose, introducing new drugs, or juggling timing. Respondents might adhere to a regular regimen in treating one condition while adopting a flexible regimen for others (see box 2). The process at its simplest was described by one respondent as "As required" (respondent 2), although this phrase masks the intricacies involved in self regulation. Descriptions of use of

painkillers emphasised a struggle between wanting to take as few drugs as possible and adequate pain relief.

Reluctance to take drugs v the inability to be "free" of drugs

All respondents expressed their dislike of drugs to some extent, and drug use was often portrayed as the "last resort." This description served to emphasise a degree of stoicism in their response to symptoms and typically their struggle to make "responsible" (minimal) use of drugs and (maximum) use of other management strategies (such as going to bed, avoiding certain activities) to restrict the amount of medication needed. People also spoke of not wanting to put "pills and potions" (respondent 8) into their bodies; of fears of dependency, side effects, or interactions with other drugs; and of being wary of a prescription as a substitute for a real "cure" or better strategy for managing their underlying conditions.

However, respondents also talked of their need for drugs, commonly for pain control and sometimes explicitly for "survival" (box 3). But respondents' accounts also focused on the desire to have a life aside from their experience of illness, to function "half normally" or to fulfil social roles or obligations (see box 3). This sense, that drugs were turned to only in extremis, was commonly voiced.

Drugs as facilitators of ability to perform social roles v drugs as evidence of inability to perform social roles

In some cases the main reason given for use and self regulation of drugs was to control symptoms in order to facilitate particular tasks or social roles and obligations (see examples in box 3). Drugs thus played a part both in suppressing symptoms and in alleviating symptoms aggravated by people doing more than they "should" in performing these roles. In some cases this led to a lengthy discussion of the moral dilemmas and ambiguities presented. This moral dimension to how drugs "should" be used could be reinforced by others' reactions: respondent 15, for example, remarked that "Other people are always on to you—'Oh you're taking too many of these pain killers, blah, blah, blah'—but they've no' got the back I've got."

However, drugs could also represent ill health and act as an indicator of dysfunction (see box 4). This sometimes had the virtue of being one way of articulating to others, and affirming to oneself, the severity and progress of chronic illnesses, thus diminishing the

Box 2: Example of complex drug regimen varied in response to symptoms

"My asthma's normally bad if I take a chest infection. So I up my inhalers and I up, I get put onto steroids to help that. If my colitis is bad I take the normal colitis tablets, plus I get put on steroids to stop if there is any blood or anything and Prepos [suppository] that you put inside you. So I take that as well. That's not all together. I mean, if my colitis is fine then I don't take anything, and if my asthma I just take, if its fine I just take my inhalers. I've got to take the blood pressure tablets, the ulcer tablets, and the inhalers every day, and the water tablets."—Respondent 10, with hypertension, asthma, colitis, duodenal ulcer, thyroid problems, and anxiety and depression

sense of "difference" and isolation consequent on having a high burden of morbidity at a relatively young age. However, drug use could equally represent a threat to identity. Thus drugs could both be seen to restore previous identities threatened by chronic illness and be the concrete representation of the threat to, or loss of, that identity.

Discussion

Drug use was central to the management of the multiple symptoms and disabilities in these chronically ill people, and self regulation to gain maximum symptom control was common.^{9,10} In common with participants in other studies,^{6,10} our respondents also showed an aversion to taking drugs, despite their acknowledgment that they depended on drugs to live as normal a life as possible. Respondents referred to trying not to take drugs, resourcefulness in stopping or minimising drug use, and sometimes a preference for other strategies (such as counselling) over medication. Drug use was discussed in moral terms to show how individuals remained competent though seriously challenged by their illnesses, were stoical in their response to illness, and were responsible in their roles as paid employees and family members. This raises the question why such chronically ill patients with multiple morbidity, who are much sicker and more restricted than others of their age, feel the need to justify their use of drugs in their accounts of managing their ill health.

Two factors could contribute to this. Firstly, these people are likely to need a complex array of drugs over a long period to control their chronic conditions. Rejection of short term use of drugs is not possible for them. However, research has shown a widespread cultural belief that drugs should be as little used as possible.^{11,12} Against this background, people who already may feel isolated or conspicuous because of their poor health may not wish to exaggerate this by rejecting common shared beliefs about drug taking.

Secondly, these people are relatively young to have such high levels of morbidity. They are likely to be conscious that they are more incapacitated and larger consumers of healthcare resources than their contemporaries. In their late 40s and early 50s, they have had to come to terms with the restrictions that their chronic illnesses impose. In this context it is unsurprising that they take such trouble to show that they are "really" ill and frustrated in their inability to live normal lives, to show

Box 4: Example of drug use to signify extent of ill health

Interviewer: "Can you tell me in as much detail as you can, in your own words, what conditions you have?"
 "I take medication for high blood pressure, which is due to a, what I was told at the [hospital] was that it's a non-specific kidney disorder. Also water tablets to help control the blood pressure as well, aspirin, and I take pain relief for my back and my leg, which I injured in work two years ago. Well, more than two years ago now. That's basically all the medication I'm on now"—Respondent 2, with disc injury, kidney problems, depression, arthritis, hypertension, and penicillin allergy

Box 3: Different presentations of "need" for drugs

For "survival"

"I've got 13 tablets I take in the morning, I take four at lunch time and five going to bed. It's a lot of tablets to be taking in a day... Who wants to be on medication for the rest of your life? I certainly don't, but I know I've got to because of the strokes and the high blood pressure. I have to, I know I have to take medication; I couldn't survive without it."—Respondent 6, with asthma, hypertension, diabetes, osteoporosis, blood clots, anxiety, and depression

To function "normally"

It's [taking a range of tablets for different conditions] routine, but I tend to the ones like the dihydrocodeine. I mark down on a diary when I am taking them so that I wouldn't go over the eight in a day. Because when I am really bad, if I didn't, I've got so much pain that I can forget when I've taken it... I would love to be able to turn round and come off all these things, but to be able to function half normally I've got to take them, and if that's the way it's got to be, that's the way it's got to be."—Respondent 8, with depression, irritable bowel syndrome, sinus problems, sciatica, ovarian cysts, migraine, and tinnitus

To fulfil tasks, social roles, or obligations

"I couldn't bear watching my three young children coming in every day and seeing me in bed. I had to do something, I knew I had to do something, and I was very loath to take these antidepressants. I only took them because I began to feel almost suicidal. At one point, my husband begged me to take them... I couldn't bear [the children] coming in from school and seeing me still there unable to function really."—Respondent 21, with myalgia, encephalitis, cyst on thyroid gland, palpitations, and allergy to dust

"Sometimes I do things I know I'm going to suffer for. But it can be a difference of, maybe, sticking a set of brake pads on my car that takes me half an hour, so maybe it'll cost me £12 to do it myself. If I'd have not done it, £60, so there's times when I say, 'I'd better just take a couple of pain killers and do it,' you know. Because they tell you you're not supposed to live like a... you know, do. At one time it was 'Lie in a bed for two, three weeks,' now they're telling you 'Just do what you want, to work as normally.'"—Respondent 15, with back pain, joint pain, photosensitivity, stomach problems, and hay fever

their moral integrity in the face of challenges to their ideal or former identities. Their complex drug regimens mean that keeping their drug use private¹³ is seldom possible, and thus it remains an intrusive and constant indicator of their poor health.

Conclusions

Part of the solution to the mismatch between prescribing and consuming drugs lies in trying to understand people's experience and use of drugs. A genuine shared decision making process between patient and medical carers can only be achieved if the complexities and ambiguities involved in drug use for those with multiple chronic illnesses are appreciated by both parties.

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Ethical approval: Approval was obtained from the Glasgow University ethics committee for non clinical research involving human subjects.

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What is already known on this topic

There is widespread aversion to taking drugs and considerable non-adherence to prescribed drug regimens

Little is known about the experience of drug taking in people with chronic multiple morbidity

What this study adds

People with multiple morbidity expressed ambivalence to taking drugs in several ways: one tension was between the use of a regular drug regimen and a more flexible regimen as people self regulated their drug use in an attempt to gain equilibrium, relief from symptoms, or sense of a "normal" life

Further ambivalence was shown in people expressing reluctance to take drugs and their inability to be "free" of them; also that drugs both enabled respondents to continue to function in social roles and acted as marker for their inability to perform such roles

Drug use was discussed in moral terms to show how people remained competent though seriously challenged by their illnesses, were stoical in their response to illness, and were responsible in their roles as employees and family members

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Appendix B Analysis

Example of line by line thematic medication coding in Nvivo

Rita - Section 1.1.1, Paragraphs 289-297, 1477 characters.

'Touch wood, no I don't, I can, I can feel if I'm ever gonna to take one, but touch
Lack of control, moral aspect, reflexive patient? - becoming aware of symptoms, experience

wood, I havenae had one for years. But it got the point where, I know when to
Improvement, things have been worse, more control now.

take a Diazepam, do you know what I mean, I know now when to take them.
Shared understanding, draws me in, experience and aversion - responsible?

Whereas when I was first put on them, I was told to take them three times a day,
Change of tense - passive voice - lack of culpability, moral adequacy?

so I done it, took them three times a day and I got hooked on them. But em, I
Responsible patient, following GPs instructions, with negative effect.

came off of them maself, I didnae get help fae anybody, I just thought this has
Changes voice to the active, moral responsibility, assumption/shared understanding?

got to stop, so insteid of taking like, one tablet three times a day, the 2 mg, I
Strong moral fibre, responsibility.

made it like two times a day and then one a day and then I thought right, I'll take
Reduction of medication.

one every second day. I just got maself off them but I cannae go without them in
Active, hard, still needs the thought of them.

ma bag. I got maself off them'.
Reinforces moral responsibility, and being active.

Anne: *'Who would you say helped you, do that, then get better?*

Rita: *'Just me, just me, I done it maself.'*

Anne: *'What made you so determined to do that do you think?'*

Rita: *'Because I don't know, I didnae want a lot of going to ma doctor and for him'*

Didn't want to go back to GP. Wanted to be in control?

to say, I'm no giving you these tablets and I would get into an awful state, so I
Anticipated the GP as not helpful, which would make her worse.

just thought I'll get off them maself. I mean I'm going back, years and years and
Has improved - describing a long past episode.

years ago, I went to a hypnotist to try and get off Valium and then I went to acupuncture. But em the
acupuncture was quite expensive and all those years

Tried alternative therapies - cost an issue, worked hard to get off valium, morality.

ago I couldnae afford it, no I just came off them maself. Don't get me wrong,
Couldn't afford alternatives, active patient.

sometimes I feel like an elastic, ready to snap, but I know when to take a Diazepam'.
Still difficult, recognises the signs, reflexive.

END

Line by line coding reduced to four codes:

Aversion to medication

Making moral claims/constructing moral identity

Control as moral statement

Reasons for negative relationship with GP

Four codes:

Check: present in other interviews?

Check similarities and differences between participants.

Then check similarities and differences between frequent and less frequent consulters.

Memo

Aversion to medication - seems complicated, what about other drugs? Same aversion?

Aversion, yet at times needs them if only rarely - this seems a contradiction - explore this.

Why making moral claims so clearly when talking about drugs - does this happen with other people, and does it happen in other areas of the accounts, other codes, for example work, family?

Example of section of matrix, memo, and process of theory building

Good days	Bad days
<p>Janet describes what she can do on a good day: ' On a good day, yeah I can go down the main street in a taxi but I can only walk about the shops for half an hour and then I've got to sit down. But apart from that I can't walk any distance at all, but I'm in a lot of pain' (1a,section28, p262) Even when Janet has a good day there is uncertainty, this long quote describes one aspect of what having a good day is like for her: ' Aye you say to yourself, I feel great today but how long is it going to last ...is it going to last to the end of the week? Is it going to last to the next day ...I feel great today ...it's a bonus if it lasts till the next day ...How long's it going to last? (1b, section 177, p590). She talks about lack of control:' You just go from day to day and hope that the wedding day you're going to have a good day in your body and your health and your pain is going to be at a minimum rather than a high but if it's a high, that's just tough ...Everyday you get up, if it's a good day, if it's not really too bad or if it's a bad day, it's not going to get worse'. It's important to Janet and her family to get through the experience and consequences of her condition as a phase, after one incident where she faints and is worried about dropping the baby, her daughter says:' ...you've got to understand ...you have bad days and good days '...If I thought for a minute you were going to pass out with the baby.'(1b, section 239, p812). The concept of good/bad days is drawn on here by the family to protect Janet's identity as a grandmother, she can still do 'being a mother and gran'. She describes a good day:' I went shopping with ma daughter ...went all round the shops ...went for a coffee ...we sat with the babies and fed the babies ...went to ma daughter's house...walked round the garden with ma other grandson ...I felt absolutely great'. (1bp45).</p>	<p>'...I was really down a couple of months back there I was crying for no reason at all and I says there is something wrong with me and I cannae cope, can't be taking this out on my family' (1a, p18). Janet links a bad day to her role as wife and mother. Janet describes her symptoms: ' It's difficult. It's very, very painful some days; the past couple of days have been really bad. The past couple of days I couldn't walk at all' (1a, section6,p21) Janet sometimes knows what causes her bad days: ' ...ma daughter's moving house there, giving her a hand recently, we were cleaning, doing cleaning of the place and I suffered for about 3 days after it, I did suffer for a few days' (1b, section77 p254) Here Janet is doing 'cleaning'. her role as mum, over rides the moral imperative to be a good patient, she risks pain because she is doing 'being a mum'. Janet talks about a different sort of day: ' It depends on what's been happening on that day I think ...if it gets me down or not. If there's something that's upsetting me it can get me really down but if there's not I can just get on with it, know what I mean?' (1b, section 109, p350) Not just physical impact but emotional stuff going on as well could mean a bad day. When so much is going on, the plate seems too full. The cumulative effect of bad days is clear, and the lack of control, Janet wakes up and: 'I thought not another day of this, I can't stand it...' (1b,p45).</p>
<p>Sarah doesn't describe good days, her main problem is pain she says:' Yeah I just cope with it, it's there and I'm aware of it you know but I've just got used to living with it that it doesn't bother me too much' (2p2-3).</p>	<p>She has bad times of the day:' It's painful yeah, I have ...pain in the morning, when I wake up which can be quite bad, but once I've been to the toilet that seems to go off for a wee while. But some days I can get a niggly pain in my right side.' (2,p2)'.Sarah knows what causes her 'bad days' and does what she can to prevent them, or control the symptoms: '...I have diarrhoea ...if I'm going on holiday or I've got something on em, the next day that I'm quite uptight about I have to take Imodium before I go to bed at night ...that's more the anxiety side of it ...there's the side that seems to be affected by diet and the side that seems to be affected by nerves ...' (2aSection 1,p33).</p>

COMMENTS - Impact function - role - control - context of the talk - Janet fears loss, issues here around identity. Sarah - seems less impact - context of her talk - she does more, ongoing pain but seems less severe and more predictable - no fear of loss here/yet.

Memo

Janet talks about what she can and can't do - in relation to control - this is a major concern and seems to have significant impact on her daily life. Control then is related to function - unpredictable, uncertain. What must this mean, not being able to plan? - impacts on her role - identity?

There are different reasons for the bad days - sometimes Janet can explain it as a result of overdoing it, she does things as a mother and grandmother, and it is worth taking the risk, it is a way of maintaining control over one aspect of her life, her role, despite the consequences - heroic self, a position which is recognised, embedded in ideology. She also refers to her behaviour in the family to demonstrate that she was going through a bad patch - she was not herself, even though she was crying and taking things out on her family, this serves to reinforce her role as responsible mother/wife, as she was 'not herself'. Also again, lack of control.

Sarah not too concerned about control - she describes a pain which doesn't seem to break up the day/activities. Sarah seems to understand why she gets good and bad days and knows what to do to treat the symptoms; she seems to have control.

Language? - cope - got used to - doesn't bother me too much - Language use a clue to the significance of the pain. On bad days the pain is niggly. For Janet it 'gets her down' - 'can't stand it' the language is different - this is how I am getting the sense of more or less impact.

Need to look at the language of others - how am I getting the sense that some 'suffer more than others? Also the context of the talk - Janet describes more limited stuff, Sarah more varied - also need to focus on this. Do other women talk in the same way? Men? Why? Why not?

IMPACT

Physical and emotional - need to look at the *context* and the *form* of the talk to gain insight into the *consequences* and the *significance* of those consequences in terms of *function, control* and *fear of/loss*. In terms of context, does Janet talk about work and social life in the same way - is she *consistent*? Do others talk about impact in similar ways to Janet? When? When different? To compare the transcripts before organising them in terms of frequent/less frequent consulters - important. Synthesise then see if any patterns are emerging in terms of the theme of impact, the sub-themes of consequences and significance, the *codes* of *family, work, leisure, medication*, and *'doing' codes*, such as how much they can *do* in these contexts, and what they are *feeling*. Then try to *categorise* in terms of how *positive* or *negative* they feel about the 'codes' - eg doing not doing 'work', family stuff, being a friend, being a patient (medication, GP).

How can I tell the significance of the accounts? Focus on the form and context.

1. How much do they say about something eg loss of ability to work?. Do they keep drawing me back to the same thing? How often/extensively/spontaneously?
2. Use of words important - Janet and Sarah use different words/forms to get their points across - Janet's language is 'physical'. Fine grained analysis is helpful here. What other types of language used? - look at tenses, first and second person, active and passive tenses.
3. Context of the talk - when they talk about pain or other symptoms is this in the context of their work/leisure/family life? What does this say about how far the symptoms intrude, on daily life or familiar self.

Theory building - GP as dispenser of capital

Name	Function	Capital	Strategies/resources	Which lead to/stem from	Comments
Janet	Loss of control - illness, life, role - mother grandmother, carer - Disruption	Loss of physical, limited social, cultural (knowledge of illness treatments which work). Loss of symbolic.	Medication Pacing/keeping busy Counsellor	GP GP GP	Limited range of resources to manage debilitating symptoms - GP helps with symbolic and physical capital
Sarah	No talk of loss and has control - mostly Contingent normalisation	Has physical capital, is able to work, go out with friends, which in turn offers more resources on which to draw - social capital, cultural capital, has symbolic.	Diet Medication Pacing/timing	Self/friends Self - usually Self/friends/ work colleagues	Less debility, world not diminished, contains symptoms. GP there on sidelines.
Dick	Loss of control, limits life. Disruption	Loss of physical, social, cultural and symbolic capital. Limited opportunities to accumulate range and volume of capital.	Medication Carer Rest Talks Walks	GP GP Self Spouse Spouse	GP central - offers relief from symptoms and hope for the future. Work together in 'struggle' against illness - helps with capital.
Johnny	No talk of loss of activities/life, some loss of control. Contingent normalisation	Has physical capital, is able to work, go out with friends, which in turn offers more resources on which to draw - social capital, cultural capital, has symbolic.	Diet Socialising Medication Drinking	Spouse, self Spouse, self Spouse, self usually Self (negative aspects)	GP - negative aspects, criticises - loss of symbolic capital, no gains.

Paul	Some debility but contained, no loss of role. Works hard at managing. Has been off work in the past. Contingent normalisation	Has all capitals; Works; holidays; breadwinner/provider knowledge of symptoms.	Pacing Flexible work Medication Alternative treatments /aids AA	Self/work Self-employed Self/other practitioner Self-help/group	GP - few gains, losses - particularly symbolic capital. GP - negative- says alcoholics weak willed.
Marie	Some debility, has been very debilitated but recovering and functions in a range of life areas. Contingent normalisation	Has all capitals, works part time, has friends, goes out/holidays/ 'enjoys life', material and economic resources.	Pacing Swimming Keeping busy/working	Self Self/financial Self/type of work	GP very few gains - no offer of capital, negative symbolic capital.
Peter	No loss of role, works, keeps active/busy. Has been very ill. Constantly working hard at managing. Contingent normalisation	Has all capitals, important for self-image - 'the protestant work ethic', few worries, no money worries.	Pacing Medication Pain clinic Work	Self Self Professional Type of work	GP - 'innocent bystander' Good relationship, offers symbolic capital, but no need for visits.
Ian	Loss of role at work, in family. Struggles against loss of control of body, and works hard to sustain old aspects of life. Disruption	Loss of capitals, has symbolic capital as he works with GP to keep on top of his illness - important part of his identity.	Socialising Medication	Self/car/electric wheelchair/ GP GP	GP pivotal for physical, social, cultural, symbolic capital. In a world increasingly diminished, the GP's role is magnified.
Lesley	Loss of role at work, limited social life and role, guilt about family role. Disruption	Loss of capitals, physical, symbolic, social, economic.	Medication Pacing 'Fights'	GP/self Self/family Self/family	GP central managing, illness occupies her in a diminished world. Loss of symbolic capital, helped by GP.
Jim	Some debility, loss of role and social life due to symptoms. Disruption/contingent normalisation	Loss of capitals, physical, economic, social, symbolic. Has cultural capital, (knowledge of treatments).	Medication Alternative therapies Pacing Socialising Seeing son	Self Self Self Friends Family	GP offers few treatment gains, does offer validation of illness status and sick note, so symbolic and economic capital. Also offers hope - maybe something will help.

Narrative analysis (Labov): Form and Rhetorical devices to build positive identity

Example 1 Jim FC

Jim: *No, I went to, what do you call it, one of they medical things, and you've got to have 15 points. So I got a letter from them saying that I didnae have 15 points so therefore I wisnae entitled to benefit, which I've got an appeal in against,*

Anne: *Okay.*

Jim: *At the minute but that can take up to six month.*

Anne: *Have you ever been on incapacity then before, did they?*

Jim: *I was on it while, prior to being discharged, being discharged fae the Fire Service.*

Anne: *Right.*

Abstract (setting the scene)

Jim: *Em an I was on it after that, I was on it for about 11 months, 10/11 months after that*
Complicating action (Ca), what happened (next)

then a went to Wilson Street for a medical

Ca

and their doctor's opinion was that I was fit for some form of work

Ca

which I disagreed with.

Evaluation (what it means, significance)

They said they would stop my benefit

Ca

so I went to the, or I phoned the employment place. Um explained to them what it was

Ca

and they says: "Well you dinnae get anything off us because you know if you're saying you're no fit for work, you cannae look for work but you've got tae be looking for work to get benefit an if you're no lookin for work you cannae get benefit"

Ca+ Rhetorical device – direct speech; personal situation/structural factors; personal situation and public matters

you know.

Shared assumption language work

So it's a catch 22 situation

Coda – returns the perspective to the present + Evaluation (what it means/significance)

you know.

Shared assumption language work

It's like a cat chasing its tail.

Coda -Evaluation

One's saying I cannae get it, I should get a job, and the other one's saying you're no fit for, you're no fit for work so therefore you cannae get money off us either.

Coda - resolution

Anne: *Could you see your own G.P. about that, would your own G.P. have anything to, you know about incapacity or?*

Jim: *Naw, no well apparently it's done through, these doctors that are employed by the DSS.*

Abstract

I mean the thing that annoys me

Evaluation

was that day I was there em,

Orientation

I actually got quite angry an I got a wee bit kinda stroppy with the young doctor that was there,

Ca

I mean, you're looking at 17, 18, 19, 20 year olds all sitting there with the baseball caps an that, an these folk had only been in five minutes, an there's maself and a woman say in her 40s, surrounded by aw these, if you pardon the expression, "bloody wasters", that have never had a job and I was in there for 40 minutes and a get put through the mill, you know.

Orientation – rhetorical device, supporting cast and positioning; moral identity

You with me, you know

Shared assumption language work

an I'm saying to mysel

Rhetorical device, reinforcement?

I've worked from, I left school at 16,

Orientation

you know

Shared assumption language work

I've never signed, never signed the brew, never in ma life, I've went straight from school to work, left the Gas Board and went into the fire service, left there on the Friday and went into the Fire Brigade in the Monday right up till I got pensioned off

Orientation

an these

Orientation - supporting cast, positioning+moral identity

you know

Shared assumption language work

these young guys an young lassies were

Orientation - supporting cast, positioning+moral identity

you know

Shared assumption language work

it was just, it was just like a shopping service

Evaluation

an with them going out an in these different rooms

Ca

you know

Shared assumption language work

an as I say in that wan a wisnae in any longer than about five minutes.

Ca

Sorry a'm digressing again.

Coda

Memo

Identity work – this is one of the most extensive pieces of talk in Jim's account **Why?** – this is when Jim's identity is at stake – he works to build his **moral identity** in the context of a **culture** which rewards hard work and stoicism.

Personal talk linked to **cultural** ideals (the work ethic) and **structural** factors (the way work/unemployment/benefits are organised). Jim describes a personal situation, by drawing on common ideas about the work ethic, and the ways in which non-work are framed.

The past linked to the present – Jim was a worker – constructs himself in the present as **being a hard-worker** despite being unemployed – past, present. What happened next (accident at work, unemployed) – temporal. Narrative approach looks at now and then – highlights loss.

Example 2 Betty FC

Abstract – (discussed throughout the interview unemployment and claiming sick-pay)

Betty: I filled in two forms (for sickness benefit) since last year

Ca

and I'm still waiting.

Orientation

I mean people getting reminding stick them in there, I think they must just be: "This year we'll just go for her. Any way we can possibly make things harder for her, we'll do it".

Evaluation

Anne: That's what it feels like at the moment?

Betty: Oh it's been like that since dot.

Orientation

I feel as if I've had to fight for everything

Evaluation

and having worked all ma life

Orientation

and not liking having to take sick pay and all the rest of it

Evaluation

I would far rather work em I feel depersonalised as it is

Evaluation

and they're just making it even more harder for me

Orientation

because I do have pride and I mean

Evaluation

as I said to, it, as, was one chap came up from the social security place, you know they do their visits,

Ca; use of a supporting cast

I said look "I didn't take any of your money, I would work"

Ca; direct speech and orientation

He said: "But you've worked all your life, you are now, you are entitled to this, it's not as if you've never done a thing in your life and you're just sitting back and taking everything"

Ca; direct speech and orientation

He says: "you are entitled to this, that's why you paid your taxes and you paid your national insurance"

Ca; direct speech and orientation

I says ah but I says: "the way things are happening, it's although instead of getting it as I should be getting it, I feel as though I'm having to beg for it and I don't like that".

Ca; direct speech to orientate, evaluate, and close - Coda

Memo

Identity work – when Betty's identity is at stake – she works to build her moral identity in the context of a culture which rewards hard work and stoicism, ongoing themes

Personal talk linked to cultural ideals (the work ethic) and **structural factors** (the way work/unemployment/benefits are organised).

The past linked to the present – Betty was a worker – constructs herself in the present as being a **hard-worker** despite being unemployed – past, present.

Use of the rhetorical device of a supporting cast and direct speech, works to draw in the listener in the interview (me). assumes a shared What happened next (accident at work, unemployed) – temporal.

Narrative approach – focus on the temporal – links past and present; moral identity

Narrative analysis – line by line – ask – what happened next? What is the significance of this? How does the past relate to the present?

Both position Jim and Betty position themselves as authentic applicants, and seem compelled to do so. Long, detailed visual descriptions to get their point across. Significance of what this means is highlighted clause by clause.

Structure of the narrative (Gergen and Gergen) – progressive, stable, regressive, nested narratives (also Labov informed)

Memo

Overall, and in section how far do the participants talk in types of narratives throughout their accounts. Do they talk in terms of any overall, when talking about particular aspects/themes/people? As in thematic, combine line by line, with sections of talk and build the notion of a plot – which direction does the speaker drive the action? What are they talking about when direction moved forward/back/stabilises?

Think here about Gergen and Gergen – the basics

Direction – temporal – events move over time to ward a given end

Establish directionality along a good-bad dimension – an evaluative framework e.g. Am I improving?

Individuals select discrete incidents across time and links them through evaluative comparisons. Jim and Betty, above seem to be moving in a backward direction

Stable – I am still the same, the pain is always there.

Progressive – I am overcoming my illness/my symptoms/adapting/managing life

Regressive – I am losing control (e.g. loss, disruption – unemployment)

BUT – I am still the same, the pain is always there, but I am overcoming the symptoms and going to work – progressive identity, stable illness

Example 1 Betty FC: regressive narrative, illness and daily life

'I felt great satisfaction. I also got very well paid. Em, but I felt great satisfaction I could past – work+high satisfaction and pay , status, moral identity

have made something of myself there. That angers me because I'm just fifty and I just feel as though my life has stopped' (Betty, FC).

Then and Now - very different, part of an account about loss and disruption, caused by illness. Loss of control – loss of job, life opportunities

'I'm (pause) I'm not the woman I was. My confidence has really been shattered em I don't past and present - work

like living off the State I've worked since I've been fifteen, sometimes two jobs, and I builds identity as worker through the narrative – harks back to the past to do so, identifies a lost future (above) – all this underlines her moral adequacy

would rather be out earning my money but I can't. And it's a very hard thing to, to accept' part of a moral community, draws on shared assumptions. Loss of self.

Example 2 Betty FC: nested narrative – progressive narrative within regressive narrative

Betty: *'I thought I'd lost it, I'd gone gaga, I screamed the place down, it was horrible'*

past

Anne: *'You didn't recognise the signs?'*

Betty: 'Mmm-mm (negative). But any time after that, I did and as soon as I start feeling iffy, I know the difference between feeling a wee bit uptight, a wee bit agitated and the difference of when I'm going down the long dark tunnel and I go straight to the doctor'.
(Betty, FC).

Memo

Regressive – part of an account of loss of control and disruption of daily life and challenges to identity and moral self.

Progressive – But within this, the account of the GP consultation forms part of a progressive narrative – going to the doctor is a way of halting the journey down the long dark (regressive) tunnel.

Example 3 Janet FC: Nested narrative. During an account of illness and daily life which forms a regressive narrative, Janet describes the GP consultation as a way to move forward ie talk around her GP is a progressive narrative throughout her account.

Section a

I think everything is just getting on top of me.

Setting scene, loss of control

What is wrong with me is,

Explanation/opener

I was such an active person, I was really active. I mean I sat on a lot of committees, I went to university myself, I mean I am a qualified social worker to Grade. And I was a hotel manageress as well to Grade.

Life in the past/identity in the past (and now)

And then all of a sudden,

Loss of control

I ran a youth club for five and a half years, I ran another club for five years.

Life in the past/identity in the past (and now)

Then all of a sudden nothing,

Loss of control

I went no, it was just getting on top of me.

Explanation/feelings

I led such an active life and now I can hardly walk to the shops.

Loss of control

It is frustrating, it's depressing it really is.

Impact

I'm now back eh, in one of my clubs so, which is not too bad, I'm not as active as I was but I was a very active person and things just get on top of me being shut away in the house (indistinct phrase). Because I was so active and then nothing.

Loss of control

As I say I sat in a lot of committees and all that and to cut that back. I still sit in a few but not as many and em for a long time there I dealt with sexually abused children as well. But, em I miss a lot of it as well, I do miss a lot. I do. I miss a lot of things that I did before. I mean I fostered for 15 years as well, I mean I've even cut that back, I still see the children but I don't take in as many as I used to. But they still come to see me and I worry about them too but it's still not the same.

Loss of life/identity

Life is just not the same anymore. It's not. I try to make it be, but it's not, it will never be the same but you just keep going.

Regressive

You just keep going, you have to you have no choice you have to. For your family's sake you have to.

Progressive/role/identity

Memo

Janet regressive, loss of control, significance in daily life. Starts and ends with main point – RA frustrating, limiting, same words to frame the start and end. Part of a regressive narrative as Janet describes the impact on her daily life, her role, and her identity – aspect of progressive in identity.

Section b

It (arthritis) restricts me an awful lot, restricted from doing things I want to do, it really is very restricting. I want to do a lot of things and I can't because it hinders me in a great deal of ma life, it hinders me terrible, very frustrating and very annoying. I can't close ma eyes because of it, it's terrible, it's so frustrating, nobody realises how frustrating it becomes because you want to do so much and you can't, you just can't, you know you can't, you try but you can't, you just can't. There's such a lot I want to do with ma grandchildren and ma family and I can't and they feel it because they want to ask me to join in and they know I'm not capable of doing it and it causes kinda (pause), not friction but it causes tension between the family. I tend to get upset because I want to do it and they get upset because they want to ask me and they feel awkward because they're not asking me which makes me feel left out which causes tension, it's terrible to be left out, usually nobody knows.

Abstract - Negative setting of scene before describing a particular episode

Like yesterday there was so much we (daughter) wanted to do shopping-wise and one thing and another
Orientation - setting

and she says "Mum you can't because you're no fit for it"

Action-what happened

and I felt bad, I felt as though I was holding her back.

Evaluation – significance, meaning

She wanted to do so much and she knew she couldn't because I was there so I felt as though I was holding her back, Evaluation – significance meaning

she kept saying "No you're not"

Action – what happened

but in myself I felt I'm holding her back here, I would have been as well staying at home.

Evaluation – significance, meaning to Janet

It's terrible to feel like that, just terrible, you feel as though you've become a burden when you're
Coda – returning to the present

out, it's a horrible feeling, horrible horrible feeling so it is, so it is.
Coda – returning to the present

I would say that was the biggest part of ma arthritis, holding me back, you know you can't do it, it
Coda – returning to the present – summing up

becomes very very frustrating, very frustrating, very
Coda – returning to the present – summing up

Section c

I'm still on them (stronger pain-killers), I've never looked back, I've still got pain but nothing to what it was, nothing, I went shopping yesterday with ma daughter, my future daughter in law went to B&Q, I couldnae before, we went all round B&Q store, came out of there and went all round the shop, eh Tesco's, came out, went for a coffee, we sat with the babies and fed the babies, came out of there and went to ma daughter's house, another coffee, walked round the garden with ma other grandson and came back home, I felt absolutely great.

Memo

Progressive narrative when taking about consequences of GP consultation. A nested progressive narrative – things are moving forward – Janet has not looked back. The GP helps Janet fulfil her role as mother and grandmother.

Section d

Because this doctor takes time to explain the procedures you are going through,

Positive/moving forward

he takes time to tell you what is wrong with you

positive/moving forward

he takes time to examine you and he gets to the bottom of what's wrong with you.

Positive/moving forward

He doesn't leave you in limbo.

Positive/moving forward

There's none of this, give you a prescription and say right try that, come back in two weeks.

Positive/positioning/reinforcement

No this doctor digs in gets to the bottom, what's wrong; and he copes with it,

Positive

Which I like. Somebody to be straight with me.

Positive/reinforcement

I don't want to be sitting there saying well I think it might be this or I think it might be that

Positive/positioning

I'd rather just get right down to the nitty gritty tell me what's wrong with me and give me something to help me along the way.

Positive/moving forward

That's fine, that's all I'm asking for, I don't think I'm asking much asking that, because I don't go to him often, but when I do go it's for something really severe and I feel when I go and he knows I'm not there a lot so when I do go he knows there's something really wrong. It's the only time I do go and this doctor knows that and he sits down, 'Right what's the problem'?

Positive/affirmation

And he'll discuss it with me and he'll go through all the options and he explains it to me and that's what I like. He explains everything to me. And if I do get the results back and he'll explain the results to me and how he came to the results and that's what I like about him.

Positive/affirmation

Memo

Account of moving through illness, elements of control, getting somewhere. Nested progressive narrative in a regressive narrative which relays loss of control of daily life, roles and challenges to identity.

Appendix C Topic Guides

(Interview 1)

I've looked at the questionnaires you filled in for the nurse over the years, but what I really want to hear from you today is your experience of your conditions, in your own words.

1. **CONDITIONS AND SYMPTOMS** So can you tell me in as much detail as possible about your conditions?

Which bothers you the most?

How does it bother you?

What about other conditions/symptoms.....?

2. **IMPACT** How does it affect your day-to-day life?

Family

Work

Leisure – What about in your spare time?

What about things in your day-to-day life, anything affect your condition?

What about other conditions?

Do the conditions affect each other?

Actions What do you do to feel better? What helps?

Do you get the sense of a good day/bad day?

How do you keep on top of things when others wouldn't?

3 **FORMAL SERVICES AND HELP-SEEKING** How helpful is your doctor?

How often have you seen your GP in the last 12 months?

Are you likely to see her/him for one thing more than another? Why?

Can you think of a time when s/he has been particularly helpful?

Has there been a time when s/he could have been more helpful?

How easy is it to see your GP?

Have you ever disagreed about anything?

What role does your GP play in how you manage your condition?

Topic Guide

(Interview 2)

1. **GIST OF INTERVIEW ONE**

I just want to re-cap what we talked about last time.....

2. **ELABORATION OF INTERVIEW ONE**

Can you tell me a bit more about.....

2. **DETAILED QUESTIONS ABOUT DIARY ENTRIES**

Read entries through with participant and ask for elaborations/clarity.

OVERALL In a nutshell, what is most crucial in how you manage your conditions alongside daily life?

Any advice for others?

Appendix D Field Notes

Interview 1a, 10th August, 2001, 12.noon, at participant's house. Duration - 40 minutes.

The house was on the edge of a large council estate. Very quiet, not much of an atmosphere of any kind. Some of the properties for sale, so some privately owned. Some of the houses were well maintained - gardens, paintwork, quite a lot were not, a couple of gardens which were not well tended had large dogs in them barking and looking rather threatening. Just past the respondent's house the area deteriorated, blocks of flats rather than houses, lots of them boarded up. Renovation work going on in the block of flats opposite the respondent's terraced house. Respondent answered the door, she was alone in the house. She showed me into a 'neat and tidy' 'sitting room' which was just inside the front door on the right hand-side. The television was on, the respondent turned the sound down. I explained about the study, showed her the information sheet which I had already posted to her, checked that she had got one and read it. Went over the consent form, she was happy for them all to be ticked: 'Yes tick them all that's fine'. She signed it and I turned the tape on.

The respondent was very chatty, quite happy to answer all of my questions. When we had finished I turned off the mini-disc player, and explained about the diary, she seemed keen to complete it. I said I would phone her and send an addressed envelope in about ten days, and asked if her husband could post it for her, I would then read it and come back for a second interview within three weeks. She said that was fine.

So, on reflection, the respondent made me feel welcome, and seemed pleased to be taking part in the study. She was eager to talk, and I felt that she was appreciative of the company, and also to have the opportunity to talk about her illness, and her family life, as well as her experiences with the medical profession.

However, I feel I need to prepare more thoroughly for the interviews. This one lasted for 40 minutes, and although it is important that I do not take up too much of their time, as I want them to agree to complete the diary and see me again, I do need try to get as much appropriate information as possible, there's not too much time for 'chat', on the other hand, make it too structured and I feel I'm not getting at what they see as important, but what I think they see as important. I am finding it difficult, asking open questions and the respondent talking is not a problem, but gaining an understanding of their use of resources in a more explicit way is a little harder. Anyway I will look at the transcripts and annotate, and see what I can learn.

Another consideration is that I was aware that the respondent was getting uncomfortable - she has arthritis and was fidgeting, and did groan a bit when she got up to let me out. Maybe she doesn't usually sit still for so long?

Interview 1b, 18th September, 2001, 12.noon, at participant's house. Duration – 1hr 10 minutes.

The arthritis is the most bothersome, the worst thing about it is the way it debilitates the R. This is harder to cope with than the pain. It causes depression. There can be an underlying tension in the family; (husband two grown-up children one male and one female who have left home but live close by, and teen-age son still at home) they joke about R making light of her debility, which she likes, but are also sometimes reluctant to ask her to join in with things because she may not be able to, yet if they don't ask her she feels left out.

Close to daughter, who had a baby during the duration of the study. R was worried about this and contacted doctor for a chat and medication. Also was in a lot of pain because had helped daughter in new flat, this had made pain worse. The frustration she feels at being unable to do things worse than the pain. She feels a burden to her family, this makes her depressed. Her daughter is not only a source of worry; she also helps R, and takes her to the doctor in her car. Her friends are important to her. They will talk to her and she can tell them how she feels, this is a great help. She feels quite in control of her health as long as she gets support. She sees her doctor as crucial, also the receptionists, and the nurse all very good, and she feels she can contact her surgery for help and advice and will get it. She can talk to her doctor and negotiate with him, but tends to defer to his knowledge, seems to depend on him quite heavily. She thinks of herself as a fighter she is not giving in. This is to do with her family; she wants to do things with the grandchildren. She thinks she is like this part because of her mother who had years of illness but was a fighter and never complained, so this was an example for her. Sometimes she likes to be on her own when depressed, she might say to her husband that she wants to go upstairs and then her son and husband will get the tea, while she has time to herself. She very clearly sees arthritis as the condition which she has to deal with and the depression which is caused by this. She complains again about her old doctor not giving her medication and her new doctor picking up on her not having HRT for the menopause. At one point the R was tearful when talking about her grandchildren and her concern that she cannot do things with them that she would like to do, she cannot take the baby out in the pram.

Husband came in at one point and made us a cup of tea. He started making faces at some of R replies, then he went out, R gave him money to go and pick up some photos. He seemed to disagree when she said she was in control of her health about 70%. He only stayed in the room for about five minutes. He came back just as the interview was at an end, I then thanked the R for taking part, and she said she would be happy to be contacted again. The R has had bad experiences with doctors in the past but her experiences now are positive, she seems quite dependent on her doctor now, using him for medication and talks, so for physical and emotional support. Her family seem to be very important also for practical and emotional support, also causing her worry and stress to the extent where she feels she needs to talk to the doctor. She sees herself as a fighter. She gets depressed because she can't do things. She takes her health a day at a time, relies on her medication and the doctor to up her medication if she needs it. She feels she will do things that might cause pain the following day but feels she is free to contact doctor for more medication if needed. She also has a good relationship with the Practice Nurse.

My Daily Health Diary

Day of first entry

If you have any queries phone Anne on:
0141 357 7560

Respondent's number

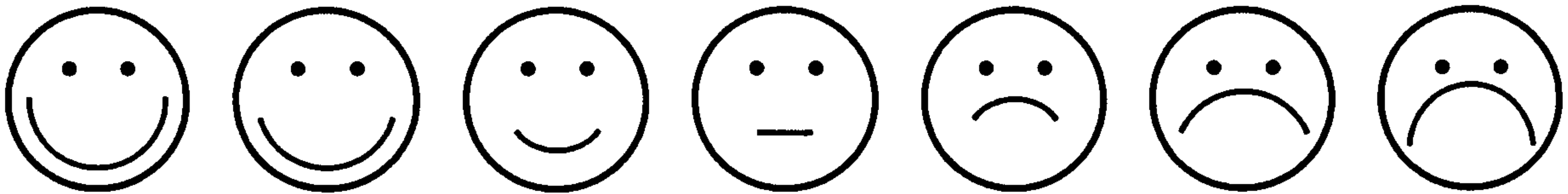
Ideas to help you fill in your diary

- ❖ Try and fill in the diary on the actual day. If you do forget or you are unable to make an entry for a particular day, then it's OK to fill it in the following day. However, I would suggest that you don't try to fill in the diary any later than one day after the entry was due, e.g. don't try to fill in Monday's entry on Wednesday.
- ❖ If you find that you have missed more than one day, don't give up, just start again from that particular day.
- ❖ I am interested in any health/fitness/illness issues. This may include things you are used to (for example not sleeping well) or see as trivial and would not normally mention (for example having a slight cold), as well as things you see as serious problems.
- ❖ I am also interested in other things which might affect how you deal with any symptoms, e.g. things that happen in your day, or just your day-to-day routine.
- ❖ If you are unsure about writing something down include it. I am trying to learn about your experiences and how you deal with symptoms in your daily life, I will be interested in anything you include.

Day

How do you feel today in general?

(Tick the face below which best describes how you feel)



Special events

Did anything happen today which affected the way you feel? Can you write down what it was, and why it made you feel that way?

Got up from bed had my tablets and something to eat. Started housework with my wife then had a bath ready to go outside went down to doctors for something for headache asked a few questions about my condition got a few answers which rocked me a bit rest of afternoon has been a bit of a blur what started of as a good day has backfired a bit

Symptoms/Feelings

Can you describe here the symptoms or feelings you had today? How severe were they? How long did they last? How familiar were they to you?

I started of positive & ended up on a downer most of day was good up to I visited the doctor after that things were not to good but I will get over my setbacks and push on

Thoughts

What do you think caused these symptoms? Did you think about discussing them with anyone? (e.g. friends, partner, doctor), or think about doing something about them? (e.g. resting, taking the day off)

The news I got from the doctor put me on a right downer it was about my HGV licence and that I might loose it altogether I discussed this with my wife and I was told I need to be positive about this its just another setback to get over

Actions

Did you actually talk to somebody or do anything about your symptoms? Can you write a bit about this here? If you didn't do anything or speak to anyone can you write why you didn't here?

As I said above I spoke to my wife and my kids but like always they all pull me out of my downer as she says things can only get better from here I'm lucky to have a close family.

Please use this page to write anything else you want to, including any comments about filling in the diary.

Appendix F: Diary Table

Authors	Study Population	Diary format, duration, purpose	Other methods	Study aim	Diary contents	Completion rate
Roghmann and Haggerty, 1972, <u>The Diary as a Research Instrument in the Study of Health and Illness Behaviour</u> US	512 Young families, random sample, urban pop', reported by mother.	Health calendar, 3 questions each day, family well being, health behaviour, illness behaviour. Matrix, questions, and checklist. 28 days Data source	Initial interview, to sensitise respondents, phone contact as often as necessary, subsequent interview five months after completion of diary.	To study a wide range of health and illness behaviour in young families on a day-to-day basis.	Symptoms or complaints, how person felt today, restricted activity, if felt need to do something about symptoms, regular health care behaviours, special or upsetting events for R (mother), if R felt stressed.	82% overall. No correlation with socio-economic status, but with age.
Kasl, Gore and Cobb, 1975, <u>The Experience of Losing a Job: Reported Changes in Health, Symptoms and Illness Behaviour</u> US	113 Men made redundant due to plant closure, one urban, one rural blue-collar, married, aged 35-60.	Daily checklist. 14 days Data source	Series of structured questionnaires and interviews with trained nurses. Also physical health measures collected.	Longitudinal study of health effects of job loss. To relate changes in health to job loss, social setting, severity of the experience.	Days complaint, days disability, % days complaint that are also days disability, days saw doctor, days used drugs	Of the men eligible for study, 79% agreed to participate.
Banks, Beresford, Morrell, Waller, Watkins, 1975, <u>Factors Influencing Demand for Primary Medical Care in Women Aged 20-44 Years: A Preliminary Report</u> UK	Random sample of 516 women aged 20-44. Of 415 remaining after checks, 63.4% took part.	Modified version of Roghmann and Haggerty's calendar. Seven main questions, open and closed. 28 days Data source	A 40-item Anxiety Scale, questionnaire completed at the end of diary period, a social and health questionnaire completed two weeks into the diary period, GP Record Card, consultations over last year.	To relate certain social and psychological variables to demand for medical care.	Perception of symptoms, action taken, occurrence of special events such as stressful situations.	2 women, dropped out at the end of the third week. All diaries included in results.
Freer, 1980, <u>Self-Care: A Health Diary Study</u> UK (conducted in Ontario).	Random sample of 26 women, aged 35-44.	Structured sheet, answers to be expressed in own words and style, based on Banks, and Roghmann and Haggerty. Coded and analyzed by SPSS. 28 days Data source	None	To collect more information on self-care, the focus being common, everyday health problems. To compare with Banks.	What kind of day, anything else bother you, or happen to make you feel good or bad, take any action, limit activities, take any medicine, persistence of problems, discuss any problems, rate health today, other comments.	2 women, dropped out at the end of the third week. All diaries included in results.
Verbrugge, 1980, <u>Health Diaries</u> US	Article provides an inventory and description of studies which have used health diaries.	Two general formats: a ledger, or a journal with lines or boxes, questionnaire, vary as to closed or open ended. 7 days - 5 years Data source or memory aid	Interviews, telephone contact, monitoring.	Review	Symptoms, use of services, restricted activity, actions, medicines, events, advice given, general health.	75%-100%
Porter, Leviton, Slack, Graham, 1981, <u>A Headache Chronicle: the daily recording of headaches and their correlates</u> US	177 females, 57 males, patients whom were known to have headaches.	One self-reporting page for each week in matrix form, open ended questions at the start, 2 page questionnaire at the end for reaction to the chronicle. 28 days Data source	None.	Patients' reactions to the chronicle, the effects of self-reporting on headache pain, and the relation between personal feelings and pain	Open questions: about headaches, causes, anything else. Matrix: pain, nausea, action, activities.	100%

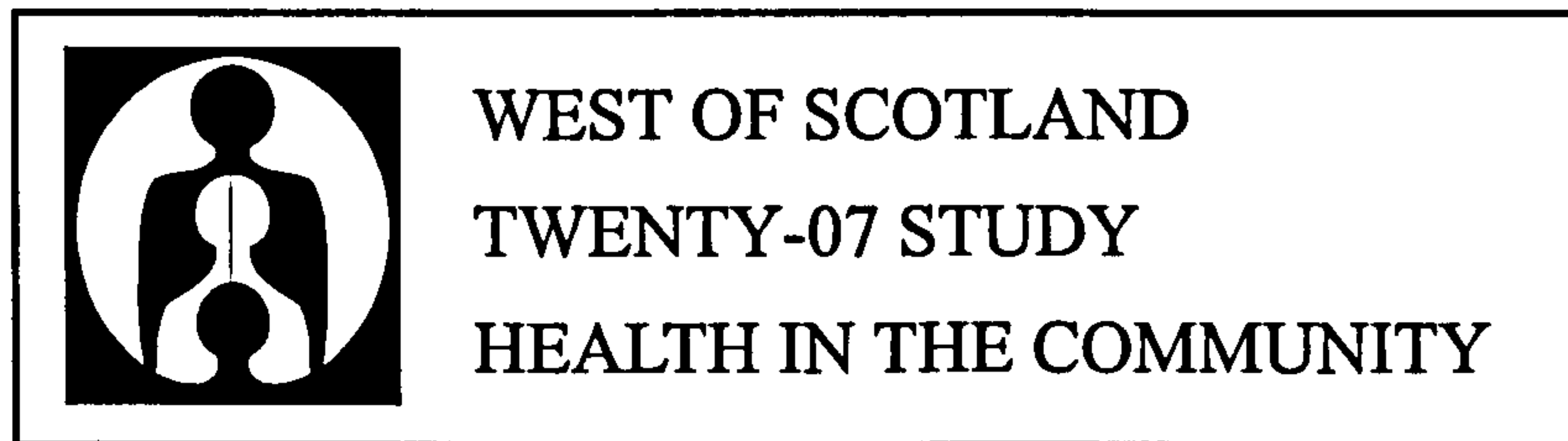
Authors	Study Population	Diary format, duration, purpose	Other methods	Study aim	Diary contents	Completion rate
Marcus, 1982, <u>Memory Aids in Longitudinal Health Surveys: Results from a Field Experiment</u> US	585 respondents, assigned memory aids, 3 stage, random probability sample, one adult per household.	Wall calendar, multi-coloured, spiral bound, a page a week, open questions. One year Memory aid	Panel survey, initial interview, assigned memory aid, for 10 months, phone interviews 6-8 weekly, asked which illness most important, then the final face-to-face interview, the same content as the memory aids.	To assess the usefulness of a memory aid technique in health studies	Describe symptoms, who they talked to, action taken.	252 used their wall calendar at least once.
Dahlquist, Wall, Ivarsson, et al 1984, <u>Health Problems and Care in Young Families-An Evaluation of Survey Procedures</u> Sweden	310 families registered in a child welfare center randomly selected.	Open questions, severity scale. 4 weeks Data source.	Questionnaires, phone interviews to compare methods.	To compare the information obtained by prospective self-diary, retrospective 24-hour recalls and one week recalls.	Symptoms of family, severity, actions taken, family, friends, relatives or formal collaboration.	Low number of non-respondents.
Verbrugge, 1985, <u>Triggers of symptoms and health care</u> US	589 White adults in Detroit metropolitan area.	Structured chart, questions, scale, open question. 6 weeks Data source.	Telephone interviews, throughout and at the end of diary period.	Triggers, eg bad moods, negative events, physical malaise, of physical symptoms and health care on a daily basis.	Symptoms, activities, medical or dental help, discuss with anyone, medicines, spirits, events, other comments.	589 out of 652
Rakowski, Julius, Hickey, Verbrugge, Halter, 1988, <u>Daily Symptoms and Behavioural Responses Results of a Health Diary with Older Adults</u> US	172 community-resident, 60 men 82 women, 62-94. Part of an original random sample of 243 surveyed by one of the investigators.	Spiral bound, two lists closed questions, one open question. 2 weeks Data source	Interview prior to the diary keeping period.	To monitor health actions as they occur on a daily basis.	Symptoms, pain, discomfort, actions, filling in the diary, other comments.	142
Bentzen, Christiansen, Pedersen, 1989, <u>Self-care within a model for demand for medical care</u> Denmark	2825 persons, 1067 households. A representative sample of Danish households with household heads above 16.	Structured, checklists. 52 weeks Data source	Diary used as part of the Danish Health Panel. A recruiting interview, a closing interview.	To count the number of episodes involving professional care, self-care or both types of care. Need to pick up less salient events and activities.	Symptoms, self-care activities, restrictions on activities, professional care sought, action taken by professional carers, expenditure. Life events reported weekly.	2661 persons, 998 households.
Tonal, Maezawa, Kamel, Satoh, Fukui, 1989, <u>Illness behaviour of housewives in a rural area in Japan: a health diary study</u> Japan	28 housewives aged 35-64, no chronic illness selected from 200 people living in a district of a rural village.	Structured questionnaire based on Freer's. 4 weeks Data source	Interview prior to the diary keeping period. Phone calls on two occasions through the diary period. Second home interview, ask which had been the main problems.	To show the health diary could be adopted for a non-Western culture, using same structure thus permitting comparisons.	Health problems, including psychological or emotional, trivial and transient. Symptoms, events, medicines, discuss problems with anyone, see someone, action taken to make self feel better.	27, one filled in 3 weeks of diaries.

Authors	Study Population	Diary format, duration, purpose	Other methods	Study aim	Diary contents	Completion rate
Gold, Weiss, Tager, Segal, Speizer, 1989, <u>Comparison of Questionnaire and Diary Methods in Acute Childhood US</u>	422 children, aged 5-11, random sample from public and parochial schools in East Boston, predominantly of Italian-American descent.	Check list. 2 years Data source	Standardized questionnaires prior to diary period, 2 weekly phone calls, some structured interviews during diary period.	Assess two methods for the prospective collection of information on acute respiratory illness, see if different methods leads to differences in identifying different symptoms.	Symptoms, severity.	1 st year 70% submitted > 6 months of diary data, compared with 92% in the questionnaire data. Two diaries in the second year contained more than 6 months data.
Montgomery, Reynolds, 1990, <u>Compliance, reliability and validity of self-monitoring for physical disturbances of Parkinson's Disease</u> US	84 ambulatory outpatients with Parkinson's, 60 men, 24 women. 59 patients volunteered, 25 participants included from another study, 73 took part.	Structured, boxes. 1 week Data source	Laboratory assessment of participants, interview, questionnaire and filming of participants as performed simulated daily activities, prior to diary period.	A self-assessment exercise to compliment traditional methods of clinical and laboratory assessment in the care and evaluation of Parkinson patients.	Symptoms, frequency and severity four times daily.	511 diaries requested, 497 received
Richardson, 1994, <u>The health diary: an examination of its use as a data collection method</u> UK	Discussion Of different types of health diaries for different types of health problems.	Structured, unstructured, journal or ledger. Data source or memory aid. Diary fatigue seems to kick in over time.	Various - usually interviews, both telephone and face-to-face, questionnaires.	To assess the use of diaries in producing valid and reliable data in nursing practice settings	.Symptoms, use of services, restricted activity, actions, medicines, events, advice given, general health.	In general good, seems to be linked to amount of monitoring.
Burman, 1995, <u>Health Diaries in Nursing Research and Practice</u> US	Discussion of different types of health diaries for different types of health problems.	Structured, unstructured, journal or ledger. Varies Data source or memory aid	Various - interviews, both telephone and face-to-face, questionnaires.	To describe current uses of health diaries in nursing research and practice, the types of typical health diaries, factors affecting the quality of diary data, and the costs and analytic issues related to health diaries. The implications for nursing are considered.	Daily problems, symptoms, self-care, lay and professional consultation, effectiveness of actions.	Vary, but typically about 80% of those who agree to take part complete, and only a small % of items are not completed.

Authors	Study Population	Diary format, duration, purpose	Other methods	Study aim	Diary contents	Completion rate
Osman, Dunt, 1995, Factors Influencing mothers' decisions to consult a general practitioner about their children's illnesses Australia	All mothers with children 11-26 months in one suburb of Melbourne identified from the health centre register. 121 mothers identified as suitable for study.	Refers to Roghmann & Haggerty. 4 weeks. Data source	Interviewed in own home using an open-ended, semi-structured questionnaire	To assess the influence of sociodemographic factors, social network, reason for choice of doctor and contact with allied health professionals on mothers' decisions to consult a GP about their children's illnesses	Symptoms, medical and paramedical consultations.	108, 72%
Elliot, 1997, The Use of Diaries in Sociological Research on Health Experience UK	Eight diarists selected from a subsample of 80 informants from a study designed to ascertain prevalence of musculoskeletal symptoms and patterns of helpseeking	Open diary, unstructured though guidance was given. 3 weeks. Data source, memory aid.	Questionnaire, clinical examination, in-depth interview, conversations when diaries were collected.	To assess: the potential of the 'diary interview', the extent it captures diarists' priorities; importance of the illuminates context of helpseeking; diaries as a record and reflection on the experience of illness; what is taken for granted.	Symptoms, actions, discussions with who, formal and informal care.	8 completed, one who was invited to take was unable to.
Bruijnzeels, Foets, Van der Wouden, Van den Heuvel, Prins, 1998, Everyday symptoms in childhood: occurrence and general practitioner consultation rates Netherlands	A random sample of 100 patients selected from each GP practice list was invited to take part, this included 2561 children, the parents of 1805 agreed to take part	21 page booklet, questionnaire, closed and open questions. 3 weeks. Data source and memory aid.	Structured questionnaire, prior to diary period, 2 phone calls during.	To investigate the occurrence of, and consultation rates for, specific symptoms in childhood in relation to age, sex, birth order, and place of residence of the child, and season of the year.	Experience of illness, self-care and formal health care.	423 completed 4 week health diaries.

Authors	Study Population	Diary format, duration, purpose	Other methods	Study aim	Diary contents	Completion rate
Rogers, Nicolaas, 1998, <u>Understanding the patterns and processes of primary care use: a combined quantitative and qualitative approach</u> UK	Three different areas in the North-west of England, with different demographic, social and economic characteristics, purposive sampling, frequent consulters, elderly, chronic conditions, communal establishments	Structured. 4 weeks. Data source, memory aid.	Two-stages, a survey and diary followed by in-depth interviews	To link health status to use of health care which may inform policy - resources, and to provide data to inform a long term programme examining the relationship between need and demand for primary care.	Experience of illness, self-care and formal health care.	423 completed 4 week health diaries
Gijsbers Van Wijk, Huisman, Kolk, 1999, <u>Gender differences in physical symptoms and illness behaviour</u> A health diary study Netherlands	A healthy primary care sample of 92 women and 61 men.	Structured, scales for physical symptoms, illness behaviour, external information, positive, negative mood 4 weeks. Data source.	Initial structured interview, telephoned at least once during diary period.	To investigate the psychological determinants of gender differences in physical symptoms and illness behaviour on a daily basis.	External information, negative and positive mood, physical symptoms and illness behaviour	139, 57 men, 82 women.

Appendix G Letter and information sheet.



18.06.02.

Dear insert name

First, thank you again for taking part in the 2000/1 round of nurse-interviews for the Twenty-07 Study. We are very grateful to you, and all the other participants, for giving up your time to be interviewed. The Study could not be the success it is without the help of all the participants.

As you know, the nurse interviews are very structured and do not give people much chance to talk in more detail about their experience of health. We are conducting a small number of extra interviews which give people much more chance to express their detailed views about some topics. I am writing to ask whether you would be willing to take part in one of these extra interviews about people's experience of managing symptoms in their day-to-day life.

Taking part in the study would involve completing a health diary for up to two weeks, and up to two interviews of around 45 minutes. These would be conducted by one of our researchers, Anne Mills, who would be happy to travel to your home at whatever time best suits you. Alternatively, the interview could be conducted at the University (with travelling expenses paid), if this would be more convenient for you. As recompense for the time involved in taking part in the study a voucher or cash payment to the value of £20 will be made.

Anne will phone you in the next few days, and ask if you would be happy to take part. If you have any questions about this interview, please do not hesitate to contact Anne (0141 357 7560).

Thank you again for all your help.

With best wishes

Professor Sally Macintyre

MANAGING HEALTH AND ILLNESS: YOUR EXPERIENCE A Research Project

What is the Research about? This research is about people's experience of managing health and illness. We are interested in hearing in people's own words what helps and hinders dealing with symptoms on a day-to-day basis.

How did we get your name? This project is based at the Medical Research Council (MRC), the University of Glasgow and is part of the West of Scotland Twenty-07 Study. We are approaching a small group of people to take part in this more detailed study.

What will taking part in the study involve? The research could involve two interviews with a researcher and filling in a health diary for two weeks. *However, if you felt like stopping at any time, and not completing all the stages, that would be fine.* The interviews could take place at your home at whatever time is most suitable. Alternatively, the interviews could be conducted at the University (with travelling expenses paid), if this would be more convenient for you.

If you decide you'd like to help with the study, the first interview will be about health issues that you see as important and how you deal with symptoms in your day-to-day life. The diary will be a daily record of any symptoms that you may experience in the two week period and how you deal with them. The second interview will be based on what you have written in the diary, and anything else you may have thought about after the first interview.

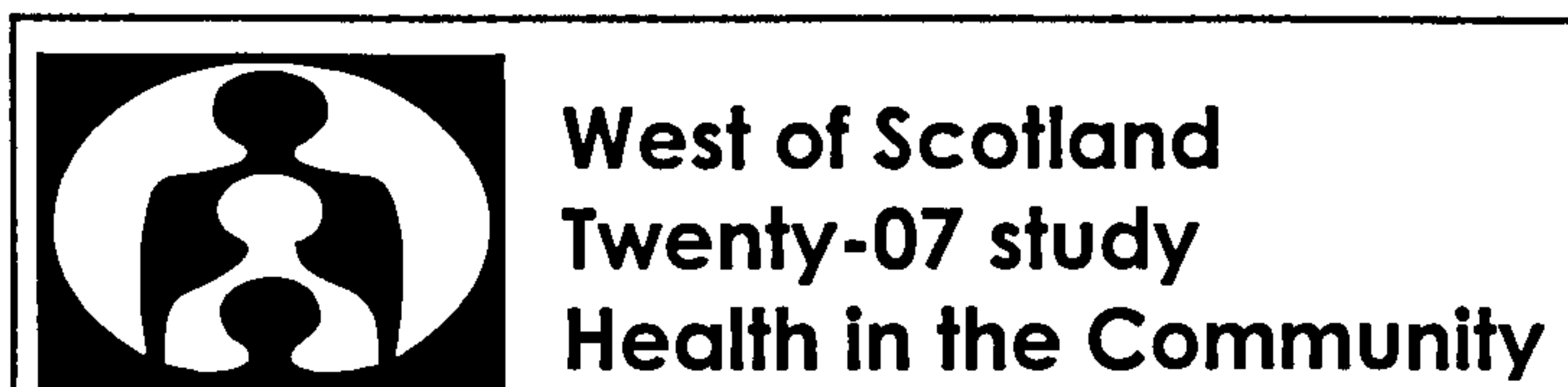
The interviews should only last about 45 minutes. If you are happy for the interview to be tape recorded then this will help to make sure that what you say is recorded accurately. You can ask for the tape recorder to be switched off at any time, or let the researcher know that you do not wish to be recorded.

Will the information be confidential? Yes, any information you give us is completely confidential. Short, anonymous extracts of your interviews may be used in research papers, but your real name would never be used. MRC requires us to keep all research documents in a locked cabinet for at least ten years, for quality assurance purposes, but your name and identifying details will remain anonymous.

What happens now? Anne Mills will contact you to see if you want to take part in the study and if you do she will arrange a suitable time and place to conduct the initial interview.

Who can I contact for more information? If you would like more information before deciding to take part in the study, please phone me. My name is Anne Mills, and my phone number is: 0141 357 7560

The research is funded by the Medical Research Council.
MRC Social & Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow, G12 8RZ



consent form

MANAGING HEALTH AND ILLNESS: YOUR EXPERIENCE

Please tick as appropriate

- I agree to be interviewed as part of this study on managing health and illness, as described in the information sheet.
- I agree that the interview may be tape-recorded.
- I give permission for brief extracts from my interview to be used for research purposes (including research publications and reports), with strict preservation of anonymity.

I understand that I do not need to answer all the questions if I do not wish to and that I may stop the interview at any time. I understand that any information I provide will be treated in the strictest of confidence.

Name -----

Signature -----

Date -----

MRC Social & Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow, G12 8RZ

Appendix I Thumbnail sketches of participants

Thumbnail sketches of participants

Frequent consulters

Dick is a frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary (14 days; comments on final page: none).

Family and work

He lives with his wife and daughter in rented accommodation. They have no family car. He was a 'charge hand in engineering' but has not worked for 14 years due to illness. His income is benefits based. His wife was a nursing assistant, but no longer works and is Dick's 'carer'. They have four grown up children; the youngest daughter is working and lives with them. Two other daughters live locally, one of whom has a son. They are in regular contact. They also have a grown-up son who lives in England.

Consulting and Illness

He had reported consulting the GP 12 times in the 12 months prior to the wave 4 interview, in June 2000 in which he had noted: angina, anxiety, depression, asthma, high blood pressure, liver problems, a hernia repair, and cataracts in both eyes. He reported having consulted the GP 12 times in the 12 months prior to the first study interview in August 2001, when he noted: heart problems, anxiety, depression, asthma, high blood pressure, liver problems, and migraine. He said that his most problematic conditions were depression and anxiety. He suffers panic attacks, which he finds distressing and debilitating.

Managing daily life

Dick takes regular medication, including tranquillisers, and uses other strategies to ease his symptoms, for example, going for walks and sitting quietly. He conveys an inability to control his symptoms. He is unable to be left in the house on his own, or go out alone. The only people he spends time with are his wife and children, and he would love to be able to 'just go to the shops on my own'.

Use of services

He finds the GP and other health workers very helpful. His wife consults the GP for medication, referrals, and advice, on his behalf, and visits the GP with him. He has been referred to see 'a carer', who will 'hopefully' help him go out and 'do things'.

Jim is a frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary (9 days, stopped because it made him too reflective; comments on final page: none).

Family and work

He is divorced and lives alone in rented accommodation. He has no car. He was a Fireman, but has not worked for about 18 months due to a disc injury. Prior to this he had experienced back pain for about 14 years. His income is benefits based. Jim was divorced about 2 years prior to the study interview. His wife was a technical clerk and they had lived in rented accommodation. They have a grown up son, who lives in Ireland, and visits about once a month.

Consulting and Illness

He had reported consulting the GP 8 times in the 12 months prior to the wave 4 interview in February 2001, in which he had noted: a bad disc injury, kidney problems, depression, arthritis, high blood pressure and a penicillin allergy. He reported having consulted the GP 12 times in the 12 months prior to the first study interview in April 2002, in which he noted: back pain caused by his disc injury, kidney problems, arthritis, high blood pressure, and a penicillin allergy. He had also developed sciatica. He said that his most problematic conditions were back pain and sciatica, which he finds debilitating, and sometimes depressing. He had been treated for depression for a short period when he had to give up work, but subsequently improved and is no longer on medication for this.

Managing daily life

Jim takes regular medication, including pain killers, for which he has a repeat prescription, and uses other strategies to ease his symptoms, for example pacing. Occasionally he has to use a walking stick. His back pain limits his lifestyle. He has few leisure activities now, and finds this difficult; his lifestyle has changed considerably since

his disc injury. He feels he has a very dull routine, and at times gets depressed but says he is able to control it, through talking to friends, going out, and 'not dwelling on things'. He is close to his son, and looks forward to his visits, when they go out for some beers, and a chat.

Use of services

He consults his GP for sick lines, but finds him unhelpful in terms of treatment, he sees 'no reason to keep going back when nothing can be done'. He collects a repeat prescription for pain killers. He has experimented with alternative therapies, for example, acupuncture.

Ian is a frequent consulter.

Interview status

He was interviewed twice, and did not fill in the health diary, because he 'doesn't like writing things down'.

Family and work

He lives with his wife, daughter and granddaughter in private accommodation, with a mortgage. He has a car which has been supplied by the Social Services. He was a Bingo caller but had not worked for more than 10 years due to illness. He is registered disabled, and his income is benefits based. Ian's wife was a nursing assistant, but she had to give up work due to illness. His grown up daughter does not work. They also have a grown up son, who lives with his girlfriend. He has had a leg amputated due to cancer.

Consulting and illness

He had reported consulting the GP 10 times in the 12 months prior to the wave 4 interview in October 2000, in which he had noted: asthma, a sore stomach, an abdominal hernia, high blood pressure, angina, had suffered two heart attacks, spondylitis, and 'worn' discs causing back pain. He reported having consulted the GP 8 times in the 12 months prior to the first study interview in November 2001, in which he reported: asthma, a sore stomach, an abdominal hernia, high blood pressure, angina, two heart attacks, spondylitis and 'worn discs' causing back pain. He also had had his leg amputated as a result of his vascular disease, and noted that he had developed erectile

dysfunction. He conveyed that the **most problematic condition** was the vascular disease, and the debilitating amputation, which he finds painful and frustrating.

Managing daily life

Ian takes regular medication including pain-killers, for which he has a repeat prescription, but consults his GP when he collects it. He uses equipment to help him manage, such as crutches, an electric wheelchair, and a false leg which is uncomfortable, and so he rarely wears it. His functional capacity and his lifestyle are severely limited. He struggles around the house, and the most basic actions are difficult. He manages, to go out and mix with his 'pals' at the local Bingo hall, where he used to work. He conveys a lack of control of his conditions.

Use of services

He finds the GP very helpful, and sees her for medication, check-ups; 'just to keep an eye on me', advice and referrals.

Janet is a frequent consulter.

Interview status

She was interviewed twice, and filled in the health diary (14 days, added comments on final page: 'it was good to do the diary').

Family and work

She lives with her husband and youngest son in rented accommodation. There is no family car. She has worked in several jobs, for instance as a hotel manager and 'supporting children with difficulties', but she had not worked for about ten years due to illness. Her income is benefits based. Janet's husband is a retired skilled labourer, and acts as her carer. Their youngest son is a teenager, and at school. They have another two grown-up children, one son who lives with his fiancée and baby on the same housing estate, who also has a child by a previous girlfriend. They also have a daughter living locally who has a car and gives Janet lifts and is in regular contact. She is married with two children, one a new-born baby.

Consulting and illness

She had reported consulting the GP 12 times in the 12 months prior to the **wave 4 interview** in July 2000, in which she had noted: asthma, high blood pressure, diabetes,

osteoporosis, 'blood clots', anxiety and depression. She reported having consulted the GP 12 times in the 12 months prior to the first study interview in August 2001, in which she noted: asthma, high blood pressure, diabetes, osteoporosis, anxiety and depression. She also had bronchitis and had had two minor strokes from which she had recovered. She had new health problems emerging, and was awaiting the results of a liver and kidney scan. She said that her **most problematic condition** was arthritis, which she finds painful, debilitating, frustrating and depressing.

Managing daily life

Janet takes regular medication, including painkillers, and tries other strategies to ease symptoms, for example, pacing, and resting. She does not take medication for her depression. She is in constant pain and this debilitates her. She is frustrated because she cannot work, and feels distressed about being unable to do things with her family, and often feels a burden. She cannot socialise, sees little of her friends, and has regular contact with her next door neighbour and occasional contact with a close friend who comes to visit. She conveys a lack of control of her conditions.

Use of services

She finds the GP very helpful, and consults him for pain relief; referrals; advice and support. She feels free to see him for both emotional and physical health problems. She is waiting to see a counsellor.

Betty is a frequent consulter.

Interview status

She was interviewed twice, and filled in the health diary (13 days; comments on final page: none)

Family and work

She had separated from her husband, in the previous 18 months, and lives with her youngest son in rented accommodation. There is no family car. She was working for BT which she enjoyed, but had not worked for about a year due to illness. Her income is benefits based. She is separated. Betty's youngest son is a teenager, at school, and acts as her main carer. Her husband was a shop-keeper, but the business failed, about 4 years previously, and they had to sell their house. He has left Betty for a woman who she says

is 'half his age'. She has three other grown up sons. Two of whom work, and one who is studying to be a teacher. He is married with a young baby. All live nearby, visit regularly, and are very supportive.

Consulting and illness

She had reported consulting the GP 12 times in the 12 months prior to the wave 4 interview, in September 2000, in which she had noted: depression, irritable bowel syndrome, sinus problems, sciatica, an ovarian cyst, migraine and tinnitus. She reported consulting the GP 12 times in the 12 months prior to the first study interview, in April 2002, in which she noted: depression, irritable bowel syndrome, sciatica, an ovarian cyst, and migraine. She had also been diagnosed with diverticulitis, arthritis, and multiple sclerosis (MS), which caused problems with her hearing and sight, and made her feel stressed. She said that the MS was her **most problematic condition**; it caused her pain, fatigue, loss of balance and incapacitated her, which she finds frustrating. She has been ill for about 15 years, but had deteriorated in the previous two years, and particularly the last year.

Managing daily life

Betty takes regular medication, including painkillers, and uses other strategies to ease her symptoms, for example pacing. She is on anti-depressants but is trying to reduce them. She feels her life has been significantly affected by her illness, including the break-up of her marriage. She rarely socialises, has a few close friends who visit her when they get the chance. She has no routine, and feels that she is not in control of her symptoms, illness, or her life.

Use of services

She visits the **GP** for medication, advice, and support. She feels he can't help much as he does not have the knowledge or the drugs. She is seeing a counsellor and an alternative therapist, and is in contact with self-help groups for information to help her manage her symptoms.

Lesley is a frequent consulter.

Interview status

She was interviewed twice, and did not fill in the diary, as she does not writing things down.

Family and work

She lives with her husband and one daughter in private accommodation and has a mortgage. There is a family car. She has worked as a cleaner, but gave this up 16 years ago due to illness. Her husband works full time, as a teacher, in a school for children with behavioural difficulties. Their daughter is training to be a psychiatric nurse. Both are very supportive and one of them tries to be in the house, as far as possible, so Lesley is not alone. Her sister also lives nearby and visits her regularly.

Consulting and Illness

She had reported consulting the GP 20 times in the 12 months prior to the wave 4 interview in September 2000 in which she had noted: high blood pressure, asthma, colitis, a duodenal ulcer, thyroid problems, anxiety and depression. She reported consulting the GP 20 times in the 12 months prior to the first study interview in November 2001, in which she noted: high blood pressure, asthma, colitis, a duodenal ulcer, thyroid problems, anxiety and depression. She said her **most problematic conditions** were anxiety and depression which incapacitate her to a significant degree.

Managing daily life

Lesley takes regular medication including tranquillisers. She uses other strategies to ease her symptoms, for example, 'keeping busy'. She does not like being in the house alone, and rarely goes out alone. She is not in control of her illness, and her activities are limited. Her neighbours and friends visit her, and sometimes she visits those who live close by.

Use of services

She finds the GP very helpful. She sees him for medication, advice and support, as well as referrals. She has seen a counsellor whom she found to be unhelpful.

June is a frequent consulter.

Interview status

She was interviewed once, but was too unwell to have the second interview. She filled in the health diary for 14 days; comments on final page: none.

Family and work

She lives with her husband and one daughter in private accommodation with a mortgage. There is a family car. She has worked as an auxiliary nurse, but gave this up 5 years previously due to illness. Her husband is a paramedic, he has just returned to work after a major operation. Her daughter works, and also has asthma. They have another older daughter who is married, has a son, and lives locally and they are in regular contact. June goes out in the car, which gives her an opportunity to get out of the house and visit people.

Consulting and illnesses

She had reported consulting the GP 16 times in the 12 months prior to the wave 4 interview in October 2000, in which she had noted: emphysema; angina; asthma and high blood pressure. She reported consulting the GP 12 times in the 12 months prior to the first study interview in June 2002, in which she noted: emphysema; angina; asthma and high blood pressure. She was also undergoing tests for pain which she had started to feel in her limbs. She said her **most problematic condition** was emphysema, which had been diagnosed 5 years previously, but she had been ill for 14 years with asthma. Her illness debilitates her to a significant degree, she finds it frustrating and depressing.

Managing daily life

June takes medication regularly uses a nebuliser, and other strategies to ease her symptoms, for example pacing. Her activities are severely limited. She finds it a struggle to perform basic actions and activities, and sometimes has to stay in bed all morning. She wants to move to a flat or bungalow, because she dreads going up the stairs, but she is not sure if they can afford it. Her social life and leisure activities have been curbed, and she is unable to play with her grandson.

Use of services

She finds the GP helpful, and consults for medication, advice and referrals.

Less frequent consulters

Derek is a less frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary for 14 days; comments on final page: none.

Family and work

He lives with his wife, only son and youngest daughter, in rented accommodation. There is no family car, nor is there a phone. He had not worked for many years, partly due to illness, which he had experienced for the last 14 years. He has 'always been a house-husband'. Derek's wife does shift work in a factory, his son works, and the youngest daughter is pregnant, and not working. They have another four grown-up daughters, one of whom lives 'across the road', and another two live locally. However, he does not like mixing with people, has no friends, and does not have contact with his wider family. He is still in contact with his father who lives in New York.

Consulting and illness

He had reported consulting the GP 3 times in the 12 months prior to the wave 4 interview in September 2001, in which he had noted: diabetes; depression, schizophrenia, an ulcer, a hiatus hernia and high blood pressure. He reported consulting the GP 3/4 times in the 12 months prior to the first study interview, in May 2002, in which he noted: diabetes, depression, schizophrenia, an ulcer; a hiatus hernia and high blood pressure. He said his most problematic conditions were schizophrenia and depression, but added that they were largely controlled with medication.

Managing daily life

Derek is on regular medication, which he relies upon totally. He is quite happy to live his routine life. He watches the television, does crosswords, and plays chess with his children and shops locally. He does not feel that he is limited, but does say that he has no friends, nor does he want them, but he does feel this is an aspect of his illness.

Use of health services

Derek is very happy with the GP and other health service workers; he sees his GP if his symptoms deteriorate which happens occasionally. He also sees a psychiatrist.

Johnny is a less frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary for 14 days; comments on final page: none.

Family and work

He lives with his wife, and two grown up sons, in private accommodation with a mortgage. They have one family car. He works in a machines factory, which he 'hates'. His wife, works as a tax officer, and both of his sons work.

Consulting and illness

He had reported consulting the GP twice in the 12 months prior to the wave 4 interview in September 2000, in which he had noted: diabetes, kidney problems, high blood pressure, depression, and alcohol problems. He reported consulting the GP twice in the 12 months prior to the first study interview, in September 2001, in which he noted, diabetes, kidney problems, high blood pressure, depression, and alcohol problems. He said that the most problematic conditions were depression, which caused him to feel nauseous and have trouble sleeping, and diabetes which caused him to have 'hypos'. He had had diabetes for over 15 years, and problems with depression and alcohol for about 5 years.

Managing daily life

Johnny takes insulin regularly, and uses other strategies to ease his symptoms, for example a careful diet for his diabetes and he drinks alcohol to relax at week-ends. He does not take medication for his depression. He drinks heavily at the week-ends and this can impact on his diabetes, one consequence is that he has lost his driving license on medical grounds. He is able to work full time and socialise with friends, which means he can 'have a laugh' and takes his mind of his job. He manages to control his depression and as he says he 'could control the diabetes better'.

Use of services

Johnny does not find his GP helpful, as he offers him medication for depression, which he does not want. The GP has also has told him to change his job, which Johnny thinks is 'daft', and offers him sick lines, which he does not want because of the way sick pay is organised.

Paul is a less frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary for 11 days: comments on final page: none.

Family and work

He lives with his wife, in private accommodation with a mortgage. They have one family car, which Paul uses for work, as he is a full time taxi driver. He had worked as a fork lift driver up until about 9 years previously, and had to give that up because of his back pain. He was then unemployed for about two years. His wife works as a shop manager, and he has one son who is working, and married. Paul works full time as a taxi driver, and explains that this is probably the only job he can do, as he can juggle time at work, and at home. He had a period of being out of work about 7 years ago.

Consulting and Illness

He had reported consulting the GP 3 times in the 12 months prior to the wave 4 interview in October 2000, in which he noted: mechanical back pain, general joint pain, photosensitivity, stomach problems, and hay fever. He was also a recovering alcoholic. He reported consulting the GP 3 times in the 12 months prior to the first study interview in November 2001, in which he noted: mechanical back pain, general joint pain, and he was photosensitive. He was also recovering from an operation on his shoulder which was related to his joint pain, and he talked of his long term alcoholism. He said his most problematic conditions were back and joint pain. He had not had a drink for about 10 years and regularly attended Alcoholic Anonymous meetings, which he felt 'had turned his life around.'

Managing daily life

Paul takes regular painkillers, and tries other strategies to ease the pain. He is trying to avoid taking stronger painkillers. He uses other strategies to ease his symptoms, for example pacing, and equipment such as special pillows. He is in constant pain and this debilitates him, but he has adjusted his routine and adapted. He feels that he could probably not have any other employment as being a self-employed taxi driver gives him flexibility. He manages to work full time, socialise and go on holiday. For now he seems to be able to control his symptoms.

Use of services

He finds his GP unhelpful, and unsympathetic, he collects repeat prescriptions, and sees little reason to consult. He also sees an alternative practitioner on occasion, and regularly attends Alcoholics anonymous.

Peter is a less frequent consulter.

Interview status

He was interviewed twice, and filled in the health diary but it got lost in the post.

Family and work

He lives with his wife, and two teenage sons in private accommodation with a mortgage. They have two family cars. Peter is a science teacher, and is Head of Department in a Comprehensive school. He explains that he would not be able to do a more manual job. His wife works full time at the University as an administrator, and their sons are at school.

Consulting and Illness

He reported consulting the GP twice in the 12 months prior to the wave 4 interview in November 2000, in which he noted: the lasting effects of a proctectomy and illeostomy, a pelvic abscess, asthma and eczema. He reported consulting the GP 3 times in the 12 months prior to the first study interview in October 2001, in which he had noted: the proctectomy and illeostomy, pelvic abscess, asthma and eczema. He said his most problematic conditions were the proctectomy and illeostomy, which had caused the abscess, and gave him severe and constant pain. He has had this for about twenty years, when he had had the operation to remove his bowel as a result of ulcerative colitis.

Managing daily life

Peter takes high quantities of pain killers and uses other strategies to ease his symptoms, for example pacing. He is able to manage work, and leisure around his symptoms, by resting, using equipment, and a complex drugs regimen. He works hard at juggling his symptoms around his daily life. He has had time off work in the past because of the abscess, but has not taken time off for his 'normal' pain.

Use of services

He finds the GP sympathetic, but 'an innocent bystander' in that they have explored and experimented, with a range of treatments, but medication is the only thing he can rely

on, for which he has a repeat prescription. Despite this he still discusses things with the GP from time to time. The GP referred him to a pain clinic which offers him 'weird and wonderful' remedies.

Sarah is a less frequent consulter.

Interview status

She was interviewed once, as I could not contact her to arrange a second interview. She did not fill in the health diary.

Work and family

She lives with her adult son and daughter, in rented accommodation. They have no family car. Sarah works full time as a Primary School teacher, and is able to juggle symptoms around her work. Sarah has been divorced for about twenty years, and both her son and daughter work.

Consulting and illness

She reported consulting the GP once in the 12 months prior to the **wave 4 interview** in March 2001, in which she noted: irritable bowel syndrome, migraine, high blood pressure and inner ear problems. She reported consulting the GP twice in the 12 months prior to the **first study interview** in August 2001, in which she noted: irritable bowel syndrome, migraine, high blood pressure and inner ear problems. She also had endometriosis which was improving. She said the **most problematic condition** was irritable bowel syndrome, causing her pain, embarrassment, discomfort and practical problems. She had had this condition for over 40 years.

Managing daily life

Sarah takes occasional medication, including pain killers, and uses other strategies to manage, for example a careful diet. She conveys that she is able to control her symptoms. She is able to work full time, and socialise with friends.

Use of services

She feels no need to see the GP for her ongoing conditions.

Mary is a less frequent consulter.

Interview status

She was interviewed twice, and filled in the health diary for 8 days, then was too busy; comments on final page: she had enjoyed writing things down.

Family and work

She lives with her husband in rented accommodation. They have no family car. Her income is benefits based. Mary is a housewife, and her husband's carer. She has worked as a machinist and as a domestic assistant in the past. She and her husband have one grown up daughter. Her husband was a driver for a builder's merchant, who has chronic co-morbidity, including cancer, he has responded to treatment. Their grown up daughter lives locally and is a nurse. She also sees her two married sisters and their husbands regularly. She has one nephew who she visits her weekly.

Consulting and illness

She had reported consulting the GP 3 times in the 12 months prior to the wave 4 interview in October 2000, in which she noted: osteoarthritis, partial deafness, a gastric ulcer, and sinus trouble. She reported consulting the GP twice in the 12 months prior to the first study interview in May 2002, in which she noted: osteoarthritis, which had improved, and partial deafness. She said the most problematic condition was her deafness, which she had had for over ten years, and for which she wears a hearing aid.

Managing daily life

Mary takes pain killers occasionally, and uses other strategies to ease her symptoms, for example pacing. She says her conditions and symptoms do not impact on her life, and so could not say which was most problematic. She socialises and visits family and friends. She has lost weight and thinks this has eased her symptoms. She has a routine which is not disrupted by her illness, and feels in control of her symptoms.

Use of services

She has found the GP helpful at times. But she has no need to see her currently.

Martha is a less frequent consulter.

Interview status

She was interviewed twice, and filled in the health diary for 14 days; comments on final page: did not see how the diary was helpful to the research.

Family and work

She lives with three sons, in rented accommodation. They have a family car. Martha works full time at the local newsagents. Martha has been divorced for 18 years. Her three grown up sons who live with her all work. She has another son who lives locally, is working, and is married, with two children. She sees him and his family regularly.

Consulting and illness

She had reported consulting the GP once in the 12 months prior to the **wave 4 interview** in September 2000, in which she had noted: high blood pressure; a collapsed lumbar disc, osteoarthritis, and long-sightedness. She had reported consulting the GP twice in the 12 months prior to the **first study interview** in July 2002, in which she had reported high blood pressure; back problems; osteoarthritis, and eye problems. She also had sciatica and thyroid problems. She said the **most problematic conditions** were her back and leg pain, but her high blood pressure worried her. She had had the same problems for several years.

Managing daily life

Martha takes regular medication, but rarely takes painkillers. She uses other strategies to ease her symptoms, for example, pacing. She enjoys her work, and she socialising with friends. She seems to have adjusted, and for now seems in control.

Use of services

She finds the GP unhelpful, as in the past she has been told that there is nothing wrong with her.

Jane is a less frequent consulter.

Interview status

She was interviewed twice, and filled in the health diary for 14 days; comments on final page: none about diary.

Family and work

She is single, lives alone in private accommodation, and owns a car. She works as an audio copy typist, and had just changed her working hours from full time, to flexi-time, due to stress. She does not like her job, and feels that her stress and anxiety have improved since she has changed her hours at work. Jane has a brother, a sister, and nephews with whom she is in contact. She has few friends and does not tend to socialise.

Consulting and illness

She had reported consulting the GP the GP once in the 12 months prior to the wave 4 interview in September 2000, in which she had noted: stress, anxiety, oesophageal reflex, numbness in her right hand, back pain, and patchy keratosis. She had reported consulting the GP twice in the 12 months prior to the first study interview in September 2001, in which she had reported stress, anxiety, oesophageal reflex, numbness in her right hand, back pain, and patchy keratosis. She also reported stress incontinence/ vaginal discharge which she had had for about 8 years, but had not reported at wave 4. She said the most problematic conditions were stress, anxiety and the stress incontinence/vaginal discharge, which she found embarrassing.

Managing daily life

Jane takes occasional medication, and uses other strategies to ease her symptoms, for example pacing. She tends to 'work around' her symptoms, and contain her illness.

Use of services

She feels seeing the GP would be a waste of time as she has had her symptoms investigated over the course of a few years, and been told nothing can be done.

Marie is a less frequent consulter.

Interview status

She was interviewed twice, and did not fill in the diary, as she did not have the time.

Family and work

She is married and lives with her husband, in private accommodation, with a mortgage. They have two family cars. She works part time as a language teacher in a comprehensive school. She had worked full time in a private school and was head of department but had had to give it up due to illness about 4 years previously. Her husband owns a restaurant, they have three grown up daughters, two work away from home, and the youngest is at university in London.

Consulting and illness

She had reported consulting the GP twice in the 12 months prior to the wave 4 interview in July 2000, in which she had noted: myalgic encephalitis (ME), a cyst on her thyroid gland, palpitations and an allergy to dust. She had reported consulting the GP once in the

12 months prior to the first study interview in October 2001, in which she had noted: myalgic encephalitis and palpitations. She also experienced bouts of cystitis. She said the most problematic condition myalgic encephalitis, which had improved significantly since wave 4, and she had just started teaching again, on a part time basis.

Managing daily life

Marie takes medication for palpitations, but avoids other drugs, and uses other strategies to ease her symptoms, for example pacing. She finds traditional medicine has not helped her with ME, and uses alternative therapies. She still experiences: muscle ache, fatigue, dizziness. However, she is able to pace her activities, with friends, and her job, feels in control of her illness, and is able to live a 'normal' life. She enjoys the gym, swimming and the sauna which she feels help.

Use of services

She does not find the GP helpful for her ongoing conditions. She feels the GP offers medication and does not explore the causes of illness and symptoms.

Rita is a less frequent consulter.

Interview status

She was interviewed once, and did not fill in the diary, as she lost it.

Family and work

She lives with her fiancé, in private accommodation, with a mortgage. They have no family car. She works full time in a garage. She and her partner were due to be married. He had worked as a chef, but had to give it up due to his chronic illness, he had chest problems and used an oxygen cylinder. Rita had been divorced for many years, and has a grown up son, who she has had no contact with for two years. She has two grandchildren who have different mothers, both of whom are separated from her son. One of the mothers does not allow her to see her grandchild. The other grandson, she sees often, but there are problems about this. She does not have a good relationship with his mother, and this makes her anxious.

Consulting and illness

She had reported consulting the GP twice in the 12 months prior to the wave 4 interview in November 2000, in which she had noted: breast cancer, anxiety, depression, panic

attacks and a gastric ulcer. She had reported consulting the GP once in the 12 months prior to the first study interview in May 2002, in which she had noted breast cancer, a gastric ulcer, depression and anxiety. She had also developed skin problems. She was about to come off her cancer medication and, she hoped, be given the 'all clear'. She said the most problematic conditions were depression and anxiety. She had experienced these for over 14 years.

Managing daily life

Rita takes regular medication for her cancer, but tries not to take anything else. She uses other strategies to ease her symptoms, for example talking to a friend. She says she is in control of her symptoms. She socialises, works and goes to the Bingo.

Use of services

She finds the GP unhelpful and unsympathetic. She gets a repeat prescription for her medication, very occasionally takes tranquillisers but has not for about a year. She went to the well woman clinic about her cancer, and has not seen the GP about this. She is in contact with the 'cancer nurse'. She does not like to take drugs of any kind, has been addicted to them in the past, which she blames a previous GP for. She is thinking of seeing an alternative therapist.

Appendix J Condition List

Card 1

- 01 Bronchitis and respiratory disease
- 02 Arthritis and Rheumatism
- 03 Cancer
- 04 Asthma
- 05 Stomach ulcers and gastric problems
- 06 Gall bladder problems
- 07 Hernias
- 08 Epilepsy
- 09 Diabetes
- 10 Problems with the nervous system. Eg Multiple Sclerosis or Parkinson's Disease
- 11 High blood pressure
- 12 Angina
- 13 Other heart trouble
- 14 Stroke
- 15 Circulatory problems eg. 'hardening of the arteries'
- 16 Liver problems
- 17 Migraine
- 18 Thyroid problems
- 19 Cystitis
- 20 Other kidney, Urinary or Prostate problems

Card 2

- 21 Spondylitis
- 22 Sciatica
- 23 Other back problems
- 24 Colitis
- 25 Diverticulitis
- 26 Hay fever
- 27 Sinusitis
- 28 Anaemia
- 39 Skin problems
- 40 Allergy
- 41 Tinnitus
- 42 Other problems with ears or hearing
- 43 Problems with eyes or sight
- 44 Problems with alcohol
- 45 Anxiety or Depression