
A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy (PhD.)
In the Faculty of Medical and Human Sciences

2011

Rebecca Lauren Morris
School of Medicine, Division of Primary Care
## CONTENTS

List of Appendices 7
List of Tables 8
List of Figures 9
Abstract 10
Declaration 11
Copyright Statement 12
Dedication 13
Acknowledgements 14
Abbreviations 15
The Author 16

Chapter 1  Introduction to the thesis 17
1.1  Introduction 17
1.2  Context and justification for the research 18
1.3  Aim and Research Questions 20
1.4  The structure of the thesis 20

Chapter 2  What influences how, and to what extent, individuals ‘self’-manage? 22
2.1  Introduction 22
2.2  Self-management for chronic illness 23
2.3  The role of formal health care in supporting self-management 25
2.3.1  The patient-clinician relationship 26
2.4  Formal self-management support: the role of education programmes and support groups 30
2.5  The meaning of illness management for an individual in a social context 33
2.6  The role of family and friends in ‘self’ management 37
2.7  Summary 41

Chapter 3  What can social networks and social capital add to the understanding of long term condition management? 42
3.1  Introduction 42
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2 Defining social networks</td>
<td>43</td>
</tr>
<tr>
<td>3.3 Defining social capital</td>
<td>45</td>
</tr>
<tr>
<td>3.4 Social networks: more than social support?</td>
<td>50</td>
</tr>
<tr>
<td>3.5 The role of social networks and social capital in long term condition management</td>
<td>54</td>
</tr>
<tr>
<td>3.6 The role of professional network members in long term condition management</td>
<td>55</td>
</tr>
<tr>
<td>3.7 The role of lay networks in long term condition management</td>
<td>56</td>
</tr>
<tr>
<td>3.8 Summary</td>
<td>58</td>
</tr>
<tr>
<td>Chapter 4 Methods and methodology</td>
<td>61</td>
</tr>
<tr>
<td>4.1 Background to this study</td>
<td>61</td>
</tr>
<tr>
<td>4.2 Research Design</td>
<td>62</td>
</tr>
<tr>
<td>4.3 Research Questions</td>
<td>62</td>
</tr>
<tr>
<td>4.4 Research Approach</td>
<td>63</td>
</tr>
<tr>
<td>4.4.1 Taking a qualitative social network approach: the role of narrative descriptions</td>
<td>64</td>
</tr>
<tr>
<td>4.4.2 A longitudinal approach</td>
<td>65</td>
</tr>
<tr>
<td>4.5 Quality and rigour in qualitative research</td>
<td>65</td>
</tr>
<tr>
<td>4.6 Methods</td>
<td>67</td>
</tr>
<tr>
<td>4.6.1 Semi-structured interviews as a method</td>
<td>67</td>
</tr>
<tr>
<td>4.6.2 Making invisible support visible: use of network elicitation diagrams</td>
<td>68</td>
</tr>
<tr>
<td>4.6.3 Recruitment and sampling strategy</td>
<td>69</td>
</tr>
<tr>
<td>4.6.4 Participants</td>
<td>72</td>
</tr>
<tr>
<td>4.6.5 Data collection</td>
<td>73</td>
</tr>
<tr>
<td>4.6.5.1 Pilot semi-structured interview</td>
<td>73</td>
</tr>
<tr>
<td>4.6.5.2 Initial semi-structured interview</td>
<td>74</td>
</tr>
<tr>
<td>4.6.5.3 Telephone follow-up semi-structured interview</td>
<td>75</td>
</tr>
<tr>
<td>4.6.5.4 Final semi-structured interviews and network elicitation</td>
<td>76</td>
</tr>
<tr>
<td>4.7 Data Analysis</td>
<td>77</td>
</tr>
<tr>
<td>4.7.1 The process of analysis</td>
<td>78</td>
</tr>
<tr>
<td>4.8 Ethical considerations</td>
<td>80</td>
</tr>
<tr>
<td>4.8.1 Obtaining consent and the disclosure of sensitive information</td>
<td>80</td>
</tr>
</tbody>
</table>
4.8.2 Confidentiality and anonymity

4.9 The role of the researcher: my role in shaping the interview data

4.10 Summary

### Chapter 5 The social networks of individuals with long term conditions

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Introduction</td>
<td>86</td>
</tr>
<tr>
<td>5.2</td>
<td>Size and basic composition of social networks</td>
<td>86</td>
</tr>
<tr>
<td>5.3</td>
<td>Unpacking the structural elements of the network</td>
<td>91</td>
</tr>
<tr>
<td>5.3.1</td>
<td>Family</td>
<td>92</td>
</tr>
<tr>
<td>5.3.2</td>
<td>Partners</td>
<td>93</td>
</tr>
<tr>
<td>5.3.2.1</td>
<td>Instrumental support</td>
<td>94</td>
</tr>
<tr>
<td>5.3.2.2</td>
<td>Emotional support</td>
<td>95</td>
</tr>
<tr>
<td>5.3.2.3</td>
<td>Barriers to illness management</td>
<td>97</td>
</tr>
<tr>
<td>5.3.3</td>
<td>Children</td>
<td>98</td>
</tr>
<tr>
<td>5.3.3.1</td>
<td>Differentiation between types of support from different children</td>
<td>99</td>
</tr>
<tr>
<td>5.3.3.2</td>
<td>Influence of maintaining parental role on illness management</td>
<td>100</td>
</tr>
<tr>
<td>5.3.4</td>
<td>Siblings</td>
<td>101</td>
</tr>
<tr>
<td>5.3.4.1</td>
<td>Shared expectations of sibling relationship shape resource provision</td>
<td>101</td>
</tr>
<tr>
<td>5.3.4.2</td>
<td>Emotional support</td>
<td>102</td>
</tr>
<tr>
<td>5.3.4.3</td>
<td>Illness related work</td>
<td>103</td>
</tr>
<tr>
<td>5.3.4.4</td>
<td>Negative role of sibling relationships</td>
<td>105</td>
</tr>
<tr>
<td>5.3.5</td>
<td>Parents</td>
<td>107</td>
</tr>
<tr>
<td>5.3.5.1</td>
<td>Adult parent-child: information and emotional support</td>
<td>108</td>
</tr>
<tr>
<td>5.3.5.2</td>
<td>Reversal of the parent-child relationship: children protecting parents</td>
<td>110</td>
</tr>
<tr>
<td>5.3.6</td>
<td>Pets: the unexpected bridge</td>
<td>111</td>
</tr>
<tr>
<td>5.4</td>
<td>Friends and neighbours</td>
<td>115</td>
</tr>
<tr>
<td>5.4.1</td>
<td>Selectivity in seeking friendship support</td>
<td>117</td>
</tr>
<tr>
<td>5.4.2</td>
<td>Friends as substitutes for familial relationships</td>
<td>119</td>
</tr>
<tr>
<td>5.4.3</td>
<td>Barriers to support</td>
<td>119</td>
</tr>
<tr>
<td>5.4.4</td>
<td>The influence of network density</td>
<td>120</td>
</tr>
</tbody>
</table>
5.4.5  Reciprocity of support 121
5.4.6  Breaking, bonding and reconnecting ties of friendship 123
5.4.7  Absence of friendships in social networks 125
5.5  Health care professionals 127
5.5.1  The interpersonal relationship between patient and clinician 127
5.5.2  Defining legitimacy of illness and health service use 129
5.5.3  Visibility of condition 130
5.5.4  Continuity of care 132
5.5.5  Medication and condition control 134
5.6  Summary 135

Chapter 6  Types of health related social networks 137
6.1  Introduction 137
6.2  Three types of networks 139
6.2.1  Defining critical moments 141
6.2.2  Comparing the three types of social networks 142
6.3  Family focused network 145
6.4  Friend focused network 154
6.5  Health care professional focused network 163
6.6  Summary 171

Chapter 7  The role of multiple conditions on illness management and social networks 172
7.1  Introduction 172
7.2  Multiple conditions and illness management 173
7.2.1  The influence of social roles on multiple condition management 174
7.3  The dynamic prioritisation of conditions 176
7.3.1  The role of expectations of illness on condition prioritisation 176
7.3.2  Relative visibility of conditions 177
7.3.3  Interactions with health professionals 178
7.3.4  Critical moments and their influence on multiple condition management 180
7.3.5  Medication management 182
7.4 Understanding of conditions 183
7.4.1 Accessing information resources 184
7.4.2 Information on exercise 185
7.5 Summary 186

Chapter 8  Changing networks, changing health management 188
8.1 Introduction 188
8.2 Positive change to health management 189
8.3 Negative changes to health management 196
8.4 Health management stayed the same 200
8.5 Summary 205

Chapter 9  Discussion 206
9.1 Introduction 206
9.2 Social networks: more than social support? Revisited 211
9.3 Multimorbidity and ‘self’-management 213
9.4 Evolving ‘self’-management? 214
9.5 Strengths and limitations of this study 217
9.6 Further research 220
9.7 Conclusion 223

References 224

Word Count: 81455
List of Appendices

Appendix 1: Blank network diagram 242
Appendix 2: Initial interview guide 242
Appendix 3: Patient demographic sheet 246
Appendix 4: Monthly telephone interview guide 248
Appendix 5: Letter inviting participants back into the study 249
Appendix 6: Final interview guide 250
Appendix 7: PRISMS Form 257
Appendix 8: Coded sheet of transcript (Tod’s final interview) 259
Appendix 9: Ethical Approval Letter 260
Appendix 10: Participant Information Sheet 263
Appendix 11: Participant Consent Form 266
Appendix 12: Journal paper entitled "Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions" 267
List of Tables

Table 4.1 Methods used to ensure trustworthiness in this study 66

Table 4.2: A table of participant demographic information and types and amount of multiple conditions reported (n=30) 72

Table 5.1: The total number of each type of relationship included in the network diagrams 88

Table 5.2: The total number of each network member placed in the network elicitation diagram per category of importance 90

Table 5.3: A tally of the total distance that each network member lives or works from the ego 91

Table 6.1: The criteria for selection and characteristics of the three types of social networks for condition management 144
List of Figures

Figure 4.1 Participant recruitment flow chart 71

Figure 4.2: Data collection flow chart 75

Figure 5.1 The personal health related social network of participant Jack 114

Figure 6.1: A summary of the specific ways that social networks influence long term condition management 138

Figure 6.2 The personal health related social network of Don 146

Figure 6.3 The personal health related social network of Tina 151

Figure 6.4: The personal health related social network of participant Ron 156

Figure 6.5: The personal health related social network of Rita 161

Figure 6.6: The personal health related social network of Tom 165

Figure 6.7: The personal health related social network of Frank 168

Figure 8.1 The personal health related social network of Leo 192

Figure 8.2 The personal health related social network of Lyn 194

Figure 8.3 The personal health related social network of Catherine 198

Figure 8.4 The personal health related social network of Chris 201

Figure 8.5 The personal health related social network of Donna 204
Abstract

The University of Manchester

Abstract for thesis by Rebecca Lauren Morris
For the degree of PhD titled: ‘Evolving ‘self’-management? A qualitative study of the role of social networks for chronic illness management in primary care’
Submitted date: 17th August, 2011

Background: Much social network analysis in health related research has focused on the impact of social networks in the genesis of long term conditions and associated inequalities. However, there has been little research on the role of social networks in the management of such conditions. This is significant at a time when increasing policy emphasis is placed on individual self-care and assumptions are often made about social support, and familial support in particular. The management of chronic illness is complex involving the interplay of personal and contextual factors and comprised of a number of daily activities which include the ongoing negotiation of management into existing roles and the degree of individual engagement with self-management. Little is known about how these aspects interact to shape and influence management, what constitutes a social network for individuals with long term conditions and whether this changes over time.

Methods: This study was embedded within the Whole Systems Informing Self-management Engagement (WISE) randomised control trial. It used a longitudinal qualitative design with initial face to face in-depth interviews, telephone follow-ups over a year and final face-to-face interviews where sociograms were also used to elicit network structure.

Results: The findings suggest that who is in the social network, and the types of relationships which are present, influence how management practices are framed and the extent to which they are engaged with. Resources available to an individual through the network support, or undermine, engagement and changed over time. Networks included family, friends, GP, nurses and companion animals. The amalgamation of the different types of relationships that constitute the social networks are characterised by three typologies; the family focused network, the friend focused network and the health care professional focused network. These network types reflected where support was sought in times of crisis. In the absence of ‘typical’ sources accounts highlighted the substitutability of network members which was often narrowly sought from key individuals. Changes in illness management, either positive or negative, were framed around critical moments as they challenged existing norms of practice and involved significant network members. Further, co-morbid conditions placed an additional complexity to management and priorities were shaped by the recursive relationship with health services which seemingly influences patients’ orientation in becoming either active assessors of health care or less engaged through being overwhelmed.

Conclusions: This thesis challenges the notion of ‘self’-management as an individual construct as many of the practices of illness management involved the support and/or negotiation of roles with others. Critical moments are a key point where normalised management practices are challenged and have particular relevance for future interventions which could foster these critical points to facilitate such changes in routines. Interventions and education need to reflect this wider setting in which chronic illness management occurs for the practices of management to become normalised into everyday routines.
Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning;
Copyright Statement

The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made only in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://www.campus.manchester.ac.uk/medialibrary/policies/intellectual-property.pdf), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see http://www.manchester.ac.uk/library/aboutus/regulations) and in The University’s policy on presentation of Theses.
Dedication

To Mum, Dad, Neil and Gran:
Thank you all for your love and support. I owe you so much.
Acknowledgements

This thesis is the result of over three years of work during which I have been supported by many people who must necessarily remain anonymous. I wish to thank you all. In particular, thank you to all the participants of the project for sharing their experiences and time with me. It was an honour. I am grateful to the staff at the general practices in their assistance in recruiting patients. I am also grateful to Caroline Gardner and Andy Bowen and all members of the WISE team for their support and assistance throughout the study.

My special thanks go to my supervisors who have taught me so much and without which this work could not have been completed. Thank you to Dr Caroline Sanders, my primary supervisor, for her guidance and advice throughout the project without it this thesis would not have been accomplished. Thank you to Dr Anne Kennedy for co-supervising this research. Her invaluable support and advice has been limitless. Finally, thank you to Professor Anne Rogers for also co-supervising this project. Her considered advice and support has been immeasurable. I am indebted to you all.

I also wish to thank Dr Stephen Campbell who was my advisor throughout this thesis and whose understanding and guidance has helped me through difficult times. It will always be greatly appreciated.

I would like to thank all my friends and colleagues at formerly the National Primary Care Research and Development Centre and recently the Primary Care Research Group for their continued moral and practical support throughout the study. I would also particularly wish to thank all the members of the self-management team and other PhD students whose support and advice have kept me going.

Finally, a very special thank you goes to my family. Without their love, support and encouragement throughout I would not have been able to complete this.
**Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDSMP</td>
<td>Chronic Disease Self-Management Programme</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>EPP</td>
<td>Expert Patient Programme</td>
</tr>
<tr>
<td>G.P.</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>IBS</td>
<td>Irritable Bowel Syndrome</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NPCRDC</td>
<td>National Primary Care Research and Development Centre</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>PRISMS</td>
<td>Patient Report Informing Self-Management Support</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>SNA</td>
<td>Social Network Analysis</td>
</tr>
<tr>
<td>WISE</td>
<td>Whole systems Informing Self-management Engagement approach</td>
</tr>
</tbody>
</table>
The Author

I am a researcher, currently working in the Primary Care Research Group, formerly the National Primary Care Research and Development Centre, at The University of Manchester.

In 2006, I graduated from The University of Dublin, Trinity College with a Bachelor of Arts (BA Hons) and Master of Arts (MA) in Psychology. During this time I developed an interest in the embodied experience of illness and the role of culture and health. That same year I enrolled on a Masters of Science (MSc) at The University of Dublin, Trinity College in Global Health and graduated in 2007. This course further developed my interest in the experiences of health and illness whilst placing it within the global political and economic settings. For my thesis, I completed a formative evaluation of the Tuberculosis Photovoice (TBPV) Project in Thailand which was part of a global evaluation of the TBPV projects. The TBPV project aims to promote dialogue through the use of photographs. I completed this study while working at the Health and Development Networks (HDN) which was a non-governmental organisation. HDN promoted grassroots dialogue of Tuberculosis (TB) and Human Immunological Virus (HIV) issues through the use of information and communication technologies based in Chiang Mai, Thailand. During this project I worked with people who had TB and HIV from a variety of ethnic backgrounds including Thai, Hmong tribe people and Burmese immigrants, as well as clinicians, public health officials and HIV activists. From this project, I developed an interest in the use of visual methodologies to promote inclusion of participants with lower literacy skills. Also during this time my interest in addressing health inequalities was further honed and my interest in the role of support and the wider context in which health management occurs to shape the ability and motivation of individuals to manage was developed.

Finally, my interest in primary care has developed from my father who was a single handed G.P. with a rural practice in Cheshire who had a particular interest in psychiatric medicine and a satellite practice in a local deprived community of the nearest local town. Growing up in a small community with my father as the doctor taught me the fundamental importance of health care within a local setting yet to be aware of the limitations of the health system that it operates within.
Chapter 1

Introduction to the thesis

1.1 Introduction

Supporting self-care for individuals with long term conditions has been a key aim of UK health policy for over a decade (Berzins, Reilly, Hughes & Challis, 2009). The Department of Health (2005) defines self-care as 'the care taken by individual towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents.' The terms of self-care and self-management have often been used interchangeably. Central to the aims of these policies has been reducing costs to the health service and improving quality of life (Department of Health, 1999). Policies have aimed to encourage the majority of individuals with long term conditions to self-manage primarily with support from primary care and education programmes such as the development of the Expert Patient Programme (EPP). Key markers of the programmes which have been developed to support self-management are focused on individuals and neglect the wider social context despite their rhetoric of supporting a ‘social model’ of illness (Kendall & Rogers, 2007). This individualistic approach has been reflected within self-management policies despite social networks being identified as relevant to support self-care in practice (Vassilev, Rogers, Sanders, Kennedy, Blickem, Protheroe et al., 2011). There has been much research on self-care and self-care as lay action (in particular in the area of the sociology of chronic illness) which has often included reference to other people in a network (Cunningham-Burley & Irvine, 1987; Anderson & Bury, 1988). The more individualistic approach to self-management seems to have emerged with the rise of self-care skills training which focuses on individual behaviour and this earlier focus in which others are recognised as being involved is lost. From the literature of the sociology of chronic illness (explored further in Chapter 2) we know that families and significant others are a reference point for individuals with a chronic condition and are involved in the day to day decision making and management about illness in domestic settings (Gregory, 2005; Richardson, Ong & Sim, 2007). There are a range of factors which may influence the effectiveness of self-management programs including the personal and social resources an individual draws upon in their everyday life, as well as the clinical resources available from the health service (Osborne, Jordan & Rogers, 2008). Yet the interface between patients’ everyday
experiences and the consultation process remains underexplored because of the policy influence of self-care on individualistic outcomes (Vassilev et al., 2011). This thesis presents a detailed examination of the individual social networks implicated in the management of long term conditions in shaping the context in which management occurs. It will examine the influence of expected roles and responsibilities of both the individual with the long term condition and the network members which influence engagement with management practices. The findings of this thesis demonstrate that considering management solely as an individual process is limited and highlights the importance of the social context in influencing illness management.

1.2 Context and justification for the research

Much health related social network research has focused on the impact of social networks in the genesis of long term health conditions and associated inequalities; yet there has been little research on the role of social networks in their ongoing management. The management of chronic illness is complex involving the interplay of a variety of personal and contextual factors. Pathways of care can be enabled, or constrained, by both individual beliefs and real or perceived access to care yet most commentators would agree that these processes do not occur within a vacuum; rather they are dynamic and embedded (i.e. an integral part of the relationship) within an individual’s social network (Pescosolido, 2011). The relationship between health behaviours, resources and support within a patient’s everyday life needs to be considered within the context of contact with clinicians and health services (Gately, Rogers & Sanders, 2007). It is through social networks that health problems are acknowledged, formal health care is sought and ongoing management occurs (Pescosolido, Wright, Alegria & Vera, 1998). These informal and formal networks of support and resources overlap to influence long term condition management.

Osborne et al. (2008) distinguished between ‘self-management’ and ‘self-management support’ with self-management being defined as ‘the actions individuals take for themselves and their families to stay healthy and to care for minor, acute and long-term conditions’. Self-management support can be defined as ‘the facility that healthcare and social-care services provide to enable individuals to take better care of themselves.’ (Osborne et al., 2008). It is the interaction between these domains which shapes the
context, availability of support and resources to an individual at any given time yet this has remained underexplored and underdeveloped in relation to policy and programme initiatives. Self-care has been central to UK policy to support people with long term conditions. There is a need to investigate how people integrate aspects of illness management, such as exercise, taking medicines and clinical appointments, in everyday life and how decisions are made in prioritising various aspects of management.

In the NHS Improvement Plan (Department of Health, 2004) which has shaped current practices in primary care and the provision of education programmes a three tier approach to long term condition management was proposed: firstly, case management for patients with multiple, complex conditions; secondly, disease management for patients at some risk of developing complications; thirdly self-management for patients at low risk of developing complications and hospital admissions. It is estimated that between seventy to eighty per cent of those with a chronic condition are expected to fit within this third tier of self-management. In the 2010 Equity and Excellence white paper (Department of Health, 2010), increasing choice and care for patients with long term conditions was envisioned through a principle of shared decision making of ‘no decision about me without me’ in order to improve patient health outcomes and reduce costs to the health service. Self-care policies necessarily need to acknowledge the role of the family and broader social networks involved in care in an attempt to address the limitations of the existing individualistic approach (Piette, 2010).

The qualitative study which this thesis is a related but separate study nested within the Whole systems Informing Self-management Engagement (WISE) approach randomised control trial (RCT). The WISE approach is a model which “envisages informed patients who receive support and guidance from trained practitioners working within a healthcare system geared to be responsive to patients’ needs” (Kennedy, Rogers & Bower, 2007). The approach is designed to be engaged with at the structural, professional and patient levels (Kennedy et al., 2007). This study has examined how self-management support provided by clinicians and health services interacts with the wider support and resources available from lay sources such as family, friends and work colleagues to influence illness management. Further, it examines how patients’ normalise new information and interactions into their routine contact with health services, and how this interacts with influences from lay sources, through the use of tools designed to support raising self-
management concerns during consultations by other members of the WISE team (the WISE model will be presented in greater detail in Chapter 2). These tools firstly consist of a disease specific information guidebook for patients with one of three index conditions of the trial: chronic obstructive pulmonary disease (COPD), irritable bowel syndrome (IBS) and diabetes (Kennedy, 2009). Secondly, the Patient Report Informing Self-Management Support (PRISMS) tool was developed during the exploratory trial which aimed to encourage patients to raise concerns during consultations and aid shared decision-making (Protheroe, Blakeman, Bower, Chew-Graham & Kennedy, 2010).

1.3 Aim and Research Questions

The aim of this study is to explore how social networks (lay and professional) influence long term condition management through the ongoing processes by which it is integrated into individuals’ everyday lives. The principal research question which this study addresses is:

“How do lay and professional networks interact to influence self-management and use of health services for individuals with long term conditions?”

The research questions addressed are:

- What constitutes a social network for people with long term conditions?
- How do social networks and health management reciprocally influence each other over time?
- What influence does having multiple long term conditions have on access to resources within the network?
- How do changes in primary care influence how an individual accesses and uses resources from their wider social network?

1.4 The structure of the thesis

Following on from this introductory chapter, Chapter 2 examines the literature on self-management at the level of the individual within the context of family, friends and work. It then explores how illness management is shaped by interactions with health professionals. It will then examine the influence of these distinct yet overlapping social components that influence the understanding of illness management in everyday routines.
Chapter 3 examines the underlying concept of a social network and the literature on social networks to explore health and health-related behaviours. It then examines the utility of taking a social network approach as an alternative approach to conceptualise the complex interaction of the variety of relationships which influence management. This chapter will explore the way in which resources, which are conceptualised as social capital, move through networks and can change over time.

Chapter 4 presents the methodology utilised in this study. It provides a critical appraisal of the research methods employed and a discussion of their appropriateness. The sampling strategy, participants, research setting, data collection techniques and method of analysis are presented and discussed. Finally, the ethical concerns relating to a longitudinal social network study are presented.

In Chapters 5 to 8, the results of this study are presented. Chapter 5 explores the basic structure of the social networks and the characteristics of the types of support and resources available through the variety of lay and professional network members. Chapter 6 examines the role of typologies of participants’ social networks and their influence in defining conditions, seeking health care and shaping the degree of engagement that individuals have with everyday condition management. Chapter 7 explores the influence of multiple long term conditions on illness management and the resources available through an individual’s social network as it challenges existing roles and relationships. Chapter 8 considers the temporal change in network composition and the reciprocal influence that this has on health and its management.

Chapter 9 summarises the findings of this study and discusses them with reference to the associated literature. It then considers the implications of the findings in relation to future self-care policy. Finally it identifies the limitations of this study and proposes suggestions for future research.
Chapter 2

What influences how, and to what extent, individuals ‘self’-manage?

In this chapter I will explore what is known about self-management at the level of the individual and in the wider social context of family, friends and work. I will examine how interactions with health professionals shape illness management. I will argue that self-management is influenced by the type and availability of resources and demonstrate that resources accessed through social networks shape management priorities and goals and as such should be considered illness management rather than ‘self’-management.

2.1 Introduction

The management of chronic illness is complex and comprised of a number of daily activities. These components not only include practical activities that should be accomplished by an individual, such as exercise and medication management, but also incorporating and renegotiating management into existing roles and responsibilities. Illness is not experienced in isolation but in a context that incorporates formal providers of health care, informal social network members and the physical environment in which it occurs (Gallant, 2003). In other words, the management of long term conditions is influenced by a number of distinct but overlapping spheres (e.g. the social context, the clinical setting and the physical environment) that shape the feasibility of engagement with management practices (such as diet control or exercise). It has been argued that it is through social networks that health problems are acknowledged, formal health care is sought and medical advice is followed (Pescosolido, et al., 1998). It is this interplay between personal and environmental factors, both physical and social, which influence self-management (Gallant, 2003). These factors do not work independently of each other, but exist rather on a continuum, influencing the timing of health care utilisation and the integration of information and support from all sources. The services and support provided by professionals are linked with the self-care activities that an individual does, which in turn is influenced by informal support (Gately, et al., 2007). The importance of a broader perspective which acknowledges a patient’s ‘life world’ experience of chronic illness in the utilisation of self-management initiatives is needed (Gately, et al., 2007). Bury (1991) described the onset of a chronic condition as a “biographical disruption” (i.e. the re-evaluation of personal, familial and work-related factors which are associated with the
onset and management of a long term condition) and as such the meaning and context of the illness cannot be separated (this is discussed further in section 2.3 below). It is artificial for research to separate the meaning and context of the illness as in reality they have an ongoing reciprocal influence. The literature on self-management crosses a number of disciplinary boundaries and so it is not possible to conduct a comprehensive review of the broad literature within this thesis. Rather, in this thesis I will examine the literature on the wider social context in which self-management occurs and demonstrate that it is most closely aligned to social network theory and as such this has shaped the empirical focus of this thesis.

2.2 Self-management for chronic illness

Patients with chronic conditions face a number of challenges which they have to overcome irrespective of their individual condition. These challenges include: coping with symptoms and drug regimens, adjusting to changes in lifestyle, disability and gaining useful medical care (Gallant, 2003). There has been a focus on supporting self-management through the development of information booklets, awareness campaigns and improving communication between patients and clinicians through promoting concepts such as shared decision making (Vassilev et al., 2011). Clinical indicators have been the measure of the effectiveness of self-management programs and interventions (Osborne et al., 2008). The conceptual framework underpinning much of the formal programmes to support self-management endorse an individual accountability to management with the notion of self-efficacy through the development of an individual’s confidence and motivation for management (see below for a description for the use of self-efficacy in the EPP) (Newbold, Taylor & Bury, 2006). Yet there remains a gap between the research on self-management and the everyday reality of living with a long term condition (Furler, Harris & Rogers, 2011). This thesis addresses this gap by examining self-management as an element of the individual’s complex everyday life to understand the processes through which it is negotiated in the context of formal and lay settings. Kleinman (1980) proposed that there are three overlapping elements to the structure of modern health care systems which influences the generic understanding, actions and management of health. Firstly, the popular sector of health care, i.e. the lay sector, which forms the largest part of the system and is comprised of several levels including the individual, family, social networks and community beliefs (see below). It is in the lay sector where illness is often first defined or identified and health management is initiated within the culture in which it is
The second sector he proposed was the professional sector of health care, which constitutes organised, formal health care. These clinical settings are also shaped by the culture and context in which they are conducted as well as the interpersonal interactions between the patient and clinician (see below). The third sector identified was the folk sector, situated between the professional and popular sectors and made up of non-professional and non-bureaucratic specialists (Kleinman, 1980). The interaction between these three sectors is shaped by the culture in which an individual lives and the relative importance that each individual places on them which in turn influences where information, advice, support and treatment are sought. This is particularly relevant when considering the context of self-management as he highlights that the majority of health care takes place outside the formal health care sector. In this chapter I will examine the literature on the meaning of chronic illness in a social context and will go on to demonstrate in particular in Chapters 5, 6 and 8 the influence that social networks can have in shaping management priorities when considered within the broader context of everyday life.

More specifically for chronic illness management, Fisher, Brownson, O’Toole, Shetty, Anwuri & Glasgow (2005) proposed taking an ecological approach to self-management by placing it within the environmental and social context; in particular, they focused on diabetes care. They proposed four ecological levels which influence and support an individual to self-manage:

1. Individual, biological and psychological level
2. Family, friends and small group level
3. System, group and culture level
4. Community and policy level

For an individual to self-manage they must link the individual required for management (such as accessing appropriate medications) with the services and support from the wider social, physical and policy context (Fisher et al., 2005). From an evaluation of diabetes self-management promotion projects within both primary care and the community, Fisher et al. (2005) proposed six key resources and supports that an individual needs in order to self-manage: access to resources in daily life; individual assessment; collaborative goal setting; skills enhancement, such as problem solving skills; support and follow-up; and continuity of quality clinical care. This approach acknowledges the complex interaction of different factors and the need to extend self-management approaches beyond the focus on
the individual towards the broader context in which it occurs. Wagner (2001) proposed that achieving the best possible outcomes in chronic condition management depends on being able to competently self-manage and make decisions based on information provided to the individual. Self-management may be influenced by factors such as age, length of time since diagnosis, functional or limitations of the conditions and the presence of co-morbidities. For example, the ability to both manage and maintain drug regimens and lifestyle modifications with conditions such as diabetes and HIV has been linked to factors such as socioeconomic status and level of education achieved, as they impact on the individual’s ability to make independent decisions about variations in their condition (Goldman & Smith, 2002). This may be further influenced by the context in which an individual lives and factors which are not directly under the remit of illness management, i.e. other priorities in life which may be considered of greater importance than the practices ascribed for their illness management. The everyday experience of illness may be considered to exist on a continuum from wellness to illness that can change over time depending on a number of factors. Paterson (2001) proposed the shifting perspectives model of chronic illness, which involves an ongoing shifting process between illness-in-the-foreground and wellness-in-the-foreground with each perspective is “representative of beliefs, perception, expectations, attitudes and experience about what it means to be a person with a chronic illness within a specific context” (p23). As personal and social contexts change, Paterson (2001) proposes that the degree to which illness is in the foreground or background changes. This in turn influences the way in which an individual understands and responds to their illness and the priorities they place on management activities.

2.3 The role of formal health care in supporting self-management

The role of formal health care in supporting self-management can be considered to operate on a number of overlapping levels. There is a need to consider the delivery of services by individual practitioners situated within the wider healthcare system that incorporates informal healthcare as well as the wider organizational context of formal provision. Two models of chronic illness management have been developed to explain the influences of the multiple factors found in formalised care, including primary care and the wider system in which it operates. Firstly, the Chronic Care Model (CCM) developed in the US which proposes that basic components of chronic care can be targeted to improve care provided by health systems. These components operate at the levels of community, organisation,
practice and patient (Wagner, 1998). To improve outcomes within this model, the patient is viewed as informed and activated supported by a prepared and proactive practice, with the community providing resources and policies to support self-management. Yet such a proactive and highly engaged approach may not be realistic within the everyday context in which the patient, or the constraints that health services, operate within. In the U.K., the Whole System Integrated Self-Management (WISE) approach has been developed to support self-management in primary care (Rogers, Kennedy, Nelson & Robinson, 2005). A whole systems approach exists within the CCM, but the WISE approach explicitly operationalizes this as it “envisages informed patients who receive support and guidance from trained practitioners working within a health care system geared up to be responsive to patients’ needs” (Kennedy, et al., 2007:968). Within the WISE model there are three levels of involvement in chronic care, the structure, the professional and the patient which need to interact in order to implement a self-management strategy successfully. By using a complex intervention which operates simultaneously at multiple levels, the effectiveness of change to health care delivery is expected to increase and maximise its effect (Kennedy et al., 2007). This approach places management within the context of everyday lives and social networks. The importance of lay networks, as well as the social and physical environment in which people live, affects the effectiveness of any self-care intervention. Informal and formal systems of care in chronic condition management influence each other; a patient is required to integrate the information from formal systems with their pre-existing lives and management, which in turn are influenced by informal systems. The ability to self-manage and the way in which it is done varies according to a variety of individual and situational characteristics including: socioeconomic circumstances, previous experiences and knowledge of the condition, as well as domestic and family arrangements and local contexts (Kennedy et al., 2007).

2.3.1 The patient-clinician relationship

Chronic illness requires ongoing contact with health professionals. Increasingly the consultation has become a focus of study with notions such as patient-centred consultations and shared-decision making as ways to improve communication. This shift has been prompted by a changing policy environment placing greater accountability on professionals and reframing patients as consumers of health care (Moran, 1999). In response, perceptions of the consultation have moved from traditionally being an accepted and relatively unchallenged part of professional practice to being a process that is examined, questioned and debated (Elwyn, 2004). There has also been a shift in
conceptualising the doctor-patient relationship from one based on paternalism to one based on collaboration. This individualisation of practice, where patients’ experiences and perspectives are identified during consultations, does not solely determine outcomes in consultations but rather is negotiated within the confines of clinical guidance proffered by evidence-based medicine (May, 2007). Patients rate highly clinicians who are helpful, supportive, compassionate and flexible and who balance clinical priorities with quality of life (Thorne, Harris, Mahoney, Con & McGuinness, 2004). These organisational and professional constraints may influence the practitioner’s priorities, but these more structural influences can be viewed as secondary to the individual social relationships which shape the encounter based on a mainly dyadic relationship (May, 2007). One main area of research has been around the interpersonal aspects of communication that shape how concerns are raised and priorities framed during a consultation. The constraints and expectations of this relationship may operate within different parameters than other potential social network relationships which may affect their inclusion, or significance if included, in a patient’s social network (this will be examined in detail in Chapters 5 and 6). Both the patient and practitioner have expectations of roles and responsibilities of each other within this space, yet these expectations change over time. Barry, Stevenson, Britten, Barber and Bradley (2001) found that some doctors changed communication strategies during different consultations, varying on the degree of clinical or ‘lifeworld’ conversation present. They found that with the ‘mutual lifeworld’ communication pattern more of the patient’s agenda was raised and the patient was humanised with their unique priorities which was advantageous for psychological as well as physical problems. If the communication pattern was characterised by the ‘lifeworld ignored’ or ‘lifeworld blocked’ this led to poorer outcomes (Barry et al., 2001). Changing strategies support the idea that clinicians assess patients rather than having a static, one-size fits all approach. Lussier and Richard (2008) argue that the doctor-patient relationship changes on a ‘decisional control continuum’ depending on the nature of the patient’s problem, either acute or chronic, and its severity. They propose that for acute, serious problems a clinician is expected to take charge. Conversely, for chronic conditions, whether minor or more serious, partnerships are likely to develop as the patient’s knowledge and understanding of the condition and treatment options available helps them to become an expert in their condition. This suggests how the patient-clinician relationship is dynamic with different types of information being sought by patients at different times.

Consultations between the patient and their G.P. can be considered a socially constructed space where both the clinician and patient make decisions about what to raise during the
consultations and how this can be most appropriately done. May, Allison, Chapple, Chew-Graham, Dixon, Gask et al. (2004) identified three factors that influence the way G.P.s frame their relationship and evaluate patients: firstly, a moral evaluation of the patient in judging the legitimacy of the symptoms, secondly, ‘the possibilities of disposal,’ i.e. relieving the patient’s problem, and thirdly, the empathic response of the G.P. to the patient. Evaluations are made of patients in which the social and cultural context as well as the clinical guidance of the system influence the actions that clinicians make.

The patient is not a passive subject during the consultation and particularly in relation to chronic conditions may a more active role. Patients have their own agenda of what they want to elicit from the consultation. Yet within the time constraints of the standard consultation this agenda will rarely be voiced (Barry, Bradley, Britten, Stevenson & Barber, 2000). They found that ‘unvoiced agendas’ include concerns about diagnosis, the future, the cause of the condition and information. These unvoiced concerns were often related to poor health outcomes. Negotiation, norms and trust can be considered important elements of the patient-clinician relationship, and are similarly fundamental traits within the wider social network (as will be discussed in Chapter 3). These relationships are an important part of the health network as they provide access to resources such as medications and information and act as a primary access point into the health service. In addition, they act as bridges to other resources by connecting patients to secondary care services. The variety of these connections, i.e. whether G.P.s connect to specialists in secondary care as well as wider community resources such as to exercise and support groups, will be examined. One study found that G.P.s have key roles as advocates for patients in accessing services and resources both within the NHS as well as other settings, for instance by writing letters to housing authorities and employers (Popay, Kowarzik, Malinson, Mackian & Barker, 2007). This role as advocate for the patient depends on the relationship established with the clinician.

Thorne and Robinson (1989) described the changing levels of trust in patients with the diagnosis of a chronic illness from a naïve trust before diagnosis of the chronic condition to a reconstructed trust where the expectations of the clinicians and themselves as patients have been redefined. The redefining of the relationship as a result of changing expectations, from acute conditions which can be cured to management of chronic illness, shifts the way in which the relationship is framed. This form of reconstructed trust may produce four types of relationships which influence the associated competencies and an understanding of the limitations of health professionals: ‘hero-worship’, resignation,
consumerism and team playing (Throne & Robinson, 1989). In a hero-worship relationship, one clinician is identified as a key informant to whom patients defer decision-making, whereas team playing is characterised by a reciprocal relationship where both patient and clinicians acknowledge the limitations of the system (Thorne & Robinson, 1989; Thorne, 1991). Conversely, a relationship that is characterised by resignation is one where there is little trust, as it is not reconstructed, patients describe being powerless to alter their situation and have little expectation of receiving meaningful care (Thorne & Robinson, 1989). In this sense, patients become disengaged from management activities and reduce contact with health professionals. The fourth type of patient-clinician relationship proposes that trust is re-constructed as ‘consumerism’, where patients learn to convince and manipulate clinicians to access services (Thorne & Robinson, 1989). Patients are not passive receivers of care, but rather re-interpret and negotiate available resources through health professionals, who can be considered as being influenced through trust and ascribed competency within the patient-clinician relationship, which may be challenged with the diagnosis of chronic illness. Similar to the expectations that professionals have of their role, these patient-defined relationships can change over time as part of an ongoing negotiation of expectations as understanding develops over the illness trajectory.

The relationship a patient has with their clinician is recursive, shaped partly by the immediate experience in the consultation and through their previous experience. This shapes the expectations one has of the interactions and the limitations of resources that the health service can offer. The process of legitimation of symptoms and roles in differentiating between the clinical significance of symptoms also determines when health services will be sought (Rogers, Hassell & Nicolaas, 1999). If these relationships are not positive, this can shape future service use. Rogers et al. (1999) describe how previous negative experiences create a reluctance to seek care in the future, and the quality of care when it is sought is questioned. Conversely, expectations change as an individual’s experience with the conditions change. Lawton, Peel, Parry, Araoz and Douglas (2005) described how patients’ disease perceptions and health service use were mutually informing: health service delivery not only shaped the way they managed their conditions, but also how their learning from the condition shaped their expectation from services. Protheroe, Rogers, Kennedy, MacDonald and Lee (2008) in a meta-synthesis and secondary analysis of four qualitative studies on self-management concluded that responses from traditional health services shaped how self-management information was engaged with and used. Specifically, in an IBD study, Rogers et al. (2004) found that
during hospital consultation the joint use of a self-management guidebook within the consultation re-emphasised and clarified information within the existing relationship. Rather than challenging individual roles, this enabled a shared ground where ambiguity and confusion could be raised. This legitimation of self-management was also reported by MacDonald, Mead, Bower, Richards and Lovell (2007) in the SHADE (Self-help in anxiety and depression) study, whereby information provided early in the illness career by an assistant health psychologist made information more credible and consequently increased its accessibility. Further, other people’s experiences with health services may influence expectations as both negative and positive accounts can be shared within the social network and shape expectations of legitimacy and advice that can be given (Rogers et al., 1999). Thus, contact with health services was not always considered, could be resisted and not only shaped management but also shaped the patients understanding of their condition from learning to live with the condition and the social context, or ‘lifeworld’, in which they live. The patient-clinician relationship is a key relationship that has been the focus of much self-management as it is primary access point to formal health care and will be examined in more detail in Chapter 5.

2.4 Formal self-management support: the role of education programmes and support groups

The impact of self-management education programmes is influenced by the biographical and social context of individuals, their relationships with health professionals and previous experiences with health services (Gately et al 2007). Although the interplay of these broader factors are key to self-management practices becoming normalised (i.e. the incorporation of illness into a patient’s life so as to become ‘normal’ (Bury, 2001)), educational interventions have been targeted at the individual. Self-management support includes information, education programmes and awareness campaigns through a number of delivery mechanisms (Osborne, et al. 2008). Yet underpinning many self-management programmes are psychological models which are targeted at the individual without taking into account the existing contexts and experiences of individuals with long term conditions (Kendall & Rogers, 2007). Formal interventions have recently comprised mainly of lay-led self-management programmes to improve motivation, as well as skills, to self-manage (Bury, Newbould & Taylor, 2005). One mechanism that has been piloted to address the gap between support from primary care and the patient managing their condition on their own has been through initiatives such as the Chronic Disease Self-management Programme (CDSMP) developed in the United States (US). This was adapted as a lay-led programme for the UK and called the Expert Patient Programme.
individual and developing their skills to management. Preliminary trials in the US suggest that in certain situations such programmes improve outcomes, are more effective than information-only education and have the added benefit of bringing together patients with chronic conditions (Bodenheimer, Lorig, Holman & Grumbach, 2002). Schlesinger (1993) found that discussion about health can promote emotional support and legitimise the experience of symptoms which was particularly important for conditions which were difficult to diagnose. An evaluation of the EPP found that despite only a moderate increase in self-efficacy, the course was rated as highly satisfactory, in particular the group aspect of the course, even though there was only a small impact on health status and varied effects on health service use (Department of Health, 2006). Furthermore, as patients have to integrate information from lay-led programmes with messages from clinical encounters (which might be incongruent with their own experiences and routines developed in their everyday context) this may add additional burden to management (Osbourne et al., 2008).

Individual factors which influence self-management include the age of onset, ethnicity and gender, as well as the way in which an individual responds to the diagnosis (Serlachius & Sutton, 2009). One key individual component proposed to enable self-management is having the confidence to complete the actions necessary to achieve management goals, i.e. self-efficacy (Bodenheimer, et al. 2002). This is the basis of many targeted self-management interventions. Self-efficacy, an individualistic concept developed by Bandura (1994), proposes that individuals can change their ability to achieve certain levels of performance by increasing their self-efficacy, as it affects how people approach difficult tasks. People with high levels of self-efficacy tackle difficult tasks as challenges to be overcome, whereas people with low levels of self-efficacy approach difficult tasks as challenges to be avoided. This focuses solely on human agency ignoring the impact of social structure and norms in determining outcomes (Taylor & Bury, 2007). It was proposed that one of the benefits of the EPP was to reduce the social isolation that can be associated with chronic conditions (Department of Health, 2006). Social networks may enhance self-efficacy through effecting motivation and coping (Gallant, 2003). However, self-efficacy is based on an individualistic approach, and using it as a primary marker of success for programmes does not adequately recognise existing knowledge about the role of social factors in how people respond to the diagnosis and management of long term conditions (Kendall & Rogers, 2007).
Lay-led training programmes are one dimension of assisting people in self-management, whereby individuals can learn from other people who have been through similar experiences and overcome obstacles. They provide an informal area where shared challenges of self-management can be raised and discussed; however, they may exclude certain groups that are unable to access them. The assumption of programmes, like the EPP, is that they will enhance self-efficacy and lead to improved self-management. Yet, self-management programmes often fail because of a lack of engagement by patients and staff, as they do not incorporate the need for family and social support or take into account cultural norms (Greenhalgh, 2009). It is important to recognise the problems with identifying causality between thought and behaviour, particularly in relation to self-management. High levels of self-efficacy may be considered a cause for coping well with ill-health or a consequence thereof (Taylor & Bury, 2007). The emphasis of increasing self-efficacy as a goal for self-management may also have unintended negative consequences. Normative judgements about the levels of self-efficacy that should be obtained and how individuals should obtain them could lead to extrapolation from successful individuals to others and how they ought to behave (Taylor & Bury, 2007). Such judgement calls could lead to blame being assigned to individuals if expected levels of achievement are not reached. Taylor and Bury (2007) argue that emphasising self-management and related programmes may lead to the inappropriate withdrawal of services and reduce the awareness of broad social and material determinants of health. Placing responsibility on individuals does not acknowledge the important role of social networks and social capital in affecting individual ability and providing the environment in which self-management occurs. Furthermore, Rogers, Gately, Kennedy and Sanders (2009) found that self-management programmes themselves are social events; positive downward social comparisons were mostly made by participants who attended an EPP course. Yet they highlight that this in turn may reinforce existing inequalities because the course may have been avoided by individuals where positive comparisons could not be made. Thus, instead of addressing problems of inequality such programmes may reinforce existing inequity.

Overall, the evidence for the expert patient model for self-management programmes shows low efficacy despite it being the preferred model for such programmes in many countries. Consequently, there have been calls for a move towards a more holistic model that takes into account the individual’s family, social and political contexts (Greenhalgh, 2009). Further, Rogers (2009) proposes that the limited impact of EPP courses lies in the limited attention given to routine aspects of management which individuals conduct
themselves to accommodate and embed new techniques in to their everyday illness management, as well as the social and domestic contexts in which it is situated. As such, future interventions must place illness work in its social and familial contexts (Rogers, 2009). Rosland and Piette (2010) reviewed existing family orientated self-management support programmes and identified three underlying models through which family support can be mobilised for functionally independent patients through formalised programmes. Firstly, Rosland and Piette (2010) propose that as many family members want to provide support but do not know how, they can set specific goals through identifying areas of low self-efficacy and discussing ways of overcoming barriers to illness management. Alternatively, family members can set goals about their own health to promote a healthier home environment (Rosland & Piette, 2010). A second type of family orientated programme they proposed focused on training family members in techniques to support communication and coping to enable adaption to changing management problems. Finally, a third type of family orientated programme involved directly training family members to support the clinical care through building on existing roles such as acting as advocates in clinical appointments (Rosland & Piette, 2010). Such targeting of family into more defined forms of support may have utility in moving models of management away from ‘self’-management towards a more contextually focused view on management. This more formalised role of family members may provide them with tools to support the individual as well as ensuring that they recognise the impact on their own mental and physical health. However, the feasibility and acceptability to either patients or family members of programmes which target family members directly remains unknown. Further, non-family members also support individuals with long term conditions and may also benefit from such programmes if they fit within their other priorities and health concerns.

2.5 The meaning of illness management for an individual in a social context

Illness management is influenced by the meaning which an individual ascribes to their condition, which in turn is shaped by the context in which it is experienced. Accounts of chronic illness are often complex and contingent as different aspects of illness management may reinforce one another and create a sense of isolation and impairment which challenge notions of self (Charmaz, 1983). Charmaz (1983) proposed that a loss of self was caused by the changing self-image from living with a chronic condition that results in individuals experiencing more restricted lives, social isolation, feelings of being discredited and burdening of others which can create strain on relationships. Common across conditions are accounts which highlight fundamental concerns and abilities as
individuals attempt to maintain normal lives (Charmaz, 1990). Thus managing a chronic illness can be considered a social issue as it can cause family and social role disruption, marital stress, adjustment and stigmatisation and in this process health care professionals can be viewed as not having a major role (Strauss, 1973). As such it is important to understand the meaning of chronic illness in its everyday context. Bury (1982, 1988, 1991) proposed that a range of biographical disruptions occur initially following the diagnosis of a chronic illness (as defined above). In other words, the understanding an individual has about their body, mind and everyday roles alters as a result of diagnosis. He proposed that through a process of biographical disruption chronic illness disrupts taken-for-granted assumptions about the world, which in turn causes individuals to rethink their biography and ultimately leads to the mobilisation of resources in response to the altered situation. This is shaped firstly by a process of illness onset, where there is a process of explanation and legitimation, secondly by the impact of treatment and thirdly through the development of resources which must be adapted (Bury et al., 2005). The extent of this can be related to the type of condition and the severity of symptoms as well as the degree to which the condition can affect social situations. Key components of biographical disruption include isolation, loss of normal rules of reciprocity and loss of expectations (Bury, 1982). Williams (1984) similarly proposes the notion of ‘narrative reconstruction’, where the process of the routine narrative that an individual has in accounting for mundane events in everyday life between the individual and the setting is reconstructed to create a sense of stability and coherence following the biographically disrupting event of illness onset. To find a meaningful place for rheumatoid arthritis to exist within participants lives, Williams (1984) describes accounts of reconstruction and repair of the reference points between the past and present and self and society. Edgar (2005) argues that chronic illness can be viewed as a practice which influences the reconstruction of an individual’s narrative allowing them to understand illness and live well irrespective of it through the resources available to make sense of the condition to the individual. This reconstruction and practice moves to place illness within the life course of an individual and influences the priorities of illness management by situating it within a broader context between the self and wider society, as well as past and present understanding.

The initial effect and adaptation to chronic conditions can be influenced by the social context and how the symptoms are viewed by the individual and others. Chronic illness is experienced through a complex interaction of factors which can lead to a fundamental reassessment of a person’s biography, self-concept and meaning (Bury, 1982). This could influence the amount and type of support that is sought through networks and may vary
depending on the condition. Chronic illness influences individuals and their families through its effects on everyday life, as well as the financial and personal care implications (Bury, 1988). He argues that the context in which an individual lives influences the meaning of chronic illness through the strength of social networks and the availability of resources (Bury, 1991). From this perspective, Bury (1991) proposed two types of chronic illness meaning: firstly, meaning is ascribed to the consequences of the condition for the individual and the disruption caused by it in everyday life at home and work. Secondly, the meaning of chronic illness relates to the significance that an individual places on different conditions through their existing understanding and conceptions of the condition in how they think of themselves and others (Bury, 1991). It is through ascribing meaning to chronic illness that an individual finds a legitimate place for its management in their everyday life (Bury, 1991).

More recently the concept of biographical disruption has been questioned. The process of disruption and legitimation that Bury (1982) proposed may in part relate to the type of participants in the study as they had recently been diagnosed with rheumatoid arthritis and were relatively young to have the condition which is often considered to affect older people. When researching the experiences of osteoarthritis in older participants, Sanders, Donovan and Dieppe (2002) found that onset was considered an inevitable part of ageing yet symptoms were viewed as having a disruptive effect on daily activities which suggested that disrupted and normal biographies can coexist. As people increase in age they have more experience of illness and so describe it as being less disruptive. Pound, Gompertz and Ebrahim (1998) also questioned whether disruption was applicable to people who had prior experience of illness. In the study, participants who had had a stroke did not describe it as a disruption to their lives but rather viewed it with resignation and pragmatism, more as a ‘normal crisis’ as many of the participants had suffered ill health prior to the stroke and their lives were characterised by hardship and struggle. Consequently, having a stroke could be viewed as ‘biographically anticipated’ (Pound et al., 1998).

Biographical flow rather than disruption has been suggested to describe the process of adapting to chronic illness as it may incorporate other factors such as age, co-morbidities and previous knowledge of illness (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004). Further it has been argued that it is biographically confirming or reinforcing in older age to develop illness as age may mediate between the experience and response to chronic illness (Williams, 2000). Similarly, Carricaburu and Pierret (1995) found that
haemophiliacs did not experience diagnosis of HIV as excessively disruptive but rather as ‘biographically reinforcing’ as they had lived with illness throughout their lives and diagnosis reinforced existing measures which they had already set in place. Thus, the meaning of illness is not only shaped by the immediate physical effects on the individual, but also the context and resources reciprocally available from family, friends and clinicians (this is examined further in Chapter 5). Further, Williams (2000) proposes that, increasingly, self-identities that are both physically and emotionally defined are reflexively generated through a contingent and cyclical process of “biographical revisions”. Locock, Ziebland and Dumelow (2009) identified that individual accounts of motor neurone disease described a process of “biographical abruption”, i.e. the sudden ending of their life because they viewed their condition as a death sentence, biographical disruption and flow leading to “biographical repair and reconstruction”, where a sense of redefined normality and control could be re-established through the development of strategies to live within these altered circumstances. Narrative accounts of biographical disruption and abruption to repair either followed linear paths or had fluctuating accounts (Locock et al., 2009). This was described as a process of repeated reconstruction as the condition progressed. This in turn affected relationships with partners and families. Some individuals described changing relationships as a result of limitations of the illness whereas others felt relationships, particularly with significant others, had not changed or had grown stronger as a result (Locock et al., 2009). Thus, the significance of diagnosis and management affects not only the individual, but also their valued relationships. Adamson and Donovan (2005) described a ‘normal disruption’ process in the roles of relatives from South Asia and African/Caribbean populations who informally care for older family members. Relatives who informally care were found to have similar descriptions of change in that they discussed their caring relationship in terms of normal and expected biographical continuity (Adamson & Donovan, 2005). However, relatives’ accounts also drew on their ‘pre-caring life’ to understand and adapt to their new situation reflecting on their previous biography and self-identity (Adamson & Donovan, 2005).

The way in which the diagnosis and understanding of chronic illness fits with, or challenges, pre-existing notions of illness and well-being mediates how illness is accommodated and normalised, shaping engagement with management practices. The management of chronic conditions can raise practical and moral challenges through attempting to maintain a ‘normal life’; valued social roles, such as ‘being a worker’, ‘being a parent’ or ‘being a husband’, and coherent identities which can produce tensions around symptom management in daily life which are further made more complex in the
presence of multiple conditions (Townsend, Wyke & Hunt 2006). Exploring the contextual factors which influence chronic illness management, as well as the continuity and disruption that are a result of chronic illness, enabled the mechanisms of maintaining social roles, such as ‘being a wife’ or ‘being a parent’, and identities to be explored within the setting in which they live (Bury et al., 2005).

2.6 The role of family and friends in ‘self’ management

Notions such as biographical disruption need to be placed within a setting of rapidly changing social relations, both at home and work (Kelly & Field, 1998). A broader perspective is necessary to understand how practices are accommodated into everyday life. Corbin and Strauss (1985) refer to three types of work which influence the individual’s illness trajectory when managing illnesses in daily life:

1. Illness work, i.e. work related to illness such as symptom management, regime work, crisis prevention and management and diagnostic-related work
2. Everyday life work, i.e. the essential daily tasks that maintain the household such as housekeeping, employed work, marital work and child rearing
3. Biographical work, i.e. the reassessment an individual makes about their body, expectations and future plans

In particular, illness work and everyday life work involve the ongoing negotiation of roles and responsibilities with others including partners, family, friends, clinicians and children. The amount of work required at each level differs with some routines being variable, such as when housekeeping is completed or managing symptom exacerbation, whereas others are fixed, such as going to work and taking medication (Corbin & Strauss, 1985). An ‘illness trajectory’ includes illness progression, as well as all related work that is completed, and the impact of this on the individual and their relationships, which further impact on the individual’s management (Schneider & Conrad, 1983). The changing relationship that an individual has with the space in which they live and work as a result of ongoing illness management, as well as the renegotiation of existing roles and utilisable resources with partners, family and friends, can influence management priorities (Corbin & Strauss, 1985). Changes in any of these settings or routinised roles may require the negotiation of resources, including time, influencing the feasibility of completing required illness tasks, which in turn may be deprioritised based on other everyday roles and work having a greater importance. This can be considered a cyclical process, where prioritisation of work is reciprocally negotiated with partners, family, friends, work colleagues and clinicians.
A personal network consists of all the people (i.e. the alters) with which an individual (i.e. the ego) is connected too (Agnieszka, Waege & Lievens, 2006). Of particular importance to self-management, or arguably illness management because of the influence of multiple people in the management of long term conditions (Vassilev et al., 2011), are individuals in the personal network that provide support and access to resources to the individual with a long term condition (see chapter 3). The informal network members who provide a form of lay care consist of family members and extended networks (Stoller, 1998). Family and friends can act as the main members of a lay health service through supporting and providing resources which foster an environment in which self-management can be achieved. Friends and neighbours are also sources of information related to health (Edwardson, Dean & Brauer, 1995). Although the accessibility of support may vary, Piette, Rosland, Silveria, Kabeto and Langa (2010) highlight that there are increasingly other demands on spousal time, such as employment or their own health priorities, which can limit the amount of resources available inside the home to support self-management that would have traditionally filled the gap remaining from formal care. They propose that ‘out-of-home informal caregivers’ may play an increasingly important role in supporting self-management (Piette et al., 2010). Yet over half of chronically ill adults in the US live over ten miles away from their children which may restrict the types of support they may be able to offer. They propose that interventions needed to target such out-of-home informal caregivers must focus on three types of enabling information support: firstly, information about the individual’s health problems, secondly information must be timely and thirdly they need information about the burden of being an informal care giver. In a further survey of four hundred and thirty nine participants, Rosland, Heisler, Choi, Silveria and Piette (2010) reported that seventy five per cent of respondents received supportive family involvement in self-care. Although there were gender differences, seventy-seven per cent of the male respondents, but only sixty-four per cent of female respondents, reported receiving family support in one or more of five self-management domains including healthy eating, exercise, medication, testing and information and decision making (Rosland et al., 2010). Network structure has been found to influence a number of health related behaviours, such as access to information (Granovetter, 1995) and the source and timing of seeking medical treatment (Wellman, 1995). The networks used for lay consultations most frequently include partners and adult children (Glasser, Prohaska & Roska, 1992).
The family has also been modelled as a producer of health through the direct and indirect returns based on links the family make with other people and the amount of resources they invest in maintaining them (Bolin, Lindgren, Lindström & Nystedt, 2003). Radley (1989) observed that differences in how participants with coronary artery disease adjusted to illness were influenced by the relationship they had with their partner. His study showed that couples with greater flexibility in their marital roles were more likely to accommodate the effects of illness than couples whose relationship could be described as a more traditional marital relationship. The expectation of individual roles shaped the way in which new practices could be accommodated, or not, into the established relationship.

The type of assistance that is provided to the individual also varies depending on the management task. Rosland et al. (2010) found that family members were more likely to assist with healthy eating than testing and medication. The size of an individual’s support network has been traditionally the focus of much research on social support, however, it is a multidimensional concept with network members providing potentially varied types and amount of support (Agneessens et al., 2006). Within the experiences of chronic widespread pain, Richardson et al. (2007) explored the relationship of support received from the family, concluding that emotional support is flexible, dynamic and reciprocal, although it is contextually dependent, complex and includes negotiating changes in roles and relationships. Support from family legitimises the experience of the individual with chronic pain (Richardson, et al., 2007). Stoller and Wisniewski (2003) identified in interviews with older adults that their networks consisted mainly of family members, in particular women and spouses, and widowed individuals were more likely to talk to children and friends and have networks outside their neighbourhood than married individuals. Chronic conditions are typically, although not only, associated with increasing age and as networks change with age this has implications for where individuals will turn to for support and assistance yet those they turn to for support may not feel that they have the skills to assist adequately.

Support available to individuals with chronic illness is not always positive and the type of support wanted may depend on gender. Support can have both positive and negative effects on health (Carpiano, 2007). Some people do not want to talk about symptoms with others (Stoller, 1993), which has been shown for a number of reasons; for instance, because of the repeated nature of symptoms patients do not want to be considered as constantly complaining (Schlesinger, 1993) and to not concern relatives (Strain, 1990). Individuals who do not discuss symptoms with family members to avoid worrying them
may also avoid changing their view of self or their position within the family (Strain, 1990). Maintaining important roles may be considered more important (as will be examined in more detail in Chapters 5 and 6). Conversely, network members may also be a source of distress. Gallant (2003) reviewed the literature on the relationship between social support and chronic illness self-management, concluding that there is a positive relationship, but some social network members have a potentially negative influence on self-management. Antonucci, Akiyama and Lansford (1998) reported that people who had negative feelings about network members were less happy, and increasing network size did not necessarily increase satisfaction. Having a large number of very close relationships was negatively associated with happiness for women, yet there was no such association of close ties with happiness for men (Antonucci et al., 1998). This suggests that a large number of network members do not necessarily have positive effects on well-being. Those who were considered most important also varied depending on the gender of the individual. Although both men and women were likely to include spouses, siblings and children as close relations, significantly more daughters were named as close than sons for women, whereas for men more sons were named as close relations than daughters (Antonucci et al., 1998). In addition, they found significantly that men were more likely to name brothers as close relations than women, although there was no significant gender difference with naming sisters as close relations. Although partners and family members may be the main source of lay support and considered the most important contacts, this does not necessarily mean that they are always viewed as positive, as relationships are complex. Furthermore, they found that women reported family support less often than men and family barriers to self-care more often. Rosland et al. (2010) found that men reported their main lay contact was also their main source of criticism about the way they manage their condition. Women reported significantly less family support and significantly more family barriers to management activities (Rosland et al., 2010). Nonetheless, the majority also reported that the consequence of the main contact’s involvement had positive effects, either feeling glad of their involvement or more confident about their management, with less than twenty-five per cent reporting that the contact made them more confused, frustrated or guilty. Thus, even though support was not always positive, it was beneficial on the whole. Yet, Rosland et al. (2010) study was based on a survey of experiences and much qualitative work on the dynamics of close personal relationships has been restricted to traditional interviews (Richardson et al., 2007; Adamson & Donovan, 2005; Lindemmeyer, Griffiths & Hodson, 2011). In this thesis, I will qualitatively combine the use of a visual hierarchical social network tool (see Chapter 4 for a detailed discussion of the social network mapping tool) to elicit the social network
structure with an interview based discussion. This will enable the function and quality of the resources available from the social network to be examined and allow for the complexity of relationships, which can be both positive and negative, to be explored.

2.7 Summary

In this chapter I have shown that chronic illness management involves the interplay of multiple factors and the ongoing negotiation of roles and responsibilities with family, friends, work colleagues and health providers and is informed through formalised education and exercise programmes. Despite this, the conceptual framework underpinning formal self-management support programmes focus on the individual to the exclusion of the wider context of management. This limits the utility of such programmes as they are based on a one-size fits all approach to illness management. This is an ongoing reciprocal process where all factors, to varying degrees, influence and shape understanding of the condition within the social context it is situated, and thus how it becomes embedded, in everyday life. Zola (1973) argued that there was little work on understanding how or why a patient goes to the doctor, as it was thought to be an obvious decision. Lay referral systems have been the focus of much research operating through social networks to influence when and how often a person goes to the doctor (DeFriese & Woolmert, 1992). This work extends this argument, by considering not only what influences how or why a patient goes to the doctor, but also arguing that rarely is it considered how a patient integrates the medical knowledge provided by professionals with the support and information, as well as limitations, of their personal lay networks. The role of wider, less direct social influences on an individual’s ability to self-manage will be examined and consideration of the influence of the multiple relationships, described above, and their interactions on self-management and how it is prioritised within everyday life. By changing the focus from acute entry into care to a broader look at self-management, the links between existing formal health care and lay health systems in influencing management priorities enables a contextually relevant approach to self-management to be taken.

In the next chapter I will examine the literature on social networks and discuss the value of the concept in relation to patient experiences of long term condition management.
Chapter 3

What can social networks and social capital add to the understanding of long term condition management?

In this chapter I begin by defining the concepts of social capital and social networks used in this thesis and examine the debate around the two concepts. I will examine how these concepts have been used in understanding how health behaviours have been acquired or terminated. Finally, I will explore the relevance of social networks and social capital in the management of long conditions.

3.1 Introduction

Relationships influence the behaviour of an individual beyond their personal attributes, e.g. gender, age and educational status (Valente, 2010). Social network research focuses on the relations and interdependency of social actors by examining the systems through which social interaction occurs at the level of the individual, group or organisation (Robins & Kashima, 2008). In other words, social networks may be considered as the connections between social entities (Faber & Wasserman, 2002). There are multiple definitions of social capital, but for the purposes of this thesis it will be defined as the resources within the social networks that an individual has access to through network ties (Lin, 2001). Social networks and social capital have been shown to influence health in a number of contexts through both the uptake and cessation of certain health related behaviours. For instance, Christakis and Fowler (2008) demonstrated that smokers in a network were clustered together, and smoking behaviour spreads through close and distant ties; groups of connected people were more likely to stop smoking if those they were connected to also stopped smoking. They also found that the type of smoking was influenced by network members in that friends and co-workers did not influence heavy smoking as much as they did casual smoking. Obesity has also been shown to be influenced by social networks with an individual’s chance of becoming obese increased by fifty-seven per cent if their friend was to become obese over the same time period, and forty per cent if a sibling experienced weight gain (Christakis & Fowler, 2007). Social network analysis has also been used to identify the spread of communicable diseases such as HIV (Rothenberg, Potterat, Woodhouse, Muth, Darrow & Klovdahl, 1998) to develop targeted testing and education intervention programmes for high risk individuals and groups (Heckathorn, Broadhead, Anthony & Weakliem, 1999; CDC, 2006). These have
important implications for the targeting of public health interventions which have traditionally focused on changing individual behaviours, as they may need to move towards a more socialised message to be of greater utility.

### 3.2 Defining social networks

Social network research focuses on the relationships of social actors by examining systems through which social interaction occur at the level of the individual, group or organisation (Robins & Kashima, 2008). Social network analysis studies examine either sociocentric networks or egocentric networks (Faber & Wasserman, 2002). Sociocentric networks, i.e. full relational networks, represent the connections of all members of a community or group (Faber & Wasserman, 2002). At the level of the individual, social network analysis focuses on egocentric networks, i.e. the actors to which an individual, referred to as the ego, is connected. Egocentric networks, or personal networks, are constructed using information obtained from the ego about the contacts, i.e. alters, that they have, whereas sociocentric networks require all network members to be contacted (Smith & Christakis, 2008). As such sociocentric network studies are less common because they are more expensive and it is difficult to obtain complete data, whereas personal network studies have been used to explore social support networks with support being considered a property of the individual through the ties they have with others (Faber & Wasserman, 2002). Ego-centred networks provide information about the importance of relationships from the perspective of the ego and as such this thesis will use an ego-centred approach to examine the personal networks of individuals with long term conditions. Studying social networks at the level of the ego is partly for pragmatic reasons of time constraints and confidentiality, but also the actions of alters may have significant meaning for the individual, which may enable and support an individual, or conversely threaten to undermine their self-management goals (this will be explored in Chapters 5, 6 and 8).

At the level of the individual, personal networks operate through a process of reciprocity and trust. Within social networks reciprocity is variable, as not all members provide help all of the time; rather, social support comes from various network ties (Plickert, Côte & Wellman, 2007). The most basic element of a network is a dyad, i.e. a connection between two people (Granovetter, 1973). The ties between actors facilitate influence and information flow (Wellman & Berkowitz, 1988). Granovetter (1973) proposed that the amount of overlap between two people’s friendship networks directly varies with their
dyadic tie to each other, and this impacts on the influence and information that may be shared across the networks.

The use of social networks and their role in long term condition management can be understood in part through examining the role of the network structure and function (also see Chapter 5). The function of a network may be explained through the resources an individual has access to and can be examined by the quality of the relationships and the degree to which ego and alters are similar, i.e. measured by homophily, or different, i.e. measured by heterophily (Valente, 2010). Social network structures may also provide insights into some of their influence by establishing how information is shared. Low density networks that consist of weak ties, where people are involved less socially with each other, have been suggested as forming bridges between different high-density networks, which consist of strong ties between members who are close (Granovetter, 1983).

Individuals with a large number of weak ties have access to a larger breadth of information, as the acquaintance from the weak tie will have their own close group and will act as a bridge between the two densely knit groups (Granovetter, 1983). This would suggest that individuals with high density groups may be of limited use in gaining new information and will have different network characteristics, e.g. maybe provide support. Close networks are more likely to be formed by people with similar attributes or those who share similar activities and develop norms, trust and group identity (Kalish, 2008). These close knit groups are homogenous but are connected through weak ties. Burt (2000a) suggested that there are structural holes between individuals who are not connected and those who utilise these holes and connect these individuals receive information and control. An individual would occupy a structural hole to obtain personal power. Structural holes and the bridging that they enable have been suggested to be more of a function of social capital than closed networks (Burt, 2000a). However, both aspects of social networks combine to produce social capital, with weak ties and the role of brokers in structural holes increasing information available to the individual. Closed networks consisting of strong ties provide the support and identity that is an important aspect of social capital in relation to self-care.

Social networks are an integral part of many definitions of social capital, as the ties between individuals or groups form the structural component of social capital (Baum & Ziersch, 2003). Features of social capital, such as trust and reciprocity, constitute the
cognitive aspects of the network. According to Lin (2001), social networks are necessary for accessing and using embedded resources, with variations in the networks producing differences in the quantity and quality of resources available to the individual. Social network theory assumes that the social structure of the network determines individual attitudes and behaviour through the flow of resources in the networks that shape access to opportunities and limit behaviour (Berkman, 2007). However, all networks are not the same, as some are small but close, while others may be larger but more dispersed. Cattel (2001) identified six types of social networks: the socially excluded network, the homogenous network, the heterogeneous network, the traditional network, the relocating network and the network of solidarity (this notion of typologies networks in influencing illness management will be examined later in this chapter and in Chapter 6).

Each network is different in the way it is structured and operates. Analysis of networks takes a structural and compositional approach and focuses on specific resources which pass through the network (Berkman, 2007). Networks can provide a sense of control, identity, self-esteem and social support (Cohen & Syme, 1985). Burt (2000b) proposed that two structures create social capital, namely network closure, i.e. social capital formed in strongly interconnected networks, and structural holes in networks, which are created when connections are made between people who would otherwise be disconnected. These networks represent the relationships between individuals. Weak ties and structural holes may be a place where health professionals can operate by connecting an individual to a service from which they could benefit. For example, community health educators (CHE) occupy this type of position within their network membership and can use this position to provide health information to targeted neighbourhoods and communities, many of which may not have equal access to health information (Chiu & West, 2007). For example, where there are different ethnicities within an area CHEs can be used to target specific ethnic groups.

3.3 Defining social capital

There is much debate in defining social capital. The concepts on which social capital is founded include the work of Durkheim, Simmel, Marx and Weber (Baum & Ziersch, 2003). Yet there remain many definitions and focuses within research that has used social capital as a construct to explore many of the dimensions which have been attributed to it (e.g. job attainment). This diversity of use has been related to the different theoretical backgrounds of those using the term and the dichotomy that exists between various sub-
Social capital can be considered at one level to be a human resource which occurs within social networks (Li, 2007). Coleman (1988) defined social capital functionally as the relationships between actors who produce social structures that form resources, and it is these resources which constitute social capital. Within this definition, social capital has many different forms which have two common characteristics: firstly, an aspect of a social structure, and secondly, an ability to facilitate certain actions of those within the structure, which would not be possible if it was not there. This would suggest that individuals with low levels of social capital have less access to resources and relationships, which then promotes inequality in access to support and important resources in long term condition management. Coleman (1988) viewed social capital as different to other forms of capital because it exists within the structure of relations between and amongst individuals. Ponthieux (2004) disagreed with Coleman’s definitions, arguing that with such a definition social capital is not produced but is a by-product of other activities, and therefore within economic terms it is not a form of capital but an externality.

Bourdieu and Wacquant (1992) proposed that social capital is the sum of resources, either real or virtual, which are acquired by individuals or groups through the institutionalised relationships of their networks. Bourdieu makes a connection between social, cultural and economic capital which allows them to be used together to investigate class advantage that is transmitted across generations (Li, 2007). Bourdieu proposed that if cultural and economic capital function properly there is no need for social capital, as the *habitus* that exists between parents and children operates as the source of transmission for educational advantage and as such external resources are not needed (Li, 2007). Such a definition of social capital has been difficult to operationalise and so has not been the focus of much research.

Putnam (1993) defined social capital as the features of the social organisation that can increase the efficiency of a society by facilitating coordinated actions; such features include trust, norms and networks. It is through associations, i.e. networks, where people learn to trust and cooperate with others to achieve common goals. Successful cooperation is generalised out of specific contexts, such as membership of groups and associations, so that trust may also disperse to the level of the whole community (Putnam, 1993). Central to such a concept is therefore membership of organisations, in particular civic
organisations. Membership of organisations and the time and commitment that active involvement entails may exclude people who are ill which in turn limits access to the positive resources that membership promotes. Putnam (1993) proposed that certain networks are more likely to create high stocks of social capital compared to others, in particular horizontal networks as there is an equal level of power and status between actors and create high levels of social capital, whereas in vertical networks there is a hierarchical power relationship which removes individual responsibility and involvement in order to achieve common goals. Putnam (2000) applied his definition of social capital to American society and demonstrated a decline of social capital due to the changing role of women in the labour market, increasing mobility, demographic changes and new technologies. These changes were considered to decrease social capital, as people were not involved in traditional organisations. However, the change in groups attended and access to people from the wider population was seen as disadvantageous to the development of trust and collective action, despite new technologies being able to unite individuals who may share similar ideals and goals and work together towards a set of similar ideals. In his later work, Putnam (2000) acknowledged the importance of informal networks, such as friendships with friends who may not live close geographically. Li (2007) argued that it is informal social connections which are the greater source of social capital, although this has not been the focus of much social capital research. It is through informal social connections where lay networks for self-care can be viewed as existing. The focus of this research is to explore the formal and informal connections, i.e. those outside of health care identified by the ego as having a role in enabling them to manage their condition through the resources they make available (this will be discussed further in Chapter 5 and 6).

Fukayama (1995) proposed that trust was a central concept for social capital and was characteristic of a country as a whole, either a country could be rated as high-trust or low-trust. Countries that Fukayama (1995) considered to have a high ability to trust were Japan, Germany and America, whereas countries such as Italy and France were low-trust countries. Low levels of trust was considered to developed from within their cultures, as individuals do not support each other, whereas in high-trust countries the opposite is true (Ponthieux, 2004). From such a perspective, there is no individual advantage to developing social capital; rather, it produces a collective good which benefits the community as a whole.

However, the concept of social capital has been used to explain many things without a clear, consistent definition of the concept and there remains an issue of tautology within
research on social capital. Also whether social capital is considered a true form of capital is contentious, as three main forms of capital are traditionally recognised in modelling the economy: financial, environmental, i.e. land, and human. Social capital is a fourth area which unites the other forms of capital, as it is the networks of human relationships produced by social capital which combines them to produce economic activity (Szreter, 1999). However, remaining is the question of whether social capital is truly a ‘capital’ as it could be considered to act more like a catalyst, unlike other forms of capital which act as producers. When considered as the resources available through the social network the utility of social capital as a concept within research can enhance an understanding of the role of social networks through conceptualising the availability of networks to influence actions.

Wakefield and Poland (2005) suggested that there are three key themes within social capital literature: firstly, the communitarian theme (whose main proponent was Putnam) where social capital was conceptualised a resource for the entire community. A second theme within the social capital was the institutional theme (whose key proponent was Evans) which proposed that social capital is necessary resource to produce organisations which are economically and politically effective. Wakefield and Poland (2005) identified a third social capital theme (whose main proponent was Bourdieu), which considered social capital as a resource for individuals or groups that reinforce existing power structures and can also be used to achieve goals that could not be achieved on their own. Bourdieu (1986) placed social capital as emerging from economic capital through its role in reinforcing existing power structures and discrimination, and defines social capital as the resources which are linked to having robust networks of acquaintances.

Definitions of social capital which operate at the micro level allow social capital to have both actual and potential resources for an individual to access and enables there to be a link between the individual and the group or population level (Waldstrøm & Svendson, 2007). The different perspectives of social capital operate at either the micro, meso or macro levels. At the meso and macro level social capital is an abstract concept which is inferred from the acts of individuals whereas at the individual level it is more direct and concrete to measure (Waldstrøm & Svendson, 2007). Glaeser, Laibson and Sacredote (2002) defined an individual’s social capital as their social characteristics from their intrinsic abilities, e.g. social skills, and the result of interacting with others. For instance, Carpiano (2007) used daily smoking and binge drinking as indicators, measured the relationship between individual health and social capital using social support, informal
social control, social leverage and neighbourhood organisation participation as the indicators of social capital. Carpiano (2007) found that the social capital indicators combined were important predictors of adult health and well-being. Individually, higher levels of neighbourhood social leverage were associated with lower levels of daily smoking, and informal social control was associated with lower levels of binge drinking (Carpiano, 2007). Higher levels of neighbourhood social support were associated with higher likelihoods of smoking and binge drinking (Carpiano, 2007), which would suggest that social capital can have positive and negative effects on health.

Much research and discussion on social capital focuses on its positive effects with little attention paid to its potential negative points. In most theories of social capital at the micro and meso level, the role of group affiliation is a determinant of the level of social capital one possesses. Homogenous groups exclude individuals who do not fit with the group and therefore the resources that are available to in-group members are not to out-group members (ECOTEC, 2001). This produces inequality in access to resources, which may be particularly important with minority groups in relation to accessing services. Stolle and Rochon (1998) proposed that associations are not equal in their production of social capital. Within societies, social capital has been found within groups, rather than between them, and is affected by the power and resource access available to groups (ECOTEC, 2001). This may reinforce existing barriers to resources and isolate individuals or specific groups. Social capital is viewed from the way in which it fosters resource access and mobilisation but it also excludes some people from accessing these resources because they are not members of the group. The implicit way that this may occur is particularly important when considering the utilisation of initiatives in primary care.

Lin (2001) considered social capital as the resource within the social networks to which an individual has access through the ties within the networks. This definition may have a role in exploring the cognitive aspects of social networks in self-management, as it is the resources that an individual can mobilise through actors within their social networks that are important in relation to self-care. Szreter and Woolcock (2004) proposed that there have been three main perspectives of social capital used within the health literature to explore its influence on health: firstly, a social support perspective with informal networks as central to health; secondly, the inequality thesis which proposes that a sense of social justice and inclusion has decreased because increasing economic disparity has resulted in increased levels of anxiety and decreased life expectancy; and thirdly, the political economy perspective where poor health outcomes occur because of a lack of material
resources due to social and political factors. The social support perspective considers the individual as having a degree of control over the factors which influence their health and suggests a sense of ownership of health that is more conducive to the management of conditions, in particular self-care.

Lin (2001) proposed three main sources of social capital: the structural position of an actor within their social hierarchy; network locations and features, such as open versus closed networks, or the strength of ties; and purpose of action, either instrumental or expressive. There are two types of returns, namely instrumental, i.e. wealth, reputation and power, or expressive, i.e. well-being, cohesion or solidarity (Lin, 2001). This view uses a social networks perspective to relate the abstract concept of social capital to a functional definition which can be measured and makes it more applicable to research within self-care. Lin (1999) assumes that the resources an individual can access and use depends on social ties through their position and strength. This perspective is a more individualistic approach to social capital, and because of its strong connection to social network theory it makes it methodologically less ambiguous. Li (2007) proposed that Lin’s thesis can be interpreted as the strength of strong ties, and it also compliments Granovetter’s (1973, 1974) work on the strength of weak ties.

3.4 Social networks: more than social support?

Social support has been considered a mediating pathway through which social networks may influence health. Berkman and Glass (2000) proposed five behavioural pathways through which social networks influence health:

1. Social support, i.e. the different types of support that can be offered
2. Social influences, i.e. attitudes may be confirmed and reinforced when compared to a group or similar others, but does not have to be through direct contact with an individual (Marseden & Friedkin, 1994).
3. Social engagement, i.e. through opportunities for engagement with others, social networks can define and reinforce meaningful social ties which consequently provide a sense of value and belonging as well as a way in which individuals can compare themselves to others.
4. Person-to-person contact, i.e. the spread of disease through direct transmission.
5. Access to material resources, i.e. access to resources and services where shared experiences may have a bearing on health outcomes and experiences (also see social capital above).

It is through such pathways that social networks may directly or indirectly influence health. Research on social support has been the dominant lens through which these influences on health have been researched. Yet social network analysis may provide the methodological tools to measure and model social actors embedded within the networks of support (Faber & Wasserman, 2002). Rather than social support being considered a property of two people, taking a social network perspective enables support to be seen within its wider context as contingent and fluid depending on the resources, timing and availability of different network members. Wellman (1981) proposed that using a network approach enables the content, composition and configuration of ties that affect the flow of resources to be explored. It also allows the role of perceived support to be incorporated. Perceived support is ‘the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled’ (Procidano & Heller, 1983;2), although they suggest that perceived support is not the same as support provided. This may be useful when considering the role of network members who seem to provide little, if any, assistance to the individual yet are included in the social network (this question of whether social networks are more than social support will be returned to in Chapter 9).

House (1981) identified a number of subtypes of social support: emotional, instrumental, appraisal and informational. Social support can be considered transactional, as it is both given and received (Kahn & Antonucci, 1981) because it can be developed and the norm through which it is provided develops within a life course context (Berkman & Glass, 2000). No single relationship can be considered as providing social support. Social support has been viewed as a generalised resource available from network members to deal with problems (Wellman & Wortley, 1989). Wellman and Wortley (1989) proposed that relationships within an informal social network are multi-faceted with many different kinds of supportive resources flowing through them, yet most network members only provide specialised care. They identified four types of support which network members specialised in providing: emotional aid, material aid, information and companionship. They found that network members provide different kinds of emotional aid or services, but often do not provide both emotional aid and services. Network members who provide major services, such as chronic health care, are the same as those who provide emotional aid, but not those who provide other services such as household aid or child care.
(Wellman & Hiscott, 1985). Few ties provided many dimensions of support; instead individuals searched through their network to access specialised assistance rather than being able to access help throughout the network (Wellman & Wortley, 1989). Specialisation of support from different network members may provide a useful insight to the various types of work that network members do and they types of networks that are implicated in long term condition management (see below and Chapter 6).

Family members have been suggested as a primary source of support acting as a mediator and moderator of health, whilst friends have been perceived as important sources of support. For instance, social networks including relatives have been found to protect against developing mobility disability (Giles, Metcalf, Glonek, Luszcz & Andrews, 2004). Williams (1993) found that parents with chronically ill children relied primarily on family networks for support. However, in comparing parents by racial groups, Williams (1993) found that white parents’ networks were double the size of black parents’ networks, yet black parents’ perceived that their network members were more supportive. Variability within support and networks depends on network members being available, as well as for the individual to want to use them at that time. Seeman and Berkman (1988) found that ties with close friends and relatives were associated with emotional support as a person ages and children were more likely to provide instrumental support but neither a spouse nor children were considered primary sources of support. However, it should be noted that such findings do not access individual variability in the need for, and use of, social support and social networks.

The physical locality of those providing support also influences the type of support that an individual may seek. For instance, emotional support may be available from network members who live outside of their immediate environment, whereas instrumental support may be provided through ‘weak ties’ with specific expertise such as an acute health problem (Granovetter, 1973). Information about the local environment may be provided by those who live locally (Coleman, 1990). Yet there remains little research on the structure and function of lay networks in chronic disease management and the influence it has on the types and availability of social support.

The support required from family and friends through informal social networks, as well as support from doctors, nurses and the health care organisation in formal social networks is an important element in the management of long term conditions. Gallant (2003) proposed that the effect of social support or the mechanisms through which it operates may vary by
illness or the type or amount of self-care behaviour. It is through the consultation, support and prompting by others that the basis of a social network perspective is formed (Pescosolido, 2001). Nonetheless, social network analysis maps the connections between individuals and other social actors, individuals or organisations. Three characteristics are used to map social networks: the network structure, i.e. the size and types of relationships, the strength of the ties and the shape of the network (Pescosolido, 2001). Yet, such a perspective does not necessarily seek to understand the quality of the connections within a network (see Chapter 5). Social networks are the structural aspect of social interactions, whereas social support refers to the exchange of various types of support within the relationship (Antonucci, Akiyama & Sherman, 2007). Illness is experienced within a social context and the response to it is both a personal and social process (Pescosolido, 2001).

One assumption of social support research in relation to social networks is that ties formed represent sources for support; however, they may also cause conflict and demands (Seeman & Berkman, 1988). Social support may increase the risk of negative health outcomes, particularly through family ties in adopting and maintaining behavioural and lifestyle choices, e.g. smoking and eating habits, which have negative effects on health (Burg & Seeman, 1994). Such reinforcement makes it more difficult to adopt the behavioural changes needed to manage a chronic condition successfully. Rounds and Israel (1985) found that the role of social support provided by a network in chronic renal disease depends on the seriousness of the disease, the impact it has on the individual’s life, the timing in the person’s life when it occurs, the stage of adjustment the individual is at, the support resources available from the network and how the individual uses the available resources. Wenger (1996) identifies in a review of social networks and gerontology that approximately one-third of social network members provide support in emergencies and fewer with everyday events. There may be certain networks which have characteristics that are more suitable to providing support and assistance at certain points within the illness career than others. Fiori, Antonucci and Cortina (2006) identified that individuals in different types of networks may vary in the quality of support received, and within structurally similar networks the amount of support received or satisfaction with the support may vary. The assumption that people have diverse networks upon which they can draw at different times and for different types of support may not always be applicable. One important dimension of support that needs to be explored is the way in which changing roles and types of support available is negotiated within relationships as this may
positively or negatively influence on management goals within the context of everyday life (this will be discussed in more detail in Chapters 5 and 8).

Changes to sources of support and networks occur over time, although there are certain notable points where networks change. Key points in one’s life where network size reduces include the end of education, starting work, starting a relationship, having children and times of hardship. Factors that increase network size include times when people seek more autonomy from partners, being single at university and getting a job in which one has invested a lot of time training (Bidart & Lavenu, 2005). It is the ties that are created during these periods that form the basis for, and type of, support provided when people are ill and as they age. Knowing how social support functions and the meaning placed on it enables greater resilience in the face of adverse life events (Rutter, 1993). Whether the support is instrumental, emotional or cognitive, it has implications for the support provided by primary care. For instance, this has particularly important practical implications as clinicians need to understand individual patients’ views of their social relationships to determine if they have the psychological support they need (King, Wiloughby, Specht & Brown, 2006). Social support is an important dimension of the role of social networks in the management of long term conditions, yet it only one mechanism through which social networks may operate.

3.5 The role of social networks and social capital in long term condition management

While social networks have been used to explore a number of different health behaviours and outcomes, such as health status (Berkman, 1984; Christakis & Fowler, 2007; Perry & Pescosolido, 2010) and mental health (Bloom, Stewart, Johnston, Banks & Fobair, 2001; Pescosolido, Gardner & Lubell, 1998, Perry & Pescosolido, 2010), little work has been done in relation to the management of long term conditions. However, drawing on the broader literature of the social and contextual influences on supporting self-management, and the limited existing studies of social networks in specific aspects related to health, there is increasingly a shift from an individual perspective of illness management (Kendal & Rogers, 2007). Individualistic notions of self-efficacy and individual responsibility, have defined much of the contemporary UK chronic illness policy and education programmes (Kendal & Rogers, 2007). This is also reflected within models of health service utilisation such as the ‘clinical iceberg’ studies (Hannay, 1979), rational choice and health belief models that have explored the way in which the use of services are influenced by individual attitudes and characteristics (Rogers & Nicolaas, 1998).
A social process approach to health care utilisation challenges the assumption that individuals are consistent in their actions and decisions but rather seek help as part of an ongoing contact with services over years that is adapted through previous experiences (Gately, et al., 2007). This suggests that illness management needs to be defined within a more socialised context. The utilisation of chronic illness resources, such as education programmes, ongoing contact with health services and types of work (see Chapter 2) involves negotiation, co-ordination and access to individuals and resources. This adaption has been described as a balance between different pressures which are learnt through a process of experimentation and experience (Paterson, Thorne & Dewis, 1998). An understanding of social networks and social capital for long term condition management is relevant for health service, planning to ensure services support or enhance individuals existing resources (see Chapter 9).

The process through which chronic illness is normalised into an individual’s daily life may be affected by multiple aspects of the person’s social network including the role of ‘professional’ network members, i.e. health professionals, through their contact with health services, and lay networks, i.e. family and friends. The typologies of support which have been developed to define the role of others for an individual’s well-being (Fiori, Smith & Antonucci, 2007) may have utility in conceptualising the typologies of networks that could be reflected with the management of chronic illness through the concept of personal communities (see below).

3.6 The role of professional network members in long term condition management

The majority of illness management for long term conditions takes place outside of formal health care. However, although contact with health services is normally only a small amount of time for most patients the significance of this contact may have a disproportionate impact on illness management (Gately et al., 2007). Individuals with long term conditions may seek help and information from a number of health professionals including their general practitioner (G.P.), practice nurse, practice receptionist or specialists in secondary care. The health service may be considered a social entity which can be divided at multiple levels into a national service, local level primary care trust, hospital, community services, individual employees as well as the virtual support provided by online services such as NHS Direct.

The reciprocal relationships which develops between patients and health providers develop over a lifetime with a normalised process of expectation of patient and clinician
roles within a consultation. Previous experiences of using services shape future help-seeking behaviour (Rogers et al., 1999). There is a process of learning about what can be expected from services which can impact when an individual seeks help (Rogers & Nicolaas, 1998). Individuals describe a complex interaction of expectations, prior experiences with services and awareness of the availability of resources before they seek medical care (Rogers et al., 1999). These relationships may not fit within a classic network member definition as they are often not reciprocal; instead they remain an important aspect in long term condition management because they are able to access different types of support, information and resources such as medications.

The patient-clinician relationship can be influenced by a number of interpersonal variables. A long term relationship with the same clinician is rated as important with patients (Rogers et al., 1999). Previous encounters with clinicians and their manner shape future expectations of the clinical encounter and patients’ decisions to when and where to seek care. For instance, if the clinician is considered unsympathetic, patients are subsequently less likely to seek medical care (Scambler & Scambler, 1984). Furthermore, if a prior experience was negative, this could lead to a decrease in future service use (Rogers et al., 1999). The role of a clinician as a network member is complex and not necessarily based on the same assumptions and expectations as other network members (e.g. family). Previous experiences and expectations may shape the trust a patient has in their clinician but that clinician may still remain the main source of formal health care. These relationships are complex and contingent on previous experiences, yet with long term conditions patients often become experts over time, potentially knowing more about their condition and treatment than the clinician which may further challenge expectations of patient and clinician roles (Rogers et al, 1999; Thorne & Robinson, 1989). This in turn may affect the power dynamic of such relationships and ultimately when and why advice and help are sought and how this in turn interacts with the information and support from lay networks.

3.7 The role of lay networks in long term condition management

When individuals need to make decisions about their health they draw on their own previous experiences, the experiences of others who have made similar decisions and clinical advice (Ziebland & Herxheimer, 2008). People not only seek guidance from lay network members, but also to act as advocates to ensure they get appropriate care as well as various types of social support (see above). Friedson (1970) proposed that individuals
use lay consultants, i.e. people who are not medical professionals, to help them make self-care decisions and changes and seek medical care at appropriate times. This process involves an ongoing negotiation and redefining of individual roles. Many illness events are managed outside of formal health care through a varying process of self-care and lay consultation (George, 2001). Lay and familial network members have been found to be an effective source of support in a context of severe distress and disruption caused by illness (as defined in Chapter 2 as the re-evaluation of personal, familial and work-related factors which are associated with the onset and management of the condition (Bury, 2001) when formal health services were unresponsive (Rogers & Nicolaas, 1998) or reached the limit of their available resources to support them (Rogers et al. 1999). When formal services failed to respond to the presentation of acute or new illness episodes, help was sought within the lay network (Rogers and Nicolaas, 1998). Family and friends play an important part of an older adult’s health-related social network (Gallant, Spitze & Prohaska, 2007). Low levels of support represent a barrier to self-care for long term conditions (Bayliss, Steiner, Fernald, Crane & Main, 2003). Gallant (2003) argued that there is a modest positive relationship between social support and self-management behaviour, but the focus of research has been on the support provided by family and not how illness management is enhanced by members of the social network. Family members may support long term condition management by framing it as a collective responsibility of the family rather than as an individual process (Gregory, 2005). Conflict and disruption within, or externally, to the family can have a negative effect on management (Gallant, 2003).

Pescosolido (1991, 2006) proposed a revised network episode model (N.E.M) comprising of four basic components: the social context, the social support system, the treatment system and the illness career. Such a model places health care within an ‘episode’ or series of events, which occurs not as a single decision but rather an ongoing process of decisions that occur when a condition flares-up to form an acute set of health problems. This model has been used to address service use for mental health impairments but this may have utility in explaining chronic condition management through an ongoing process of decision making, which an individual may become more aware of at times when conditions are exacerbated. Similarly, Kahn and Antonucci (1986) developed the convoy model of social relations to understand the role of social relations in the quality of life of older people. They propose that over the life course personal factors, such as age and gender, and situational factors, such as culture and history, determine the structure of social networks and the availability of social support to influence the quality of life in older adults. Through social networks, resources are available at times of need with
personal and situational characteristics influencing the type of social relationships people develop (Antonucci & Ajrouch, 2007). Such a model has utility in explaining multiple factors that influence the resources available to an individual through the context and situation in which someone lives, as well as their personal characteristics in the types of relationships they form. Drawing from this review, this thesis will examine the influence of the changing role of social relations to consider the influence this may have on long term condition management by longitudinal qualitative design which will allow comparison within the same case as well as across respondents (see Chapter 8).

Typologies of social networks may also have value in explaining their influence on illness management. Although presently a typology of social networks for long term condition management within the literature does not exist, a number of network typologies have been developed to explain the role of social networks for support and well-being, in particular the work of Fiori et al. (2007) and Pahl and Spencer (2004). Fiori et al. (2007) identified six network types which could differentially predict well-being: family focused, diverse-supported, friend focused-supported, friend focused-unsupported, restricted-nonfamily-unsupported and restricted-nonfriends-unsatisfied. They found the network types varied on depressive symptoms, morbidity and subjective well-being. For instance, individuals in a friend-focused supported network type had lower subjective well-being and higher levels of depressive symptoms than those in diverse-supported, family-focused or friend-focused unsupported network types (Fiori et al., 2007). Similarly, Pahl and Spencer (2004) identified six types of personal communities, a term they used as interchangeable with personal networks, when identifying community members who provide support: friend-like, friend-enveloped, family-like, family-dependent, partner-based, professional-based. They formed typologies based on the centrality of friends and family within a concentric circle network map. These typologies challenge the role of the ‘traditional’ family in providing support and the centrality of friends within the networks to provide support. This may suggest that friends, or professionals, may have a central role in the social networks of individuals with long term conditions. Such social network typologies for illness management may provide a useful insight into where and who individuals turn to for various types of support and how resources from lay and professional network members may interact to support the individual (see Chapter 6).

3.8 Summary

In this chapter I have shown that social networks influence a number of different aspects of health and health-related behaviours. Social support is one mechanism through which
social networks may operate, yet a considerable amount can be learnt from examining the structure and function of different social networks and the relative meanings and significance different members have for the ego. The way in which resources, which can be conceptualised as social capital, move through the networks varies over time, and how individuals adapt to this needs to be understood. Social networks for long term condition management may constitute both health professionals and lay network members. The priorities of different network members and the information and support they provide, although perhaps different and potentially conflicting, may be equally significant and relevant yet the way in which they interact to define management priorities may provide useful insights into the lack of adherence to formal health messages. Networks are not static over time, nor do they always have a positive influence, which is important to consider when conceptualising their role in illness management because some network members may hinder management. These are essential elements to be considered when examining how individuals continually negotiate and redefine their role within their illness management. Illness management does not occur in isolation, but is rather a process of balance between other roles and priorities within everyday life. Nonetheless, there remains little research on the influence of the structural and compositional network elements in defining these priorities. The development of network typologies usefully unpacks some of these elements, but such typologies do not exist for long term condition management, despite their ability to provide insights into existing networks and their relative roles in influencing illness management. This concept of typologies will be used in an integrated way to examine the data and in Chapter 6, the typologies of the social networks for the respondents with long term conditions identified in this study will be discussed.

The literature reviewed in chapters 2 and 3 offers insight regarding the roles of family members and significant others in supporting illness management. Social support has been the main focus of such literature with little consideration of how structural elements (e.g. size, density, reciprocity, proximity) may influence the availability and flow of resources through specific ties. Reviewing existing literature on social networks reveals a focus on the genesis of illness but less on the management of existing illness. In the existing social network literature, social support is presented as an emergent property of the social network ties. By considering social support as a product of the social network it enables the positive as well as negative dimensions of support and access to resources to be examined as a property between several interconnected network members. A social network approach enables the structure of the network and the influence it has on how and where resources (which includes support) are sought to be examined. Existing literature on
self-management reviewed in these chapters also highlights a major focus on individual psychology and behaviour which has often neglected the importance of social context. This thesis addresses this gap by taking a more socialised perspective on illness management to examine how an individual’s orientation to management is shaped by specific relationships. It examines the taken for granted assumptions about how relationships in a social network operate in relation to each other, the impact this has on illness management and conversely, how illnesses influence social relationships. A social network approach to long term condition management enables a critical exploration of the role of the types of networks which may support or undermine the practices and processes involved in management through direct and indirect mechanisms.

In the next chapter I will go on to describe in detail the methodology used in this study.
Chapter 4

Methods and methodology

In this chapter I detail the methods and methodological approaches used in this study. Firstly, I will describe the context of this study and its position in relation to a larger randomised control trial. I will then restate the specific research questions and the methods selected to address them. Details are provided of the sampling strategy, techniques of analysis and ethical concerns related to this study. Finally, I will examine the role of the researcher in generating data and establishing ongoing relationships during data collection.

4.1 Background to this study

This thesis has drawn upon data collected whilst undertaking the exploratory phase of a self-management RCT, which is implementing the WISE model in primary care. The aim of the exploratory trial was to develop an intervention that incorporated insights from previous self-management interventions. The WISE model draws together the components of successful interventions to develop and test an integrated approach to self-management which simultaneously aims to engage self-management support at multiple levels of the patient, the professional and the system (Kennedy, et al., 2007). Furthermore, a training package has been developed for all relevant practice staff to support this (Kennedy, Chew-Graham, Blakeman, Bowne, Gardner, Protheroe et al., 2010). Following this exploratory trial, the definitive trial aimed to establish the clinical and cost effectiveness of the intervention. In parallel to the exploratory and definitive trial phases were related qualitative studies. Three qualitative studies were conducted: firstly, to explore the appropriateness and acceptability of various patient self-management outcome measures; secondly, to identify the processes through which new ways of managing long term conditions are normalised by clinicians into routine work; and thirdly, to identify the processes by which long term condition management are normalised (as defined in Chapter 2 as the incorporation of illness into everyday so as to become ‘normal’ (Bury, 2001)) overtime by patients and integrated within their existing social networks through a patient level longitudinal study.

The study upon which this thesis draws was the qualitative patient level project that examined the normalisation of long term condition practices within existing social networks. This study took place between June, 2008 and November, 2009. I worked as a
research training fellow on this project, collecting all the qualitative data for the patient level longitudinal study. Although the initial research questions for the proposal of this project were established before my involvement, as this was a qualitative study it enabled the research to be an iterative process and the research questions were developed and topics emerged during data collection which enabled me to incorporate them during the process. Furthermore, I was able to contribute to the development of the patient-level interview for the process evaluation of the definitive trial drawing on the longitudinal study and conduct some interviews and data analysis.

4.2 Research Design

The research design provides the logic of the study that is appropriate to the research (Green & Thorogood, 2004). This study formed part of an exploratory trial for an RCT. The decision to adopt a longitudinal qualitative study was pre-determined in order to identify the processes involved in normalising new ways of chronic disease management by patients and their integration into individuals’ pre-existing social networks. A nested qualitative study within an RCT enables the complexity of the existing ways in which individuals manage their health to be taken into consideration (Rogers, 2011). Further, a social network approach allows the ways in which connections within the network may generate opportunities and constraints (Crossley, 2011). Thus, the aim of my PhD was to explore the way long term condition management becomes a normal and routine part of everyday life and the qualities of social networks which influence this. From this aim research questions were developed.

4.3 Research Questions

The aim of this study is to explore how social networks (lay and professional) influence long term condition management through the ongoing processes by which it is integrated into individuals’ everyday lives. The principal research question which this study addresses is:

“How do lay and professional networks interact to influence self-management and use of health services for individuals with long term conditions?”

The research questions addressed are:

1. What constitutes a social network for people with long term conditions?
2. How do social networks and health management reciprocally influence each other over time?
3. What influence does having multiple long term conditions have on access to resources within the network?
4. How do changes in primary care influence how an individual accesses and uses resources from their wider social network?

4.4 Research Approach

A qualitative approach enables the in-depth and detailed study of a topic (Patton, 2002). It has been argued that reality is socially constructed as it is shaped by historical, social and political processes (Green & Thorogood, 2004). This differs from the philosophical tradition of positivism which underpins much quantitative research (Bryman, 2004). Positivism assumes that there is a reality which exists independently and can be examined objectively (Green & Thorogood, 2004). Unlike quantitative methods which typically seek to quantify data, qualitative methods aim to explore and examine the understanding of social phenomena in a natural rather than experimental context, to emphasise the meanings, experiences and interpretations of participants (Pope & Mays, 1995). The choice of research approach should depend on what is being investigated as both qualitative and quantitative approaches can be used appropriately to address different research questions. Qualitative studies are typically characterised as addressing questions of ‘what’, ‘how’ or ‘why’, whereas as quantitative approaches typically address questions of ‘how many’ or ‘how much’ (Green & Thorogood, 2004). Qualitative research has been criticised for being unscientific or subjective (Denzin & Lincoln, 2008). Yet, these criticisms of qualitative research often assume that quantitative research is value-free despite the interpretation of the instruments developed to collect the data, e.g. questionnaires. The interpretation of measures by respondents may lead to ambiguity in the data as the standardisation of these measurement instruments assumes that they are interpreted and answered in the same way (Collins, 2003). Conversely a qualitative approach explicitly acknowledges the socially constructed nature of reality, the role of the researcher in shaping the study and the constraints of the context in which it occurs. It is important to establish the parameters of the research approach taken, as it is embedded within the broader debate encapsulating qualitative and quantitative research. Qualitative research emphasises the ‘qualities of entities and on processes and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount,
intensity or frequency’ (Denzin & Lincoln, 2008: 14). As this study aimed to identify the processes and meanings of the social networks for people with long term conditions taking a qualitative approach supports these aims.

4.4.1 Taking a qualitative social network approach: the role of narrative descriptions

Similar to the above discussion about the merits of qualitative research, the decision to take a qualitative social network approach should be addressed. Early social network research was predominantly qualitatively based (for instance Bott (1957) examined the impact of network structures on marital relationships). Yet there has been an increasing shift to a more quantitative examination of social networks with the development of computer programme such as UCINET or PAJEK (Scott, 2000; Wellman, 1983) which reduce relationships into a binary code in order to examine the network effects over whole network samples to the detriment of understanding the qualities of these relationships. Much contemporary social network research reduces the complex interactions between network members into a quantitative form and comparatively fewer studies have examined what is actually transmitted or exchanged through the ties in the network or what motivates and maintains these relationships (Valente, 2010). Cohen-Cole & Fletcher (2008) highlighted the limitations of social network analysis when comparing the significance of social network effects on health outcomes such as acne or height. For instance, a person was more likely to have acne if they had friends with acne (Cohen-Cole & Fletcher, 2008). This highlighted the importance of understanding more than just the social network ties in the data but potential sources of confounding variables. Phillipson, Bernard, Phillips and Ogg (2001) proposed that taking a social network perspective allows ‘for no particular assumption about the type of relationships in which people are involved’ (p26). A practical and flexible approach to considering what defines a community enables exploration of personal change and change in resources over the life course. A network approach enables the variety of important relationships to be identified. Adopting a qualitative approach complements the more structured approach to mapping networks and allows greater exploration of the meaning and significance of social relationships for supporting management and supplements the visual representation of the network map.
4.4.2 A longitudinal approach

One final consideration in the research approach taken is that of the longitudinal approach to this study. Longitudinal qualitative research is a ‘deliberate way in which temporality is designed into the research process making change a central focus of analytic attention’ (Thomson, Plumridge & Holland, 2003: 185). However, examining what occurs over a period of time as a linear approach does not necessarily make the meaning of the events clear as meaning and time interact with individual agency to determine the meaning of the events (Neale & Flowerdew, 2003). In other words, time, when considered as embedded within context, shapes the meaning and significance of events. Time from this perspective can be viewed as a relational process which is fluid, while the meaning of the events can shape future actions around key turning points (Neale & Flowerdew, 2003). Conducting a longitudinal study with the same cohort of participants enables a detailed understanding of the patterns of continuity and change (McLeod, 2003). Similarly, Wright and Pescosolido (2002) found that changes in the personal networks of people with newly diagnosed mental health problems over a period of twenty four months depicted actual changes in the network composition that can be reliably recalled. A longitudinal approach allows emergent themes to be identified as they arise and to examine how change can be prompted to occur.

4.5 Quality and rigour in qualitative research

There has been much debate within qualitative research about ways of verifying research findings and assessing the quality of the study (Donovan & Sanders, 2005). The central components of assessing the quality of scientific research are validity and reliability (Silverman, 2006). However, it has been argued that using these concepts of reliability and validity is inappropriate in qualitative research. For instance, Agar (1986) called for a rejection of standard markers of credibility in exchange for developing the trustworthiness of the research through the ‘intensive personal involvement’ of the researcher. Such an extreme rejection of making explicit the processes involved in establishing the credibility of qualitative research may undermine the process of qualitative research and its findings. Instead, adapting these notions or using alternative criteria to establish the trustworthiness and authenticity of qualitative studies has been proposed (Lincoln & Guba, 1985). Fundamentally, the credibility of a qualitative study relies on the use of rigorous methods, the credibility of the researcher and a belief in the value of qualitative inquiry (Patton,
To establish the credibility of this research study, in this chapter I have detailed the methods and analyses used and my role as a researcher in shaping the data, and critiqued the methods used to establish the parameters of this study. Bryman (2004) proposes using four criteria to establish the trustworthiness of qualitative research, which parallel those used by quantitative researchers: firstly, credibility which is the equivalent of internal validity; secondly, transferability, which is parallel to external validity; thirdly, dependability which is the equivalent to reliability; and finally, confirmability, which equates to objectivity (see Table 4.1 for a description of the criteria and the way in which this was addressed within this study). Furthermore, Saldana (2003) proposes that trustworthiness in longitudinal studies is guided equally by principles similar to broader qualitative research, but must consider the trustworthiness of changing types of data or the data collecting methods used. He argues that the emergent nature of qualitative research allows for different types of data to be collected through a repertoire of methods which can be deployed over time. In this study, the methods used were complementary and included to increase the clarity and meaning of the exploration of social networks. By refining the interview from the initial contact with participants to the inclusion of the network elicitation exercise in the final interview, it enabled the roles and meanings of the network members to be explored in greater depth and added to the quality of the interview data.

Table 4.1 Methods used to ensure trustworthiness in this study

<table>
<thead>
<tr>
<th>Trustworthiness Criteria</th>
<th>Description (Bryman, 2004)</th>
<th>Methods used in this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Refers to the way in which the researcher arrives at their findings.</td>
<td>Providing detailed accounts about the methods deployed and the findings made during this study.</td>
</tr>
<tr>
<td>Transferability</td>
<td>Refers to the extent to which the findings can be found in another setting by other researchers.</td>
<td>Providing a detailed description of the sample and findings.</td>
</tr>
<tr>
<td>Dependability</td>
<td>Refers to establishing of the merit of the research</td>
<td>Keeping clear and detailed field notes. Transcribing interviews accurately.</td>
</tr>
</tbody>
</table>
and how it was considered through an ‘auditing’ approach. Analysing the whole data set. Providing a detailed account of the research process and data analysis decisions. Regular meetings throughout data collection and analysis to discuss emerging themes.

| Confirmability | Establishing that the personal values or theoretical perspectives of the researcher do not ‘sway the conduct of the research and findings derived from it’ (Bryman, 2004: 276). | Critically examining and making explicit my role as the researcher and how this may have influenced the data collection. Enabling the reader to assess the interpretation by providing details of the context in which the quote is set as well as the prompts used by the interviewer. By analysing the disconfirming and deviant cases. |

4.6 Methods

4.6.1 Semi-structured interviews as a method

Semi-structured interviews are shaped partly by the interviewer’s pre-determined topic schedule and in part by topics that emerge during the interview (Bloor & Wood, 2006). A qualitative interview ‘aims to discover the interviewee’s own framework of meanings’ (Britten, 1995). Semi-structured interviews, either face-to-face or via telephone, were chosen as the main type of data collection method during this study. This type of interview was chosen as it enabled the interviewer to raise a number of topics which were pre-identified as relevant whilst allowing for topics which emerged during the interview and were of significance to the participant to be explored. Further, the iterative nature of qualitative research allowed for the schedule to develop over the course of the interviews and as this was a longitudinal study these topics could then be followed up across the sample.

Interviews are not asocial or ahistorical occurrences (Wengraf, 2001). Rather, an interview is a social encounter which is co-constructed by both the participant and the researcher (Cicourel, 1964). A research interview is a social interaction and the meanings of the content negotiated between the interviewer and interviewee (Rapley, 2001). Furthermore,
the interviewer must be aware of how they are perceived by the interviewee and the effect they may have on influencing the participant’s narrative (Britten, 1995). This is in part shaped by the rapport between the participant and interviewer, which is often difficult to establish in a single encounter but more likely over multiple contacts (Green & Thorogood, 2004). By conducting a longitudinal study, this development of rapport occurs as a result of trust that develops between the interviewer and interviewee. Nevertheless, respondents may still present themselves in a certain way which may be felt to be a more acceptable version of themselves (Bloor & Wood, 2006). This is referred to as the ‘public account’, as it affirms and reproduces a moral order which is non-controversial and considered acceptable to the listener (West, 1990). Cornwell (1984) also commented that public accounts are more likely to be given in response to a direct question. The private accounts are the more personal, reflexive and honest accounts of an interviewee’s experience (Bloor & Wood, 2006). In reality, respondents’ accounts contain a mixture of these public and private representations (Dingwall, 1997). For instance, one respondent in this study described starting to cycle to work and the positive effect it had on lowering his blood pressure. However, in the final interview he revealed that he had lost his license and that was why he had started cycling to work yet still continued to refer to the health benefit that this had. The loss of a driving license could be controversial to the listener and a moral judgement could be made about the respondent, yet over this study the rapport had developed between the participant and myself so that he felt able to disclose this information. Holstein and Gubrium (2004) propose that whilst recognising that interviews are contextually bound social events and not a neutral event, they may produce ‘reportable knowledge’ (p141). It would be false to reject this as a method of inquiry; rather, it is important to identify and acknowledge this as a limitation within this method, as all types of methods have limitations which should be made explicit when considering their appropriateness in addressing the research questions.

4.6.2 Making invisible support visible: use of network elicitation diagrams

By using only semi-structured interviews in the initial interview it became evident that participants described their network in terms of the main types of support they received and broad categories. To access the nuances of the relationships and to gain an understanding of the relative importance of different network members an adapted version of the Hierarchical Mapping technique was used. This method was originally proposed by Antonucci (1986) and has been adapted by many studies which have taken either directly or indirectly a more qualitative social network approach (Phillipson et al., 2001; Spencer
& Pahl, 2006). The method uses three concentric circles with ‘you’ placed in the centre (see Appendix 1) to provide respondents with a framework for describing their social network (Antonucci, 1986). This approach was developed because it supports the elicitation of social networks and is based on the principle of no particular assumption about who should be included in the network (Antonucci, 1986). Use of a network diagram as a visual cue can allow novel lines of enquiry to emerge, which would otherwise not emerge when interviewing alone, as trying to verbally represent the complexity of a social network is very difficult (McCarty, Moline, Aguilar & Rota, 2007). In completing the diagrams it is important to have time to consider who and where to include network members and to be able to contrast the relationships (Spencer & Pahl, 2006). To enable participants to have flexibility in where they situated network members as they reflected on their importance, I let participants add, relocate or remove network members. Using personal network visualisation is only useful when considering interpersonal relationships (McCarty et al., 2007). One criticism of personal network studies is the role of recall error in data collection and the reliability of personal network data (Suitor, Wellman & Morgan, 1997; Wright & Pescosolido, 2002). Wright and Pescosolido (2002) identified that the majority of changes in the social network representations reflected real changes. This demonstrates that the use of personal network diagrams can serve as a complementary tool during a semi-structured interview for examining interpersonal relationships. In this study I used personal network diagrams in the final interviews.

4.6.3 Recruitment and sampling strategy

The trial targeted three index conditions: diabetes, chronic obstructive pulmonary disease (COPD) and irritable bowel syndrome (IBS). The practices involved in the trial were in an economically depressed area in the North West of England. Participants were initially recruited by members of the WISE team when attending their G.P. practice (see Figure 4.1) for an appointment (which was not initiated by the researchers) and was asked by the receptionist (or directed to a poster on the reception desk) if he/she has either diabetes, COPD or IBS and would be willing to talk to researchers about the WISE study. If they agreed then the receptionists identified the researchers to the patients. Patients were informed of the trial and their consent was sought for audio recording of the consultation and/or to be contacted about associated qualitative studies (irrespective of whether they agreed to the consultation recording). For the participants that agreed to be contacted about the qualitative study, their information was passed to me and from this database
participants were purposefully sampled. Thirty participants were purposefully sampled to cover a range of conditions, gender and ages to include the variety of types of resources and support that might be needed at different times over the lifecourse and to examine the influence that age and gender may have on the types of social networks implicated in long term condition management. This sampling strategy was selected as it aims ‘in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry’ (Patton, 2002). Purposeful sampling enables the careful choice of cases which highlight a certain feature or process of interest to the study (Silverman, 2010). After participants were identified through purposefully sampling within the database, I would then phone to recruit either for the longitudinal study or another qualitative study for the trial.

A further consideration in longitudinal study recruitment is: what constitutes a manageable size of participants for the study given the amount of follow-up proposed versus contingency for attrition of participants over the period of the study (Sterling & Peterson, 2005). Saldana (2003) proposed that as participants may become available or withdraw through the study process, it is advisable to start with more participants than might be necessary. The decision to recruit approximately thirty participants was made in the basis of striking a balance between ensuring that if some participants did drop-out that there would be sufficient case studies to be useful and the practical constraints, such as time, which limited how many participants could be followed up. There was flexibility to add further participants until saturation was reached so that their new ideas or themes emerging from the data.
Patient enters the surgery (either practice ‘a’ or ‘b’ in the exploratory WISE trial) to attend an appointment and is asked (or directed to a poster on the reception desk) by the receptionist if he/she has either diabetes, COPD or IBS and willing to talk to a researcher (n=unknown for practice a or b)

If no, the patient does not receive any more information about the study (n=unknown for practice a or b)

If yes, patient is asked if they would be willing to speak to a researcher about their willingness to participate in the WISE exploratory study consultation recordings or to be contacted about other qualitative projects (n=unknown for practice a or b)

The study is described to the patient and given an information sheet. Consent for participation was sought for consultation recordings or to be contacted about other qualitative projects.

Patient consent given to be contacted about qualitative studies, patient information was passed to research team
Practice a (n=28)
Practice b (n=32)

**Longitudinal social network study recruitment**: For each practice, the participants were ordered in relation to age and split by gender and condition. Participants sampled for a range of ages for each condition and both genders at each practice.

Participants selected were telephoned and the study was introduced, described based on the information (given to participants at the GP practice) and involvement was discussed.

If consent to participate in longitudinal study was given, participants were interviewed. Written consent was obtained before the interview began.
Practice a (n=19)
Practice b (n=11)

If consent was not given, participant information was erased from the qualitative study database
Practice a (n=4)
Practice b (n=5)

Figure 4.1 Participant recruitment flow chart
4.6.4 Participants

In the initial interviews, thirty participants were interviewed (see Table 4.2). Nineteen participants were from Practice A and eleven participants from Practice B. Sixteen respondents were female with a mean age at the start of this study of sixty years (ranged from 25 to 84 years old, 2 participants’ ages were unknown). Thirty of the thirty nine people invited to take part in this study agreed. The participants had at least one of three index conditions: diabetes (n=15), IBS (n=8) and COPD (n=7). Furthermore, twenty three participants had at least one co-morbid condition including chronic depression, rheumatoid arthritis or multiple sclerosis (MS) (see Table 4.2).

In the final interview twenty-six of the original thirty participants were interviewed. One participant withdrew after one month because of severe deterioration in health. Three participants were unable to be reached after positively responding to the re-invitation to the study letter and the decision was made to stop attempting to reach them after three months.

Table 4.2: A table of participant demographic information and types and amount of multiple conditions reported (n=30)

<table>
<thead>
<tr>
<th>Participant Pseudonym</th>
<th>Gender</th>
<th>Age at start of study</th>
<th>Index condition</th>
<th>Co-morbid conditions (self-defined)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catherine</td>
<td>Female</td>
<td>36</td>
<td>IBS</td>
<td>Occipital neuralgia, reoccurring cystitis</td>
</tr>
<tr>
<td>Chris</td>
<td>Male</td>
<td>65</td>
<td>Diabetes</td>
<td>None reported</td>
</tr>
<tr>
<td>James</td>
<td>Male</td>
<td>59</td>
<td>Diabetes</td>
<td>High blood pressure, cholesterol</td>
</tr>
<tr>
<td>Beatrice</td>
<td>Female</td>
<td>46</td>
<td>Diabetes</td>
<td>None reported</td>
</tr>
<tr>
<td>Abbie</td>
<td>Female</td>
<td>53</td>
<td>COPD</td>
<td>IBS, depression</td>
</tr>
<tr>
<td>Tina</td>
<td>Female</td>
<td>69</td>
<td>Diabetes</td>
<td>Stress incontinence, eating and sleeping problems, hair loss, eye infections, skin and gum infections</td>
</tr>
<tr>
<td>Adrian</td>
<td>Male</td>
<td>82</td>
<td>Diabetes</td>
<td>Rheumatoid arthritis, high blood pressure</td>
</tr>
<tr>
<td>Don</td>
<td>Male</td>
<td>48</td>
<td>Diabetes</td>
<td>Cataracts and eye problems, tendonitis</td>
</tr>
<tr>
<td>Adam</td>
<td>Male</td>
<td>--</td>
<td>Diabetes</td>
<td>Knee problems, kidney problems</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Condition</td>
<td>Other Health Conditions</td>
</tr>
<tr>
<td>---------</td>
<td>--------</td>
<td>-----</td>
<td>----------------------------------------</td>
<td>------------------------------------------------------------</td>
</tr>
<tr>
<td>Danielle</td>
<td>Female</td>
<td>66</td>
<td>Diabetes, MS, underactive thyroid, high cholesterol</td>
<td></td>
</tr>
<tr>
<td>Natalie</td>
<td>Female</td>
<td>57</td>
<td>IBS</td>
<td>Blood pressure, cholesterol, hypertension, COPD</td>
</tr>
<tr>
<td>Lyn</td>
<td>Female</td>
<td>57</td>
<td>COPD</td>
<td>IBS</td>
</tr>
<tr>
<td>Leo</td>
<td>Male</td>
<td>51</td>
<td>IBS</td>
<td>None reported</td>
</tr>
<tr>
<td>Frank</td>
<td>Male</td>
<td>65</td>
<td>COPD</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Tom</td>
<td>Male</td>
<td>52</td>
<td>Diabetes, high cholesterol</td>
<td></td>
</tr>
<tr>
<td>Rachel</td>
<td>Female</td>
<td>--</td>
<td>COPD</td>
<td>None reported</td>
</tr>
<tr>
<td>Jane</td>
<td>Female</td>
<td>55</td>
<td>Diabetes, epilepsy</td>
<td></td>
</tr>
<tr>
<td>Sarah</td>
<td>Female</td>
<td>31</td>
<td>IBS</td>
<td>None reported</td>
</tr>
<tr>
<td>Debbie</td>
<td>Female</td>
<td>62</td>
<td>IBS</td>
<td>None reported</td>
</tr>
<tr>
<td>Ron</td>
<td>Male</td>
<td>84</td>
<td>Diabetes, ischemic heart disease, arthritis</td>
<td></td>
</tr>
<tr>
<td>Ted</td>
<td>Male</td>
<td>83</td>
<td>IBS</td>
<td>Hearing problems, high cholesterol, memory problems, back pain, signs of angina (participant wording)</td>
</tr>
<tr>
<td>Isabella</td>
<td>Female</td>
<td>50</td>
<td>Diabetes, chronic depression</td>
<td></td>
</tr>
<tr>
<td>Kate</td>
<td>Female</td>
<td>84</td>
<td>COPD</td>
<td>High blood pressure, blackouts</td>
</tr>
<tr>
<td>Nancy</td>
<td>Female</td>
<td>76</td>
<td>COPD</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Jack</td>
<td>Male</td>
<td>65</td>
<td>Diabetes, high blood pressure, high cholesterol</td>
<td></td>
</tr>
<tr>
<td>Todd</td>
<td>Male</td>
<td>44</td>
<td>IBS</td>
<td>None reported</td>
</tr>
<tr>
<td>Zac</td>
<td>Male</td>
<td>65</td>
<td>Diabetes, heart bypass, ulcers on bottom of feet that won’t heal</td>
<td></td>
</tr>
<tr>
<td>Rita</td>
<td>Female</td>
<td>25</td>
<td>IBS</td>
<td>Anxiety problems</td>
</tr>
<tr>
<td>Matthew</td>
<td>Male</td>
<td>69</td>
<td>COPD</td>
<td>Oesophageal problems (caused by a hiatus hernia), feet problems</td>
</tr>
<tr>
<td>Donna</td>
<td>Female</td>
<td>54</td>
<td>Diabetes, high blood pressure and high cholesterol</td>
<td></td>
</tr>
</tbody>
</table>

### 4.6.5 Data collection

#### 4.6.5.1 Pilot semi-structured interview

Interview guides were devised to examine a range of themes such as contact with health services, where support was sought, illness management and social capital. A range of questions was developed to probe each of these categories. The sequencing and wording of the questions was considered during this stage, with questions designed to set the scene for the participants’ experiences such as length of time with the condition. This question was placed at the beginning of the interview guide to allow the interviewee to become comfortable with the interview and the recording, whereas more complex questions were placed later in the interview. Similar considerations shaped the sequencing of the telephone and final interview guides.
A pilot interview for each part of the data collection, i.e. before the initial and final interviews with a face-to-face interview and a telephone interview, was conducted with an individual with diabetes. This piloting of the interview guides and using the network elicitation diagram enabled me to identify whether the questions were ordered in a logical manner and that the phrasing and instructions for using the network elicitation diagram were clear. The participant was asked at the end of each interview to comment on its structure and content and make any suggestions that may improve it. As a result some minor changes were made to the phrasing and order of some of the questions to make the interview flow more smoothly.

4.6.5.2 Initial semi-structured interview

Thirty initial interviews were conducted from June, 2008 to December, 2008 (see Figure 4.2). The participants were recruited through the two general practices during the exploratory phase of the RCT (see Figure 4.1). For the initial interview, a semi-structured guide was used (see Appendix 2) and a short demographic questionnaire was administered (see Appendix 3). During the initial interviews a number of topics were covered including how they would describe their current health status, the presence of other conditions and how they viewed their illness now and how this may have changed since they were diagnosed. They were asked about their contact with health services and their relationships with different health professionals. The impact of their condition on their daily life, ways they managed their illness, resources they accessed and from where these were sought. Their expectations of the health services were examined in order to establish a baseline of their current use and expectation of services and wider resources. The interview then went on to examine the role of social networks, neighbourhood and civic engagement. At the end of the initial interview, participant involvement in the monthly follow-up interviews was discussed and agreed. The participants were asked for their opinions on the best way and times to contact them. The participants received £20 as a token of thanks.
### 4.6.5.3 Telephone follow-up semi-structured interview

Fourteen participants completed one telephone follow-up interview which were conducted between the initial and final face-to-face interviews from July, 2008 to September, 2009 (see Figure 4.2). Of these fourteen participants, four completed a second interview and one completed three telephone follow-ups approximately four months apart. A semi-structured guide was also used for these telephone follow-ups (see Appendix 4). The participants were asked about current health status, any changes they had made to the management of their health, contact with health services, friends or family members and contact with voluntary organisations. Notes were made during the telephone interview, as it was though this could be deemed too intrusive to record the conversation. The participants were initially contacted at the time they had identified as suitable and, over the course of this study if they could not be reached, they were phoned at varying times on a range of days.
4.6.5.4 Final semi-structured interviews and network elicitation

Twenty-six of the initial participants completed the final interviews (see Figure 4.2). As participants had been unreachable for the telephone interviews, it was decided to send a letter to all participants to re-invite them back into the study and enclosed a stamped-addressed envelope for them to return a contact form (see Appendix 5). Final interviews were conducted between October, 2009 and November, 2009. An interview schedule and network elicitation diagram was created for the final semi-structured interview (see Appendix 6 & 1). Initially participants were asked to complete the network diagram, or if they preferred I would write in the diagram under their direction. They were asked to consider (a) in the central circle: the most important in terms of their health, (b) in the second circle: those they considered important in terms of their health management but not as important as the central circle and (c) in the outer circle: those they considered important in terms of their health but not as important as in the other circles. Participants were then asked to highlight which network members knew each other, how often they had contact (verbal or written) with the network member and how far away they lived from the network member. The participants were then asked who the most important network member was, why each network member was included and what they did for the network member. They were also asked to compare between the types of support or resources that they sought from different network members, and how this significance may have changed at different times such as when they were first diagnosed. The participants were then asked to consider how their illness management had changed over the previous year, how their contact with primary care had changed, whether they had noticed any changes in delivery of the care and the consultation, specifically whether they had used the PRISMS form (see Appendix 7) and their contact with wider voluntary and local services. The PRISMS tool is designed to encourage patients to consider the symptoms or personal problems which are important to them to support a joint exploration of their problems or needs with clinicians through promoting shared-decision making to help establish priorities and agree a plan of action. Finally, the role of multiple conditions in long term condition management and the concept of care planning emerged were examined as they emerged as relevant during the study. At the end of the interview all participants were given a copy of their initial transcripts and £20 as a token of thanks.
The same topics were covered across each interview, although as the interviews were semi-structured the introduction and discussion was dynamic. If topics were not included in the schedule but were relevant to how they managed their condition they were encouraged to talk about it at length. The interview schedule was a guide, so if the participants raised topics that were on the schedule but at a different point they were encouraged to discuss it then. As the interviews progressed, I consulted the schedule to ensure all the topics were covered and allowed for emergent themes to arise. All the initial and final interviews were audio-taped and transcribed. Due to the length of the interviews the majority were transcribed by professional transcribers, but for the final interviews I transcribed 6 interviews.

4.7 Data Analysis

Denzin and Lincoln (1994) described qualitative research as ‘bricoleur’, as it utilises a variety of strategies and methods in the collection and analysis of data. Bott (1957) described the challenge in collecting and analysing qualitative social network data as:

‘When there are many factors one can choose some particular aspect of the situation and remain blind to the others. One is caught in a dilemma between succumbing in confusion and choosing some simple but false explanation. We decided to succumb in confusion in the hope that it would be temporary we endured uncertainty for a time in the hope that constant careful comparison could eventually lead to a formulation of specific problems that would do justice to the data without being so complicated as to be meaningless.’ (p8-9)

In longitudinal data analysis it may be appropriate to examine between and within cases to consider the temporal changes which reflect individual experiences as well as the themes that emerge across the data. However, thematic and narrative analyses are considered to be extreme opposites, with thematic analysis dividing data into discrete codes and narrative analysis considering the context of the data (Bury, 2001). Different types of analysis are not necessarily mutually opposed; rather, combining thematic and narrative analyses can enhance the interpretation of the data (Ziebland & McPherson, 2006). A thematic approach enables themes to be identified across all interviews and deviant cases to be identified (Green & Thorogood, 2004). Conversely, narrative analysis ‘takes as its object of investigation the story itself’ (p1), which is constructed to express meaning (Reissman, 1993). In order to preserve the context of the story the interview is taken as a whole or series of stories (Donovan & Sanders, 2005). The longitudinal design also enabled topics
which emerged to be discussed in detail and the experiences of illness and social network interaction to be situated within the temporal context of narrative accounts and changes to health (Robinson, 1990).

4.7.1 The process of analysis

A combination of thematic and narrative approaches to analysis was chosen for this study, as it allowed themes that emerged across the data set to be identified whilst enabling the stories and context which are central to understanding how networks as a whole shape engagement with management, as each network is individual. An underlying assumption in analysing the data thematically was that certain relationships would be present that could differentially affect condition management, whilst the relevance and temporal significance may be embedded contextually and their meaning would be lost if not considered within the network as a whole and the processes and meaning involved in these changes in support. Analysis of the data was an ongoing process, which began with writing fieldnotes after the initial interview. I wrote fieldnotes which detailed the setting of the interview, any relevant or particularly notable comments or reactions, for instance, the reasons why people had become upset (for example one participant got upset discussing the process of applying for benefits as she was too ill to work) as well as personal notes reflecting on my feelings and observations during the interview. I emailed my supervisors after the interviews which allowed me to further reflect on the interview and to compare responses across interviews which allowed emerging topics, such as comorbidity, to be identified and incorporated into subsequent interviews. I immersed myself in the data through reading and re-reading transcripts and making detailed notes about responses. I reviewed each transcript and the notes I had written before each telephone interview which, although was a lengthy process, allowed me to be immersed within data throughout the study. Lofland and Lofland (1995) proposed that writing notes is part of the ongoing coding process which has four components:

1. Fieldwork, i.e. notes taken about the data collection and initial analysis
2. Housekeeping, i.e. notes on the setting, people and everyday events
3. Chronological notes, i.e. recording the order in which the events occur
4. Analytical notes which record emerging themes from the data and coding items.

The systematic recording of notes is essential over a longitudinal study. Strauss and Corbin (1998) suggest making bi-weekly or monthly ‘maintenance checks’ of the notes to generate coding, analytic or theoretical notes so emerging themes can feed into the
ongoing study focus. This process of note taking continued throughout this study, and this continuing consideration of theoretical and analytical concepts that emerged as a result developed through regular meetings with my project supervisors to discuss these emerging themes and deviant cases. Themes that emerged during these stages were used to inform later data collection. Although this was a qualitative analysis, to understand the relative prevalence of themes, the patterns and frequency of the themes of the data set can be supported by the use of descriptive statistics to relate these themes across the data set.

Atlas.ti version 5.2 (a qualitative data analysis software package) and VennMaker version 1.03 (a social network software package which allows the social network diagrams to be inputted within the same spatial representation of concentric circles and the ties between network members as collected during the interviews) were used to support the analysis. Using data analysis software enables the systematic searching of the data, being able to identify supporting and disconfirming evidence. Coding (see a sample of coding in Appendix 8) and categorising the transcripts with Atlas.ti and using electronic visual representations of the network diagrams supported this process. This enabled all data to be searched, compared and anonymised. The use of computer software enables coding to evolve and maintain this complex coding through memos and linking of code hierarchies, yet these software programs do not code for you (Saldana, 2009). Rather, analysis is supported by those programs through storing and being able to retrieve the codes created by the researcher. This systematic storage of codes and memos is important in a longitudinal study in order to keep track of ideas over time. As memos and code could be linked, this enabled me to develop my analysis of the data through reading and re-reading transcripts and to develop my concepts. As I coded the interviews I broke down the initial categories that I had used further, such as initially I used the term ‘partner relationship’ I further reduced this into two categories of ‘positive partner relationship’ and ‘negative partner relationship’, as the complexity of the relationships was not adequately captured by broader categories.

The analysis of the network diagram involved two stages which I then combined with the interview accounts to illuminate the meaning of the structures. Similarly to Wellman, Carrington and Hall (1988), I analysed all the network ties present within the data set across the network diagrams to describe the ties in aggregate and create one data set. I then considered each social network as a separate unit of analysis to describe variations within an individual network. This was complimentary to the combination of thematic and narrative approaches to the interview analysis. By analysing the social network structure
in two stages, it enabled me to compare the relationship types across all the social networks, as well as allowing me to consider each network as a case within the context in which it was told.

Analysing all the transcripts of each respondent as a unit of study may illuminate the individual experience which thematic analysis is unable to accomplish, as it does not identify the individual context in which the themes occur (Murray, Kendall, Carduff, Worth, Harris, Lloyd et al., 2009). Rather than fragmenting the data, narrative analysis considers the story as a whole (Mishler, 1986). The whole account is analysed and placed in the context in which it was told (Bury, 1991). To manage the individual’s story over the longitudinal study, I created timelines which summarised the key topics and events that occurred and the role of different network members (Flick, 1998). This timeline allows important themes and significant network members to be identified, and preserves the context in which the narratives were sent. This enabled me to represent each participant as a case and to be able to examine how the respondent’s narrative changed during the study and allowed me to compare who was discussed and considered important within the narrative with who was placed into the network diagram and their relative position. In the results chapters that follow this chapter, both themes will be presented as well as case studies, where appropriate.

4.8 Ethical considerations

Ethical approval was sought by the WISE group for the RCT, which included approval for this qualitative longitudinal study. Approval was granted by the Oldham Research Ethics Committee (REC reference: 07/H1011/96). The University of Manchester endorsed the study based on NHS approval. Research governance was obtained from Salford Primary Care Trust (PCT) (see Appendix 9). Of central importance to research ethics is protecting the welfare of research participants and is conditional of ethical approval and outlined below is the procedures that I used during this study to ensure this.

4.8.1 Obtaining consent and the disclosure of sensitive information

The minimum requirement for all interview based qualitative research is written consent from participants after they have been verbally, and in writing informed about the purpose of the study, types of questions which are likely to be asked and how the results will be
used (Richards & Schwartz, 2002). It is a fundamental part of the study to inform participants about what it means to be involved, to address issues of confidentiality and anonymity, give participants the opportunity to ask any questions they may have about their involvement and the research. This develops mutual trust and respect between the participant and the researcher. All potential participants were given an information sheet about the research by members of the research team at their practice when they gave initial consent to be contacted (see Appendix 10). Following up on this initial consent to be contacted, the participants were phoned and given an explanation of this study and the level of commitment involved in the longitudinal study, and then given the an opportunity to ask any questions. Before the interview, the participants were given a consent form (see Appendix 11) and each point was read and discussed with participants. Furthermore, as unexpected information may emerge during interviews (Lee, 1993), I felt it was important that participants were comfortable and could control what they disclosed, particularly if something was raised with which they were not comfortable. We agreed a cue before we started so they could indicate that I should ‘move on’. This was important as it can be difficult for participants to refuse to give information they would rather not disclose (Green & Thorogood, 2004). I felt this was a necessary component of establishing mutual trust with the respondents, as the data collection took place over a year and there was the potential for difficult topics to arise during this study. As sensitive and upsetting topics were raised some respondents became emotional. When this occurred I stopped the recording to allow them to compose themselves, and offer sympathy. In such circumstances, participants were offered the opportunity to end the interview but all the participants wanted to continue as they said they wanted to tell their story. France, Bendelow and Williams (2000) proposed that consent is an ongoing process rather than an initial act and in this study to ensure consent was ongoing I verbally asked again for consent and assured participants of confidentiality and anonymity before the final interview.

4.8.2 Confidentiality and anonymity

Confidentiality is a core principle of ethical research practice (Green & Thorogood, 2004). It involves not disclosing any confidential material, whereas anonymity involves changing details to the extent that the individual cannot be identified, but in a manner that ensures that it does not alter the meaning or the value of what is being researched (Wengraf, 2001). This is to ensure that no harm, either physical or emotional, comes to the participant as a result of participation (e.g. negative effects on a relationship with a spouse.
or G.P.). This is of critical relevance when considering social network data (Borgatti & Molina, 2005). On initial phone contact and before the start of the first interview, I assured the participants that the transcripts would be anonymised and the interviews confidential. They were also given a unique identification number through which all data and fieldnotes were identifiable. As this study examined people’s social networks, transcripts and network diagrams were anonymised using relationship codes and pseudonyms. Furthermore, all electronic copies of the interview transcripts were stored and encrypted on a password protected computer and hard copies were kept in a locked cabinet. The transcription of the interviews was conducted either by myself or a transcriber with an established relationship with the department.

4.9 The role of the researcher: my role in shaping the interview data

It can be argued that ‘all research is interpretative’ (Denzin & Lincoln, 2008). In order to increase the trustworthiness of data interpretations, qualitative researchers must be explicit in how methodological decisions are made and interpretations produced (Reissman, 2008). These processes were established earlier within this chapter but remaining is the way in which I, as the researcher, influenced these processes. This is important because the researcher cannot exclude themselves from data collection, interpretation and reporting, as qualitative research is a reflexive process (Holloway & Biley, 2011). This begins with the first contact made between the participants and myself. Participants’ initial contact about this study was with members of the research team in their G.P. practice. I stressed that participation would not impact on the care they would receive and that information would remain anonymous to ensure that participants would not be concerned about the impact on their care if they revealed negative experiences about their clinical experience. I made it clear that the interviews were an opportunity for the research team to understand and identify people’s experiences of living with a long term condition, the role of others in supporting (or not) this process and whether this changes over a year. Reflecting back over the data, I do not believe that this initial practice of recruiting through the participants’ practices influenced what they shared with me, as their accounts incorporated both positive and negative depictions of care and relationships with various health care professionals.

In conducting the interview I was aware of how I may be perceived. As such, I wore smart clothes but attempted to not be too formal in an attempt to make sure the participants felt
comfortable, but conversely not too casual so participants knew I valued their accounts and took them seriously. Thus, I always wore smart trousers and a blouse. I offered them the option of meeting up somewhere that was comfortable and convenient for them. All participants opted to be interviewed in their own home, and when I arrived before I began the interview by prompting an informal chat about their garden or my journey, to help put them at ease and begin to develop rapport. I tried to continue to develop this rapport through active listening, as this also helped to identify the topics that were important to the participants (Wengraf, 2001). Furthermore, when participants became upset during the interview I would stop the recording and allow them to compose themselves. In some cases I offered to come back and continue the interview another day, but all participants continued the same day after a short break.

The telephone follow-up calls were also a part of the process that I was aware had a potential impact on the participants. At the end of the initial interview, the participants agreed to be contacted once a month and I ascertained convenient times and days of the week to get in touch. For the first month after the initial interviews, from the first G.P practice I was able to reach the fourteen respondents. Before I phoned a participant I would read the transcript of the interview and fieldnotes to familiarise myself with their details (Wengraf, 2001). I was aware that I could not see if the participant was alone and would always ask if they were free to talk; if not, I would phone them back at a time which they identified. However, it became difficult to reach participants and I was aware that I did not want them to feel harassed by answer phone messages; consequently, I recorded the times when I phoned and I would not leave answer phone messages every time. When looking to re-engage participants back in to this study for the final interview, I was aware that some participants’ telephone numbers or circumstances might have changed. Following discussions with my supervisors I sent a letter to all the participants to re-invite them to the final interview. In this final interview I did not raise the issue that I had not been able to reach them explicitly, as I did not want to alienate those who may have felt they had failed the process in some way. Rather, I encouraged them to discuss their experiences of living with a chronic illness over the past year and their contact with services and their wider social networks. Through this I learnt that experiences, such as changing work, prolonged periods in hospital or being bed bound at home, had restricted individuals and so they were unable to engage with this study. For others it had simply been a matter of bad timing and they recalled the answerphone messages. For one participant this had prompted them to write on their calendar whenever they had been
unwell, visited their practice or the hospital or experienced any key events that they felt would be relevant for this study. The final interview allowed for any gaps in understanding to be identified and for the participants to reflect on changes over the course of the study (Saldana, 2003). To support this I made sure that there was enough time for discussion about topics that emerged from the first interview, and gave each participant a copy of the transcript from their initial interview. At the end of the interview I wanted to make sure participants were thanked and we discussed the next step in this study and writing of the thesis to make sure that they knew that their participation was valued.

I regularly held meetings with my supervisors throughout the data collection period to discuss the interviews and transcripts and obtain feedback. In these meetings we also discussed emerging themes which I was then able to draw on to help raise any outstanding questions in the final interview. The analysis was aided by the use of Atlas.ti computer software which aided in identifying important themes across the data set but also over the year in analysing each participant as a case as well as to identify themes across the cases. As all analysis is based on interpretations which are shaped not only by the context in which it occurs but also by my own world view, there is the potential for the data to be interpreted differently by someone else. Discussions with my supervisors were particularly useful in discussing the adequacy of the interpretations. Thus, I believe that the results presented are a thorough and transparent representation of the accounts that I heard.

4.10 Summary

In this chapter I have described the research approach underpinning this thesis and outlined the background to this study. I also detailed the methods used in data collection and techniques used for the analyses. Finally, it highlighted the ethical considerations of qualitative and social network research and how these were addressed within this study.

In the next four chapters I will present the results of this study which emerged from the data collection methods discussed in this chapter. In Chapters 5 and 6, I will explore the basic components of how social networks shape where information, support and resources are sought, the relative value and impact of different relationships, as well as the network processes such as bridging or substitution, which influence where support can be sought.
In the third results chapter (Chapter 7), I will explain the role of multiple conditions on illness management and the challenges it creates for the relationships and roles of both the individual with the long term conditions and members of the social network. In the final results chapter (Chapter 8), I will examine the fluidity of networks and health management over time as condition management and social networks were reciprocally and dynamically influential.
Chapter 5

The social networks of individuals with long term conditions

This chapter I begin by explaining the structure of social networks related to health. I then explore how the size of networks and types of relationships reported influence management through identifying the role of different network members. Finally, I identify how networks change over time and their influence on health and its management.

5.1 Introduction

To understand the role of social networks on health management, firstly the key dyadic relationships, the most basic form of a network (Scott, 2000), must be identified and the mechanisms through which they influence management will be examined. Townsend et al. (2006) found that people with chronic illnesses negotiate symptoms and illness management though valued social roles such as ‘being a mum’. They proposed that there was a desire to function in these social roles as well as to maintain the familiar lives which preceded illness. Social networks and social capital have been shown to influence health in a number of contexts through both the uptake and cessation of certain health related behaviours. In this chapter I will examine how varied social roles (e.g. partner, friend, patient, parent, worker or child) are affected when expectations change due to illness. Pathways of support are complex, with both positive and negative influences interacting to shape ongoing engagement and the normalisation of management practices into everyday life. Subsequently in Chapter 6, I will then go on to examine typologies of networks and the influence on management, and in Chapter 7 how the influence of having multiple conditions affects the resources available through social networks and relationships within the network will be explored. Finally in Chapter 8, I will examine the influence that breaking or losing valued network ties, or establishing or reconnecting network ties, has on health management.

5.2 Size and basic composition of social networks

The basic structure of the social networks described by participants shows the variety of important network members. Twenty-six participants completed the network sociogram
during the final interview. There was an average of eleven network members per network, with a maximum of thirty four and a minimum of three network members. The four main network members types were the G.P., partner, children and friends (in decreasing order, see Table 5.1). Out of a total of two hundred and seventy eight network members reported, one hundred and thirty seven were female, one hundred and twelve were male and twenty nine had an unknown gender (either individuals with gender neutral titles or non-human network members), of which nine were pets (see Table 5.2). Participants were able to include whoever they considered important in their management, and for one participant this meant including a deceased friend in the network because of the importance of that person in his life:

A: He’s [friend] dead, deceased... Great old...great bloke he is.  
Q: What made you think to put him in here [network diagram] in sort of the people that you talk to? 
A: ... he were the only one ... I used to meet twice a week... That concerning fishing and concerning... the running of the club... He were one of their members, but I’ve always known him since, well... since I were 12, and it were him who really started me on fishing... we got talking one day and that were it.  
Q: ...he’s a really important person? 
A: Yes.

Adam’s final interview (diabetes, knee problems & kidney problems, Male, Age, unknown)

Further, other participants described the ongoing guiding influence of the memory of deceased relatives. The following participant described how, when she struggles with daily activities and depression, the memory of her mother telling her not to give up helps to keep her motivated:

A: I’m trying... it’s only these past month, to be quite honest with you, that I’ve had this, I’ve got to have this attitude...I get restricted with it, I can’t walk, fifty yard sometimes. I can’t get in the shower if it’s too much steam, I have to get out of the shower and sit on the toilet ...I’m on my own when this happens ...my daughter can’t be with me 24/7, she has a full time job, she’s here when she can be and help me... I am stubborn, I suppose, but there are times when I feel like giving up because of it. And then whether my mum, God bless her, spurs me on, somebody spurs me on and says, ‘No, you can’t, (participant name), keep going, keep going, don’t give in.’

Abbie’s initial interview (COPD, IBS, depression, female, Age: 53)

By including inanimate organisations, pets and deceased people in their social networks, this study extends the definition of a personal community from that of Wellman and Wortley (1990) who defined personal communities as “a person’s set of active community ties, is usually socially diverse, spatially dispersed, and sparsely knit” (p 559). Thus, personal communities should not be spatially bound to a traditional view of community
based on locality (see Wellman & Wortley, 1990 for a review). Rather, the definition should be extended to include inanimate or non-human members as the meaning of these network members is not bound by a traditional provision of support but instead through their ongoing meaning and connection to the local community and other groups. Further, it is through this meaning ascribed to these ties and their dynamic influence (whether this is direct through walking pets (see below), or through an interpretation of how they would be expected to act by a deceased person), which shaped participants’ understanding and engagement with management and the meaning it has in their everyday life. These ties promoted a sense of belonging and connection to communities (irrespective of locality) and the social roles, such as ‘being a parent’ or ‘being a friend’, which participants valued and shaped illness management.

Table 5.1: The total number of each type of relationship included in the network diagrams

<table>
<thead>
<tr>
<th>Relationship/title</th>
<th>Tally of each type of relationship per participant included in the network diagram (i.e. if one participant mentioned 2 separate sisters this will be recorded as one mention)</th>
</tr>
</thead>
<tbody>
<tr>
<td>G.P.</td>
<td>21</td>
</tr>
<tr>
<td>Partner</td>
<td>19</td>
</tr>
<tr>
<td>Children</td>
<td>18</td>
</tr>
<tr>
<td>Friend</td>
<td>17</td>
</tr>
<tr>
<td>Nurse</td>
<td>10</td>
</tr>
<tr>
<td>Sister</td>
<td>9</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>9</td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
</tr>
<tr>
<td>Neighbours</td>
<td>7</td>
</tr>
<tr>
<td>Work colleague</td>
<td>6</td>
</tr>
<tr>
<td>Cousin</td>
<td>6</td>
</tr>
<tr>
<td>Pets</td>
<td>5</td>
</tr>
<tr>
<td>Specialist</td>
<td>4</td>
</tr>
<tr>
<td>Manager/supervisor</td>
<td>3</td>
</tr>
<tr>
<td>Brother</td>
<td>3</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>3</td>
</tr>
<tr>
<td>Brother-in-law</td>
<td>2</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>2</td>
</tr>
<tr>
<td>Organisations/group participation</td>
<td>2</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2</td>
</tr>
<tr>
<td>Mother-in-law</td>
<td>2</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
</tr>
<tr>
<td>Nephew</td>
<td>1</td>
</tr>
<tr>
<td>Niece</td>
<td>1</td>
</tr>
<tr>
<td>Great nephew</td>
<td>1</td>
</tr>
<tr>
<td>Great niece</td>
<td>1</td>
</tr>
</tbody>
</table>
Twenty-one participants had at least one family member in the network and twelve participants did not include any health care professionals. Although participants were asked to distinguish between the ‘most important’, ‘important’ and ‘less important’ people in their social network in terms of managing their health, nine participants only used two categories to distinguish between network members which was predominantly (eight participants) the ‘most important’ and the ‘less important’ categories. One participant (Tom) only used the central ‘most important’ category and did not distinguish between the significance of three people (his wife, G.P. and nurse) that he included, although he distinguished their different roles in facilitating his health management. For instance, his wife was directly involved by cooking meals and reminding him to make appointments; the practice nurse and G.P. were distinguished as a source of information, access to medication and routine check-ups. One participant (Frank) also placed one network member outside of the network diagram as if there were four circles, because he distinguished between the support that he received between his eldest and youngest sons. Some participants included their extended family; for instance, one participant included great-nephews and nieces who were babies and infants (for example see Tina’s description in Chapter 6). Although very young relatives were unable to offer support, for participants who included young or infant relations in their network this was framed in the narratives in terms of the context of management amongst other priorities, an expectation of the participant within the family and the value of this, as well as considering all family members as important. For participants with smaller networks, there was a greater focus on either more functionally important relationships or they did not have an extended family which they could, or wanted, to include (for example see Leo’s case study in Chapter 8). Inclusion of the extended family did not necessarily increase the functional...
size of the social network, as even participants with structurally large networks selectively sought support and information from a smaller subset of the network members. It is these relationships which influenced the quality of health management, which will be explored in greater detail below, through exploring the meaning of the relationships to the participants (see ‘unpacking the structural elements of the network).

Table 5.2: The total number of each network member placed in the network elicitation diagram per category of importance

<table>
<thead>
<tr>
<th>Most important category (Inner circle)</th>
<th>Important category (middle circle)</th>
<th>Less important category (outer circle)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children 18</td>
<td>Friend 20</td>
<td>Friend 20</td>
</tr>
<tr>
<td>Partner 15</td>
<td>Work colleague 13</td>
<td>Niece/nephew 6</td>
</tr>
<tr>
<td>Friend 13</td>
<td>Neighbour 12</td>
<td>Niece/nephew-in-law 4</td>
</tr>
<tr>
<td>Sibling 12</td>
<td>Children 9</td>
<td>Nurse 3</td>
</tr>
<tr>
<td>Grandchildren 10</td>
<td>G.P./doctor 8</td>
<td>Work colleague 3</td>
</tr>
<tr>
<td>Pets 8</td>
<td>Specialist/surgeon 5</td>
<td>Sibling 3</td>
</tr>
<tr>
<td>G.P./Doctor 7</td>
<td>Grandchildren 4</td>
<td>Cousin 3</td>
</tr>
<tr>
<td>Parent (mother n=6, father n=1) 7</td>
<td>Mother 3</td>
<td>Grand-nephew 3</td>
</tr>
<tr>
<td>Children-in-law 5</td>
<td>Sibling 3</td>
<td>Pharmacist 2</td>
</tr>
<tr>
<td>Nurse 4</td>
<td>Partner 3</td>
<td>Neighbour 2</td>
</tr>
<tr>
<td>Hospital 2</td>
<td>Nurse 3</td>
<td>Podiatrist 2</td>
</tr>
<tr>
<td>Step-children 1</td>
<td>Children-in-law 2</td>
<td>Sibling-in-law 2</td>
</tr>
<tr>
<td>Ex-wife 1</td>
<td>Cousin 2</td>
<td>Children 2</td>
</tr>
<tr>
<td>Parent-in-law 2</td>
<td>Aunt 1</td>
<td>Herbalist 1</td>
</tr>
<tr>
<td>Podiatrist 1</td>
<td>Cousin-in-law 1</td>
<td>Dog 1</td>
</tr>
<tr>
<td>Alternative therapist 1</td>
<td>Organiser 1</td>
<td>Staff at G.P. surgery 1</td>
</tr>
<tr>
<td>Friend (deceased) 1</td>
<td>Specialist clinic 1</td>
<td>Church group 1</td>
</tr>
<tr>
<td>Counsellor 1</td>
<td>G.P. 1</td>
<td></td>
</tr>
<tr>
<td>Cousin 1</td>
<td>Organisation 1</td>
<td></td>
</tr>
</tbody>
</table>

There was also considerable variability in the extent to which the networks are situated locally or are more geographically dispersed. Two hundred and thirty eight network members live or work up to one hour away from the respondents (see Table 5.3). Respondents’ expectations of support varied dependent on the types and expectations of relationships (this will be explored in more detail later in this chapter). Locality affected the availability of practical support and, to a lesser degree, emotional support. For one participant (James), the journey to see his brother who lived over an hour away limited
how often they would see each other. Respondents described keeping in contact with important friends and family who did not live locally via email or telephone calls. Conversely, some respondents described seeking emotional support from those who do not live locally as there was a sense of confidentiality as they were less connected to other network members and were able to discuss problems with other people in their network (see section 5.4). The role of proximity may have reduced the amount of contact that respondents described having with network members who lived further away, particularly if they had lived locally in the past. The significance of the contact was in the meaning and support provided, i.e. quality of contact, when they did communicate rather than the quantity of contact.

Table 5.3: A tally of the total distance that each network member lives or works from the ego

<table>
<thead>
<tr>
<th>Position in social network diagram</th>
<th>Co-habiting (a)</th>
<th>Short work away/drive i.e. less than 5 minutes (b)</th>
<th>Lives up to one hour away (c)</th>
<th>Lives over one hour away (d)</th>
<th>Unknown/deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most important category (Inner circle)</td>
<td>26</td>
<td>41</td>
<td>40</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Important category (middle circle)</td>
<td>9</td>
<td>31</td>
<td>44</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Less important category (outer circle)</td>
<td>1</td>
<td>9</td>
<td>35</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Placed outside the circles</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

5.3 Unpacking the structural elements of the network

Much research on the role of social networks on health related behaviours has focused on the quantity of social network members and there are fewer studies which have explored the meaning of these relationships in the context of the social network and the interaction of lay and professional network members. Similarly, this is a criticism of broader social network research, which has focused on the quantity rather than the quality of social networks (as was discussed in Chapter 3). For instance, Christakis and Fowler (2008) demonstrated that smokers in a network were clustered together and smoking behaviour
spreads through close and distant ties; groups of connected people were more likely to stop smoking if those to whom they were connected also stopped. Furthermore, they found that the type of smoking was also influenced by network members; friends and co-workers did not influence heavy smoking as much as they did casual smoking. This relative influence of different relationships within the social network has also been demonstrated to influence obesity, with an individual more likely to become obese if their friend becomes obese rather than their sibling (Chistakis & Fowler, 2007) and family members can be either the most or least helpful in weight control (Marcoux, Trenker & Rosenstock, 1990). Using a social network approach enables systems that influence health management to be broken down into a set of ongoing ties which shape everyday life through a variety of mechanisms such as support, consultations or suggestions (Pescosolido, 2001). The support, as well as many of the benefits of social networks, for instance information transfer influence and control, occurs predominantly through verbal exchange (Perry & Pescosolido, 2010). Moving beyond identifying related behaviours and characteristics of social network members, a qualitative social network approach can be utilised to explore the nuances of these relationships and frame them within the wider social context of competing demands for resources shaped by personal expectations of social roles, e.g. ‘being a worker’ or ‘being a friend’. In the remainder of this chapter, I will examine the different relationships that constitute a social network for individuals with long term conditions and the mechanisms through which management is continually negotiated and normalised into everyday management.

5.3.1 Family

The role of family members was important and complex in supporting and influencing management priorities. Twenty-one out of twenty-six participants included at least one family member in their social network diagram. All participants' narrative descriptions highlighted either the current impact of family members on management or how they shaped understanding and expectation of illness. This section breaks down the concept of ‘family’ into the key members who have both positive and negative influences. Family members have been defined as two or more persons who are related in anyway either biologically, legally or emotionally (Institute for Family Care, 2009 in Rosland & Piette, 2010). For the purposes of this thesis, family will similarly be defined and extended to include pets because of the emotional attachment to the animals. Respondents considered pets to be part of their family because of the proximity, amount of contact and the daily
role they had in respondents’ lives (see section 5.3.5). Conversely, more distant relatives were excluded from this analysis after preliminary analysis identified them as less likely to have any direct or indirect effect on management. Rather, respondents’ descriptions of these relatives were of sources of potential support through an expectation that as a family member they were obliged to offer support if needed when all other avenues of potential support had been exhausted. Family members had multiple roles in supporting an individual with a chronic condition such as acting as an advocate in a clinical setting, medication management, types of food available in the home or having time to exercise (Rosland & Piette, 2010). Conversely, Gallant et al. (2007) found that there were more negative influences from family than friends and individuals with chronic illness could more easily talk to work colleagues about their conditions than family members. Yet, ‘family’ is a broad term which encompasses multiple relationships with potentially competing demands and expectations. As such, it is important to examine the various relevant components of the family unit. By focusing the discussion on those family members who shaped the meaning of management, this section will unpack the notion of these components to examine underexplored relationships between, for instance, between adult children and adult parents beyond that of adult children being carers for older parents.

5.3.2 Partners

Partners were the most significant non-health professional network members as fifteen participants considered their partner as one of the ‘most important’ network members and differentiated them as the most significant person in their network. Four people placed their partner in the middle circle as an ‘important’ network member. There were six wives, seven husbands and six unmarried partners included in the network elicitation. Yet there was little differentiation between the roles and types of support provided and reciprocated in the narrative description as to whether respondents were married or unmarried, as the relationships were long term and partners were important confidantes and consciences in shaping adherence to management practices.

Q: So who would you say is in your support group?...
A: My wife and daughter are my conscience… If you look at a cake it, it's, "You're diabetic."... My wife and daughter definitely fall into that group, but beyond that um, I don’t really rely on anybody else, because I’m in too many places. I don't have a set work day;

Tom’s initial interview (Diabetes, high cholesterol, male, age: 52)
I've always talked to the wife, she seems to be, she's like my best mate as well so I can always talk to her...

Tod’s initial interview (IBS, Male, Age: 44)

5.3.2.1 Instrumental support

Partners were also an important aid to memory when consulting with health care professionals, particularly if participants had multiple concerns to raise with the clinician. This was especially important for the following participant, who described how because of memory and hearing problems, he struggled during consultations. He described how, with multiple concerns to raise during the consultation, his wife helped him to focus and prioritise concerns so that he at least addressed the most important topics. Although the boundary between this being a supportive act to one of undermining confidence was fine, the participant described how his wife’s assistance led to him being unable to keep up with a conversation because she ‘takes over’:

I used to make a list of things… trying to remember things and saying things right has been the pattern. I get tongue tied with the doctor sometimes, so it does help sometimes when [wife] is with me, but she does take over a bit and she fills all the cracks in where I just tell you all the things and it is quick, otherwise you would be here till next week... she’ll take over

Ted’s initial interview (IBS, hearing problems, high cholesterol, memory problems, back pain, signs of angina (participant wording), male, age: 83)

A key element of partner support was the provision of instrumental support, which could take ‘typical’ gender roles. For male participants, wives played an important role in maintaining the house and controlling their diet because they were the primary cooks in the household which reduced their individual responsibility for condition management. For married male participants, wives were considered their most important network member and provided both emotional and instrumental support. This is similar to Fuhrer and Stansfield (2002), where over ninety two per cent of married or co-habiting men reported their wife as their closest person.

It's just a safe to keep the pain down and that. But same as he said [G.P.]... you've had the diabetic, he says 'you've done well not to be on insulin and that'. He says 'you've done well to just be on diet diabetic'. I said 'well the wife watches what I eat

Adam’s final interview (diabetes, knee problems & kidney problems, Male, Age, unknown)

... it is possible I suffer from dust mites... the wife always forever Hoovering and it's not just doing the sheets she does everything...The mattress, the carpets, the windowsill, the
curtains... she is concerned about me, so stuff like that, that she can do she does ... I don’t have anything fatty or everything is grilled or boiled or whatever, she makes sure I have five portions of vegetables and all that sort of stuff... she has always done that for ages

Frank’s initial interview (COPD, hypertension, Male, age: 65)

5.3.2.2 Emotional support

For female participants husbands were also an important source of support. Married female participants described the most important person in their health management as their husband, as they would discuss problems with them. However, married female respondents described getting instrumental support from their husbands but also had a wider network of friends for emotional support (for further discussion of the role of friends see below). Fuhrer and Stansfield (2002) similarly reported that eighty per cent of female respondents report that their closest person was their spouse or partner. Yet when they compared the gender of the closest person reported, over ninety-one per cent of men nominate a woman as their closet person, usually their wife, whereas thirty per cent of women nominated another women because of the different types of support, i.e. emotional versus practical, provided (Fuhrer & Stansfield, 2002).

Well there's only two of us; I've no children there's just me and [husband’s name] ...he eats what he gets. Simple as that. He walks through the kitchen as somewhere to get out of the house... he's totally undomesticated is my husband, so he, he, eats what I give him and we're of that age now where we need to be careful anyway... He's quite happy

Donna’s initial interview (diabetes, high blood pressure, high cholesterol, Female, age: 54)

Similar to Wellman and Wortley’s (1990) findings that strongly tied network members enjoyed helping each other and provided companionship, respondents described a similar cherished value to the social role of being a partner. Respondents described trying to reduce the burden on their partners and to support them with their own health problems, which were framed in terms of a comparison of severity and an expectation that the partner with the least severe condition would complete more of the everyday work tasks.

A: ...my family's grown up...although me husband is quite poorly... I think I'm the stronger person, 'cos he was quite poorly at one time, he was in intensive care for three week ... since that he's lost all his confidence, so it's on my shoulders now to...in fact he's worse than what he was...sometimes it's really hard, because you feel you get more things on your shoulders than what you need really... but nothing you can do is there really...You see he thinks he can do things and he tries to do things, but he can't and this gets him very frustrated, ...I've just got to be careful how I tread...in a way we're closer
because we do things more together...but sometimes I want to just do things on me
own...he doesn't go out often, but when he comes, when he wants to go out he's very slow
and he's got to keep stopping ... but I'll keep patient

Danielle’s initial interview (Diabetes, Multiple Sclerosis, underactive thyroid & high
cholesterol, female, age 66)

Participants’ accounts depicted how selective they could be in what they told their partner
in an attempt to protect them until they knew what was wrong, because they would be
unable to help them. The importance of the reciprocal relationships was highlighted by the
following participant following the loss of his wife. He had been advised by his G.P. that
he wear a mask to sleep in as he had sleep apnoea but the disruptive process of getting the
mask fitted whilst having to care for his wife meant that he disengaged with the process of
getting the mask fitted. He described how his own health problems were minor in
comparison to his important role in caring for his wife, despite the seriousness of his own
health problems.

A: I don't have it now I took it back. But there again the follow up on it was very poor, I
had to take it back after; you use it [mask for sleep apnoea] for a fortnight, take it back
and if there are any problems, but at the time we were in Christies... so I took it back
and said I won't be able to make the next appointment ...since that they put me back and
put me back three times...so I just give it up in the end ... the chap who did it, he only does
it part time the mask after you have gone through all the rigmarole ...I mean if you miss
him or...and there's that many people waiting, it's .... So I give it up in the end and just
carry on struggling.

Q: Did you go back to your G.P. about that and talk to him about it?
A: Yeah, he knew...he said if you can get used to it, you'd lose weight, you get a proper
night's sleep you will have more energy ...but I just couldn't...it’s a bad time as well for
me trying it ...I had the wife here and she was on her last legs and that and I couldn't
settle properly at night

Jack’s initial interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

In the final interview the participant above described the ongoing impact of the loss of his
wife, partly practically in terms of diet control, but also the loss of connection to others as
his wife had acted as a bridge to other people in a wider network. Although types of
support maybe to some degree interchangeable (see Chapter 8), the significance of the loss
of his wife had an ongoing impact as he described himself as restricted in activities.

A: ...I used to go out a lot with the wife you see and that different places...but everything’s
dropped off sort of... Like when she went part of me went... because we were married like
forty-five years and it's a bit of a blow like when she's just gone like ...So, because we
went everywhere together...I find it a big change like going on my own...

Q: Is there anyone you can ask to come with you?
A: Not really. See my daughters, they've got their own families sort of, thing like...and
they've all got their own family and that to sort of... So that's the biggest thing.
loneliness... I suppose being on your own. I suppose if I'd met somebody I'd be a lot different... But it's just meeting somebody.

Jack’s final interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

Relationships not only shape management priorities but also, conversely, the participants reported their condition affected their relationships by restricting their ability to take on certain marital or partner roles or altering their temperament, which caused distress:

... he (G.P) likes to know what, how we [wife and participant] are again, because I went to see him one year once, about me losing my temper with my wife...and he gave me some tablets, and it, they were good. It eased my... blood pressure, it brought my blood pressure down, which were on an uneven keel...and I was falling out with, with the wife...

Adam’s final interview (diabetes, knee problems & kidney problems, Male, Age, unknown)

5.3.2.3 Barriers to illness management

Despite all respondents with partners describing some positive elements of support from their partner, this was to varying degrees and could be supplemented with support from other network members. Respondents identified limits to the support that their partners could or would offer. Family barriers to self-management include unhealthy eating, missing exercise, incorrect information and missing medication and tests (Rosland et al., 2010). Similarly, the respondents described functional and emotional partner barriers to their management practices.

Q: What about your partner? Why wouldn't you talk to her?
A: ...well she wouldn’t, she doesn't see it, it's not a physical thing. She had more sympathy when she could see my actual foot than being a problem with diabetes... Well, because it's an ongoing thing... I have not a lot of patience with illness, so I try to put it to the back of my mind all the time, but you can't because you've got so much that it's difficult. So to get somebody to talk to is very hard and she's not the easiest person to talk to and whenever I do try and say 'I don't feel well.' 'Oh, well I've been working all day and I...type of thing.

Zac’s final interview (Diabetes, heart bypass, ulcers on bottom of feet that won’t heal (participant wording) male, age: 65)

For example, one participant described how following her diagnosis of diabetes her husband “developed a sweet tooth”. When he would buy chocolate he would also get some for her. Although this was described as considerate, as he did not want to exclude her, it undermined her resolve to eat healthily:

...and then we'll have a meal at night which is usually meat and veg and then the bugger of it is I nibble after that... it is not all down to needing nibble... it's like everybody
else... it's sitting watching the telly... he makes it worse 'cause he'll come in with chocolate, I mean he never used to have a sweet tooth um, at one time, but as he's got older it's, "Mmm, what's for pudding?" ... Well it makes it worse, because if he buys himself some chocolate he buys me some... and it's there and it haunts me... a bar of chocolate there for me, so I have to have it. But we don't buy in massive quantities it's just like the odd bar .... and he'll like maybe say if we are going on a journey he needs a bag of sweets to suck on or chew on...what I mean, and I'm doing it and thinking don't really want it it's just there... I think to myself, oh that's it now got to stop it I am not eating any more sweets, next time I am not having any more, I am not very strong willed I am afraid.

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

Further, when partners were viewed as trying to restrict participants’ actions, or they felt they were criticising, the respondents described them as “nagging”. Similarly, Trief, Sandberg, Greenberg, Graff, Castronova, Yoon and Weinstock (2009) also identified this as a partner behaviour which did not help participants living with diabetes. ‘Nagging’ and other behaviours, which were viewed negatively, made participants’ conditions visible to the participant and highlighted restrictions because of their health.

I've been doing the house up a lot since I've retired. I promised her that I'd do the house up when I retired... there's a lot of dust ... I do get worse ... So she's always nagging me, but wants it doing... I've got to carry on... this last few days I said, 'I'm starting with another chest infection,' and she says, 'Oh, it's the dust, the dust.' I think this time it is

Frank’s final interview (Male, COPD, hypertension, age: 65)

5.3.3 Children

Children were an important element in shaping ongoing management. Eighteen participants included children (twelve participants included daughters and twelve included sons) and seven children-in-law into their personal communities. Eighteen out of twenty-nine children included in the social networks were considered ‘most important’ groups (see Table 5.2). The roles and types of support that children undertook were influenced partly by the age of the child and the importance of maintaining their valued parental role. Older children were an important source of regular contact and practical support such as providing lifts, collecting shopping and cleaning for the participants. This support increased around exacerbations of conditions and events, which highlighted to children the increasing frailty of elder parents. For example, the following participant described in the initial interview the regular contact that he had with his daughters. In the final interview he described how this contact had increased from one of his daughters following a holiday he had had with his wife and his daughter as she had seen his ability to walk decline daily.

A: she (daughter) knows it and this is why she gets worried now, and she's phoning up more now than what she's ever done... some days she'll phone a couple of times. She'll
phone in morning when she's got to work and then she'll phone when she's got back from
work and if she thinks; ... there's something going on when I'm speaking...then she'll jump
in car and come over.

Q: ...do you often ask her for help or to do things for you?
A: Well I like doing my own things. I always have, but I can't do it the same and... I still
do cooking, I love cooking

Adam’s final interview (Diabetes, knee problems & kidney problems, Male, Age,
unknown)

The support from older children was described as supplemental to existing support from
their partners. This was particularly relevant when partners had their own health problems
and declining ability which restricted their normal roles, such as shopping.

Q: And have you ever talked to your G.P. about getting any social support...
A: No I'm alright ... my wife looks after me smashing...and if you wanted anything at all
you've only got to mention it to my daughter or son and straight away. Lucky in that
respect.

Adrian’s final interview (Diabetes, rheumatoid arthritis, high blood pressure, male, age:
82)

5.3.3.1 Differentiation between types of support from different children

Although respondents with children described being able to generally ask any of their
children for assistance if it was needed, they were able to differentiate between children
based on shared experiences and the ability to reciprocate support. Similar to Murphy,
Williamson and Nease’s (1994) findings that women were more likely to receive help
from adult daughters, female respondents described seeking support from their daughters.
The following participant described being able to talk to her daughter, who is a parent as
well, because they have more in common.

Q: And do you tend to talk to your daughters about different things to your sons?
A: Well probably yes ... she's got the family, she's got the two children ... [son’s name] he
lives on his own, he's got a girlfriend but he lives on his own... so they've not got the same
in common...
Q: ... with your daughter you've got more in common it makes it a bit easier to talk about
things?
A: Yeah.

Danielle (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female,
age 66)

Although less likely to seek emotional support from their children, when they needed
practical assistance they would turn to children if their partner was unable to help them.
This was shaped less by shared experiences and more by to whom they would be less of a
burden. One participant described how he asked his older son to help when he needed lifts to the hospital or assistance that his wife could not provide because she was deaf. He asked his oldest son because he did not have young children whereas his youngest son had three young children and the respondent felt like his son already had a lot to manage and asking for assistance would be a burden (see the case of Frank in Chapter 6).

5.3.3.2 Influence of maintaining parental role on illness management

Four participants had dependants under the age of eighteen, and two had infant children. The participants described the influence of having a long term condition in terms of transferring knowledge to their children, in particular about healthy eating and a responsibility to make sure that their children are healthy. Further, children act as a conscience as parents viewed their health as not only affecting their wellbeing but also their children's:

... I think they [children] keep me motivated...the main person to me is [wife], because the food that she makes is like vegetables and everything...I don't eat muck in other words. I eat a proper balanced diet which I never did before... I mean, the kids are like that... 'You're not drinking that, Dad?' Oh, alright stop that then...'How many have you had now?' Yes, I don't drink as much as I did. I don't go out as much as I did anyway but, every now and again you have a blow out like, but I mean, I don't like; I don't, you see some of these kids and how, some of the stuff that they drink. Glad I wasn't born then... the amount of stuff that my kids eat is like... a lot of vegetables, we eat a Sunday roast that has got three vegetables in it...

Todd’s final interview (IBS, Male, Age: 44)

Being a parent was a valued role for all participants who had children. Although participants would ask their children for emotional and practical support, irrespective of age, the participants described trying to protect their children and maintain their role as parent by trying not to burden them with their own concerns.

And then with my mother, as I say being diagnosed with the breast cancer... I don't have a partner and I don't have any brothers and sisters... if there is somebody at home you can bounce off, lay it all out say, 'sod it' whatever, make a cup of tea, whatever, you can kind of, deal... I have got one son and I think when it comes to a parent, there is a limited amount you can put onto your children.

Debbie’s final interview (IBS, female, age: 62)
Siblings remained an important source for a variety of types of support as participants aged. Nine participants included sisters, and three participants included brothers, into their network representation. Of the eighteen siblings represented in the network diagrams, twelve were categorised in the ‘most important’ category. The role of siblings varied across respondents; some siblings were considered active ties, as the respondents described their relationships as more intimate and with regular contact. Whereas other respondents’ relationships with their siblings did not have these characteristics of an active tie because of physical or emotional distance, which meant they were less important comparatively than other network members.

Q: ...do you have brothers and sisters?
A: Two brothers...
Q: Do you see them much?
A: The middle one not a lot because he works a lot... me younger brother, I see him most weeks.
Q: ...Would you talk to your...middle brother sort of on the phone more or is it kind of one of those where you kind of every so often catch up?
A: Just ever so often really, I mean we are always there if anything needs doing or we want...a bit of help with something.

Leo’s initial interview (IBS, male, age: 51)

5.3.4.1 Shared expectations of sibling relationship shape resource provision

Respondents’ relationships with siblings were framed around shared understandings and expectations of roles which had developed over the life course, although these expectations could change temporarily depending on the context. The following respondent described when she was first diagnosed with diabetes she spoke a lot to her brother who also had diabetes. As she had learnt how to manage her condition, and normalise practices into her everyday routines, the expectation of the support that he could provide returned within its more traditional parameters defined by their other competing roles within their families. Conversely, the relationship she described with her sister was more consistently supportive.

A: there's my brother...he's diabetes... I did speak to him a lot...but I don't see him so much really...it would be practical advice really...And just comparing... medication I had and medication they had...
Q: ...you don't talk to him as much about it now?
A: Well no I don't see him... I mean, he is off they go away a lot ...so I don't see him. I see him at family occasions...Because he's got his own, you see when you've got you've got your own family and then they've got their family, so you tend to stick to your own family... you can't see everybody all the time like you used to...you've got your own lives and your own families...I think you tend to see your sisters more than your brothers really

Danielle’s final interview (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

Consistently across accounts, the gender of the sibling was highlighted as an important factor in influencing what type of support was sought or offered. Respondents who had both brothers and sisters described typical gender role expectations, such as women providing more emotional support than men (Wellman & Wortley, 1990). Sisters were generally considered better for emotional support. Brothers were considered to be able to help with practical problems.

Q: How come you didn’t pop your brother in the circles?
A: ...I don't speak to my brother about being poorly really... we are close... all my family are dead close, but I think because my sister and my Mum live together, obviously my brother has got his family and things... they only live like twenty minutes away, but I don't tend to speak to him every day and I don't speak to him about being poorly... I've been brought up with my sister... I could speak to him...there's not a problem there, I just don't.

Sarah’s final interview (IBS, female, Age: 31)

5.3.4.2 Emotional support

Siblings were an important confidante for respondents because they were because they were external to their relationship with their partner and so were an important source of emotional support:

Q: ... And so if you were upset who would you talk to on here?
A: Me sister...I think me and me sister have always been close. If she has trouble she tells me, if I have trouble I tell her... Cause sometimes I can tell [husband’s name] and he gets a bit and then I get roasted then, then it ends up in a, me saying well go away don’t speak ... if I get worked up and upset I talk to me sister

Lyn’s final interview (COPD & IBS, female, Age: 57)

When respondents sought emotional support there was a higher degree of selectivity over which network members they would go to for assistance. This was moderated by the amount of trust that had developed in the relationship and the different expectations of roles for different network members. For the following participant, when her father was very ill in hospital she sought support from one of her sisters as they could be equally
supportive and exposed emotionally. With other family members she valued maintaining her identity as the strong daughter and sibling and so did not turn to them for support.

Sometimes I'd just go to her and I'd sit there with a box of tissues crying my eyes out, but that was my pressure valve... I didn't want to break down in front of my mum, and my brothers and, me and [sister’s name] used to sit and have a sob sometimes together ... and she was very good, because you think you're a failure can't even do this, can't do that and she says, 'You're not a failure, you got up this morning, you got yourself dressed that's a vast improvement to what you felt like last week'... And then gradually I realised well yes, I'm doing this and oh, today I've done that

Jane’s final interview (Diabetes and epilepsy, female, age 55)

Respondents described their relationships with their siblings as changing. For the following participant in the initial interview she described her sister phoning every day and offering to take her shopping, but she said “I want to be as independent as I can”.

However, in the final interview her health has deteriorated and she had experienced a number of unexplained blackouts which restricted her confidence and ability in completing her everyday tasks.

She is very good my sister... I never ask her if she'll do anything for me but she always rings if she is going out shopping or if she’s um, going to the Trafford Centre to pay Debenhams bill or something like that... So it makes a change for me to get out, because I don't even feel like going across the road now to the paper shop... because since I had those blackouts I do get a bit nervous that I have one while I'm out.

Kate’s final interview (COPD, high blood pressure, blackouts, female, age: 84)

5.3.4.3 Illness related work

As close networks were attuned to subtle physical changes, the participants described how they could detect the early signs of a change in their condition. For the following participant the visible signs of becoming hyperglycaemic were detected by her sister and then subtly addressed even though the participant herself was not aware of these physical indicators.

Um, me family know and that’s all that need to know; they know at work ... if I'm, a bit hyper they'll say, eh she's had a cake, let her run round a bit, she'll go home and scrub the floor and she'll be fine... that's what I do find that if my sugar is a little bit high... it isn't an issue at all; it's just part and parcel of me and me family know if ... I'm pale, I lose colour if me sugar is low ... I'm out on a Saturday with my sister shopping she'll say, oh God let's get you something to eat... they see it before I see it... 'cos I carry on and do it anyway, but she’ll say, she’ll go, I think I go a bit clammy... but it doesn't get that far because
everybody spots it... I have a good support network.
Donna’s initial interview (diabetes, high blood pressure, high cholesterol, Female, age: 54)

Further, siblings acted as bridging network members, connecting respondents to resources and other services to help them with the different types of work identified by Corbin and Strauss (1985), in particular everyday and illness work types. The following participant described how her sister took her to a weekly luncheon where she could meet other people, as well as assistance shopping. In addition, her sister had contacted a nurse she knew to help her complete a disabled parking form and acted as advocate with the G.P. when the respondent was ill.

...then when I got up this leg, I don't know whether it was caught under the bed, but it swelled up like mad by my ankle and anyway my sister came. I told her it had happened again so she came; she doesn't live very far away and she said, "Get the doctor." Anyway, the doctor couldn't come until in the afternoon...my sister rang them up and she said, "I think my sister should have a doctor to have a look at her." Anyway, they sent a stand-by doctor

Kate’s initial interview (COPD, high blood pressure, blackouts, female, age: 84)

Siblings provided varying degrees of information from their experiences and knowledge, such as if they also had a long term condition. The following participant described the reassurance of being able to discuss health concerns with her sisters who had nursing backgrounds as they would provide information and qualify when further assistance should be sought from the G.P.. It is through these network members that seeking health care was made legitimate.

I don't think it encroaches on your normal everyday life, in the way that other things do...you are not wearing a big badge saying 'I am diabetic'. I mean it disturbed me when I first found out ... because you think oh my God what else is going to come along...I don't suppose you get to my age... with a clean bill of health anyway...I've got two sisters with nursing backgrounds ... I can talk to either of them...They'll say you need to go back to the doctors because you need to ask him about that... if I don't know how to handle... I discuss with them and they'll advise me... that's how we deal with it.

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

Familial comparisons about health problems were common with siblings more than with any other kin relationship, which had a direct influence on shaping management. The following participant’s brother had recently had a stroke and James identified that he had a similar unhealthy diet and exercise routines as his brother and he described how this had motivated him to start to exercise more regularly.
Q: ...your girlfriend and your daughter, they’re very supportive?
A: Yeah... Well, my brother’s actually just had a stroke, but he was drinking all t’ time and that’s really put me and said, well, I don’t wanna be like him...cos he’s lost his left-hand side...And my brother’s like sixty, he’s just got sixty one now as I’m sixty in September, he’s sixty two in September, sixty one in September.

James’ initial interview (diabetes, high blood pressure and high cholesterol, male, Age: 59)

Familial comparison also shaped how participants framed their condition and whether they sought support from other family members as resources were limited. Respondents’ accounts depicted an awareness of a threshold of support that family members would be able to provide. For the following respondent, despite speaking daily to her brother, she did not discuss health concerns because comparatively they were not as serious as her sisters. Instead, she sought support from two close friends because the flexibility within the roles of network members measures alternative routes for sources of support.

... I've got like my brother and his wife and my two nephews um, most nephews are like really young, but mine are like twenty-two and nineteen so they're adults ...I do speak to them like nearly every day but I don't speak to them about health and stuff. Not for any particular reason really. I think sometimes I just think I don't want to dwell on it, because we've got my sister who is poorly in the family

Sarah’s final interview (IBS, female, Age: 31)

5.3.4.4 Negative role of sibling relationships

Relationships with siblings are complex because they have developed over the lifecourse and as such were not always positive. Familial ties could be strong as they have developed over many years, so that if they remain in contact in older adulthood then the expectations of roles had become established. These relationships were characterised by a shared sense of history which may be distinct from the relationships with parents as these were shaped by different expectations (as the parent and child role) than with siblings who were their peers, despite any tensions. Despite these established expectations, participants’ accounts depicted a negative dimension to their relationships as changes to their health and the subsequent support available highlighted the limits to the resources available from their siblings. The following respondent described how his brother, who lived abroad, had decided to return for a visit soon after the participant had had a heart attack. While the participant was trying to make the lifestyle changes he had been recommended, his brother expected to continue to eat his normal diet, which the participant had to cook for him, and smoke. Further, he had increased the everyday workload for the participant to the extent
that the respondent said later in the interview that he would not tell his brother again if he was ill and did not include him in his network diagram. This was in contrast to the initial interview, where he described his brother in terms of a role model for a healthier lifestyle and was considering moving abroad as well.

Q: What sort of, things would you talk about?
A: Well everything, what's happened ... and he (brother) like tries to advise me like what's best to do ... Because I've just had my brother over...he's not very good really... I was on that diet sort of, thing to start when he come and I was just getting into it and then he come over, then he's on his pudding and chips everyday and egg an bacon in the morning, so that was awkward and he smoked and that, so he had to like to sit outside ... everything didn't work out so well... I think he was bored half of the time... he was supposed to be coming over to give me a lift, so he says... I ended up doing all the work...It was harder still for him coming over like, more of a hindrance more than anything like...and he was over for a month as well near enough, three and a half weeks. But that was a bit of a problem that was really... But, so while I was clearing up and washing up after him, it was hard. Hard work

Jack’s final interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

Siblings’ negative comments could have a greater impact than those of other people as they were grounded in personal, familial markers of health. The following respondent described not wanting to be perceived as an old women but a comment made by her sister about having lived to being older than their mother was very upsetting as it was marker in terms of expectation of her own life expectancy.

I don't want to let myself go... so that people say, oh, that old woman ... I am happy in this house as I am now and I just hope I am going to be here for a long time, but whether I will or not I don't know. Because my sister said to me the other day, I could have smacked her...' she said 'you've beat me Mum.' I said, 'What do you mean I've beat me Mum?' She said 'Mum died when she was eighty-three.' 'Oh' I said, 'God,' well I said 'there's only twelve months in it.'

Kate’s final interview (COPD, high blood pressure, blackouts, female, age: 84)

Participants described equally knowing where support could be more readily sought as well as where it could not. Support was sought and accessed comparatively with other siblings. Yet, despite knowing that support from certain siblings was typically more negative, they would remain in the network as potential support. Relationships considered more positively supporting were more active ties. Furthermore, support from family members was potentially limited by how embedded the family member was in the network. If siblings were highly connected with other family members, and to a lesser degree, non-familial network members, some participants identified limiting the degree to which they would confide in them about other network members.
A: To sound off and somebody to sort of, say ... this that or the other...I'm very close to my sister like I say and I tell her most things, but you feel that, I felt that if I talked about the problems me and [husbands name] were having at the time, I was being disloyal to him...Something you can't take back, if I tell them something I can't take it back.
Q: You felt like it's not confidential.
A: Yeah. I can't take it back when it's family, they know then...whereas with somebody neutral, I could get it off my chest and then once it's off your chest you can look at it then can't you?

Jane’s final interview (Diabetes and epilepsy, female, age 55)

Central to accounts of relationships was the reciprocal expectation of support and resources. This was particularly evident when sharing information about conditions. The following respondent’s sister had more recently been diagnosed with IBS and she identified in her sister the similar problems of stress and poor diet that she had when she was first diagnosed. She had given her sister advice from her experiences to help her to learn how to manage her condition.

Q: ... So you've got in the close circle you got family, you got your mum and; is it mostly just your mum that you talk to?
A: I'd say and my sister as well because she suffers with it quite a lot, so put her on there. I'll put the same numbers on there as well.
Q: ...What do they, do they kind of, give you advice or is that just...?
A: Not really to be honest. I'm more giving my sister advice and trying to tell her how to; I think she's suffering from anxiety as well, but I think hers is more to do with... she's got a lot on and even though she doesn't feel stressed I think deep down it's all getting to her a little bit and it's making her get really bad belly aches and stuff like that, but I've just been giving her advice really.

Rita’s final interview (female, IBS, anxiety problems, Age: 25)

5.3.5 Parents

Eight participants included one or more parents in their network diagram (mothers n=8, father n=1) and two included their mother-in-law and one participant included their father-in-law. The participants who included parents were younger with ages ranging from twenty five to sixty two, and one participant (aged twenty five) lived with her mother. The participants whose parents, whether alive or deceased, had had a long term condition predominantly described a hereditary expectation that they would also develop the condition, similar to description of ‘biographical anticipation’ (Williams, 2000). This shaped expectations of condition onset as well as uptake of routine testing and the normalisation of information of management practices.

A: Well I think I knew most because my mother, my brother is diabetic... and my eldest son who passed away two years ago, he was diabetic...So I knew quite a lot...
Q: So you knew there was kind of a history?
A: Yeah, in the family kind of thing

Danielle’s initial interview (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

[I’m] extremely tired all the time, actually to the point of… my Mum said to me, because she’s diabetic, go and get yourself checked out for diabetes because you sound very much like I started. So that’s how I come to have the, the test for it.

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

The experiences of parents shaped understanding of the way in which medications reacted with the body. Respondents identified practices that their parents had had a negative response to, which made them reluctant to follow clinical advice. This was particularly evident around medication prescriptions and was partly influenced by beliefs about the hereditary nature of diabetes and belief about the hereditary reactions to medications.

I, I think I’m going to go back to him this week and say I don’t really want to take Aspirin… me mother had a stroke and found out…I found out it was a brain haemorrhage…Now, if you take Aspirin, and you see my genetics have shown me that I… I’m just like me mum…So I thought is it a good idea to take Aspirin if you have a brain haemorrhage?

Tina’s final interview (female, diabetes, stress incontinence, eating and sleeping problems, hair loss, eye infections, skin and gum infections. Age: 69)

5.3.5.1 Adult parent-child: information and emotional support

The focus of much literature relating to adult children and their parents focuses on the role of the children caring for their ailing parents (Loomis & Booth, 1995; Stoller, 1983) or the practical assistance, such as babysitting, that parents can offer. However, one dimension of the parent-adult child dichotomy that remains underexplored is the reciprocal informational and emotional support sharing between parents and children that continued throughout their life. The following respondent described how her mother remained a key confidante, particularly for emotional support along with her partner.

A: ...I would talk to my G.P. about anything, I would talk to my Mum and partner (partner’s name). I think I've put them in there because if I did have a concern in the first place I would probably discuss it with (partner).

Q: Before you go to your G.P...?
A: Probably yes, which would probably spur me on to going to the G.P...my mum would mainly be for sympathy... she doesn't always say the best things and she does probably worry me more than anything. If I say that I thought something was wrong it would be, ‘Oh, well, you need to get that checked out.’ So probably (partner’s name), but obviously
because my mother I can talk to her about anything...even though I don’t always get the reply I want, she is very important to me.

Catherine’s final interview (female, IBS, occipital neuralgia, reoccurring cystitis, age: 35)

Although parents were important confidantes for sharing ideas and information, for some participants this information was seen as out of date, which undermined the value of the information they offered. One participant described his mother, who also had diabetes, as his main source of emotional support because he felt that his wife did not understand the spectrum of physical and psychological reactions that he continued to experience and struggle with (this case of Don is explored further in Chapter 6). His mother could understand his reactions from her own experiences, and although he felt that her information was dated, this was outweighed by the value of the reciprocal support offered. Conversely, for the following respondent the advancement in understanding, in particular for food control, meant that information and learning from his mother’s experiences were limited:

Q: And you said your mum was diabetic, did you know much about diabetes from her?
A: No…You’re talking twenty five, thirty years ago… things were, nobody knew nothing about anything then… well, nobody could tell you anything. It’s like this food now, the obesity and all this lot, I said, ‘Well, I’ve been drinking since I was fifteen and a half…’ Look at me, all this food, all this shit food we’re eating now, I’ve been eating it since I was born. I don’t know what it is but it was better food then than what it is now, it’s not, it’s more greasy now than what it was when we was young.

Jame’s initial interview (Diabetes, high blood pressure and high cholesterol, male, Age: 59)

Information sharing was reciprocal with parents and children sharing ideas and experiences. Some respondents described their parents seeking advice from them. For the following participant, the narrative was a reversal of the traditional parent-child relationship with the respondent describing giving advice, but doubting that it was utilised.

Q: ...do you talk much to your family about diabetes or …?
A: I do to my dad, cos my dad’s got it…My dad’s on tablets for it and he’ll come down and say, ‘Oh, I’ve been feeling rough today.’ And all this, so we talk about it that way. Me trying to help him understand and all that…I don’t think he understands it as good as what I do.
Q: Do you find you give him advice on how to …?
A: Well, I try. It’s whether he takes it onboard and does it (laughs) is another thing

Beatrice’s initial interview (diabetes, female, Age: 46)
Eight mothers and one father were included in the network. Wellman and Wortley (1989) found that fathers are nearly as emotionally supportive as mothers, yet showed their support practically. For respondents in this study, discussions about health concerns were apparent within their relationships with their parents as they had developed over time and participants described historically having talked to their mother over their father about health problems, unless their father also had the condition. Respondents described their mothers as important sources of emotional support, whereas fathers tended to offer instrumental support.

Q: So looking back at the circles, who is sort of, most important to you in terms of sort of, at the present that would help you?
A: My Mum probably, you always turn to your Mum don't you I suppose?...: She just knows; she'll say, 'Oh I'll go and get this at the chemist for you or type of food for you' and she just ... she always seems to know what to do... My Mum doesn't work as well, so, say if I'm, say if I'm working like tomorrow or something and I've got a busy day on today or something she's like, 'Oh I'll go and get peppermint teabags from Tesco' ...and she always likes has stuff; when Mum or my Dad really, I'll go to my Mum and I'll go away like with a load of food because they don't think I eat, but obviously I do, so it’s just parents that worry about you I suppose and... I would have put my Dad in there but I don't tend to speak to him... I don't tend to speak about being ill...I'm so skinny my Dad thinks I'm anorexic anyway...he just thinks if you've not got any meat on you then you've obviously got an eating disorder. He's just quite blunt like that, he really is...It doesn't bother me at all...

Sarah’s final interview (IBS, female, Age: 31)

5.3.5.2 Reversal of the parent-child relationship: children protecting parents

Respondents’ accounts which depicted a reversal of the parent-child relationship were more likely to frame their narratives in terms of protecting their parent. This change in relationships was mirrored by a change in support sought from parents. The respondents’ accounts depicted being able to substitute this support through other network members, in particular partners and friends. The flexibility of support seeking was similar to the selectivity outlined by Wellman and Wortley (1990) who described individuals selectively drawing on ties and a range of resources depending on who is most useful for that particular function at that specific time. Such accounts of specificity in the use of support were depicted throughout the narratives. The significance of the continuing parental role in adulthood was clearly demonstrated through the loss of one or both parents. The loss of one parent was clearly linked to a change in the structure and function of the social network if they had been a significant member (this will be examined further in Chapter
8). Furthermore, the loss of emotional support provided highlighted an absence of support that could not be substituted by remaining kin.

Q: Okay. And if you were upset who would you talk to? Is there anyone in your diagram that you’d talk to or is it other people?
A: Well unfortunately I feel on that side of it very lonely. I have nobody to talk to in that way. Like I’ve got three children, but I wouldn’t talk to them about it because they’ve all got their own type of problems and I just feel because both of my parents are dead and I just have nobody to talk to, and I do feel lonely and insecure in that way

Zac’s final interview (Diabetes, heart bypass, ulcers on bottom of feet that won’t heal (participant wording) male, age: 65)

The loss of one parent could cause a significant change in the relationship with the remaining parent. For example, the following respondent described trying to protect her mother following the death of her father by not telling her about health problems such as finding a lump in her breast; instead, she spoke to her older sister. She described how the family had become increasingly family-centric to ensure that her mother remained active.

A: …mum’s on her own now we…we’re a lot more involved…I mean I did see my mum and dad, don’t get me wrong, but we all had our own little …But now we’re very integrated…“Do you fancy going out for a meal?” and they all…we all go for a meal and things like that [laughs]. “We’re going round to my brothers,” … we’ll all tag along…we have like a family night and it’s very nice…I mean I have got friends and I used to go out… more on my own…what I mean, with my friends, my partners not very social, …he’s…unsociable… like with my girlfriends, we used to have girly nights and things… whereas he’d rather sit and watch the telly or [both laugh] watch football… my friends were very important to me, they were my social circle…since dad died it’s more gone family social circle…So my friends are important to me and my work…my workmates and that as well, but my centre circle is that and I’m trying to think, who’s more important after that? I think it’s friends…

Jane’s final interview (Diabetes and epilepsy, female, age 55)

5.3.6 Pets: the unexpected bridge

Pets were an important non-human element of the social networks. Five participants included nine pets in their network diagram, of which eight pets were placed in the ‘most important’ category. The pets discussed were dogs, cats and fish. Further, a total of eleven of the twenty-six participants discussed the meaning of pets for their everyday lives, which were relevant in terms of the setting of management because pets were always there and this made them an important part of the participant’s everyday contact; they may not see people everyday, whereas they would see their pets. Furthermore, pets also had a
direct influence on management practices. In particular, participants with dogs talked about having to walk daily, making them get exercise, which was similar to the findings of a review on physical activity, health and dog ownership which concluded that dog owners were more physically active than non-dog owners (Cutt, Giley-Corti, Knuiman & Burke, 2007). This sense of obligation and purpose was similar to that of the trusted companionship described by Tuan (1984). This obligation could have the most direct impact on recommended condition management practices because they felt a duty to the animal. For instance, the following participant described his dog as the ‘most important’ member of his network as she was the only company he had every day and as he needed to take her for walks it made him get the exercise he had been recommended to do to manage his conditions (see Fig. 5.1).

Q: Is there anyone here that is sort of, most important?
A: Well, the dog... she's always here. I don't know how I'd have gone on without her to be quite honest... Oh, she’s company... Company for me really and especially when I lost my wife... and she’s always here like... So I think without the dog I'd get...

Q: ...would you take [dog] obviously for walks and things?
A: Oh, yeah, every day... She makes sure. She stares me out when she is ready to go.

Q: She makes you get up?
A: Oh, aye

Jack’s final interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

Conversely, one participant identified not having a pet as a barrier to exercise, as he did not have the same motivation to get up and do something for the pet or company whilst walking. Similarly, Ball, Bauman, Leslie and Owen (2001) found that for respondents, in particular women, having no company or pet to walk with made them less likely to walk for exercise or recreation. Animals could also be a reminder of ageing and decreasing functional abilities.

I’ve felt I need to slow down...there’s certain things I don’t do that I should do... I don’t exercise. I don’t go and walk... I just don’t like walking on me own. If I had a dog I’d go. But then again I’m too old for a dog and it wouldn’t be fair for the dog. I had one and I had to get rid of her because of I couldn’t exercise her enough.

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

A: No. I, I have trouble though...used to do all the gardening, got the garden nice, dug a, a fish pond... going to have to get rid of the goldfish, but I don't want to get rid of the Koi carp... I can’t, er, do things, if I... try, do work outside... little things with spanners and that, oh, it just leaves me like that [dropping], bloody spanners.

Q: You get frustrated that you can’t do it?
A: Yeah. I start bloody smiling.

Adam’s final interview (diabetes, knee problems & kidney problems, Male, Age, unknown)
Pets were considered an important member of the family, particularly for participants who lived alone. Dogs in particular acted as bridging network members for participants, as they connected them to their local communities beyond their familial and friendship networks. For example, the following participant described the reassurance of discussing his own health problems with another dog walker who also similar problems.

A: *But I was talking to a chap when I take her down on the field at the bottom, he’s exactly the same problems what I’ve had...he’s had the metformin and he’s had this burning and they swapped his tablets over and he said I've never looked back since...And he's had this camera down, down his throat, because he was having this heart burn thing like ...and he had this camera...*

Q: Did you find it was good to talk to somebody who had been through it as well?
A: *Oh, yeah, because he was just going for this test, this camera the other week and I said, "Oh, let me know how you go on like, because I may have to have one meself .."*

Q: And did he kind of come back and let you know?
A: *Oh, yeah he said it's alright, once you've just you've got to relax if you can, which is hard to do, but once they've just got it down he said it’s no problem you can just concentrate on breathing...*

Q: Did you find that kind of reassuring?
A: *Yeah*

Jack’s initial interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)
Figure 5.1 The personal health related social network of participant Jack
Furthermore, the loss of pets limited access to these groups because the loss of a shared interest in the pets which had acted as an ice breaker to further conversations. Without the connection that a pet had, acting as a bridge to other pet owners, participants described a sense of loss of connection to the community as they did not meet people in the area and broaden their social networks.

...we can leave the key with them [neighbour’s]...I go in daily and feed the dogs and (neighbour) just beyond (location) and next door but one, they've got a dog and they're starting to nod. We used to have a little terrier and you got to meet people who had dogs and that drives the biggest dog walking...Since the dog has died we've noticed we don't talk to half as many people as we used to do.

Tom’s initial interview (Diabetes, high cholesterol, male, age: 52)

...that was a big upset that [loss of two dogs]. It really was. I think that hurt a lot as well during the year... it made it worse... Because my wife was, I was devastated... She [dog] used to protect me...You do meet a lot of people doing that... I got chatting to them ...you just meet people... faces rather than anything. Well to be honest with you when you’re a dog walker you don’t recognise the person, you recognise the dog.

Don’s final interview (Diabetes, cataracts & eye problems, tendonitis, Male, Age: 48)

5.4 Friends and neighbours

Friends were an important, non-familial part of seventeen respondents’ social networks (over other types of relationships with similar characteristics e.g. co-worker). The role of friends varied depending on factors such as age or the seriousness of other relationships, i.e. whether the participants had a partner and family. Spencer and Pahl (2006) identified friendship on a continuum of simple to complex, with friendship types categorised as either associate, useful contact, favour friend, fun friend, helpmate, comforter, confidante or soul mate. The simpler the relationship type (for example favour friend or fun friend), the more limited the expectation of interaction with that individual. The more complex the relationship, the more multi-faceted the interaction. Similarly, respondents in this study described a spectrum of relationship types which had varying combinations of the characteristics. Friends were an important dimension in framing the support of their health management as well as defining part of their self-identity. Despite every relationship being unique there were a number of key characteristics of the relationship which shaped expectations of friendship roles and whether discussing health was legitimate in the context of their mutually defined relationship. In other words, some friends included in the
social network as important were not necessarily there for health discussions, but rather as a contrasting ‘light relief’ to the everyday work and illness practices (i.e. the self-management practices associated with policy and clinical recommendations, such as managing medications or diet, as well as from personal experiences) that shaped more closely family and work colleague relationships. However, despite positive aspects of friendships, the respondents also described negative dimensions to these relationships which affected management. Friendships did not always provide the expected support, and in some cases they reinforced practices which undermined respondents’ management goals (also see Chapter 8: change in health, change in networks).

For friends whose relationships were more complex, two distinct although overlapping categories of friendship in relation to health emerged. First were friendship relationships, which were considered important in helping respondents manage conditions. The expectations that various types of support would be reciprocally provided was a defining characteristic of these relationships which were shaped by high levels of trust. The second type of friendship category depicted by participants was of friends who they would not talk to about their health. These relationships more closely resembled the simpler relationships described by Spencer and Pahl (2006) as they had a limited expectation of their interactions defined around an activity. These relationships were considered less important in terms of their daily illness management but still important in relation to general wellbeing, i.e. friends they socialised with and maintained a valued role. These simpler relationships were not defined or shaped by expectations of deeper levels of support. The two categories of friendships were mutually important with complex friendships requiring more commitment of resources which simpler relationships did not require. This maximised use of limited resources, such as time, that is available to the participant within their daily routines yet increases access to potential support if these closer relationships are lost or unable to assist. For participants who depicted their friendships only in terms of simpler relationships, maintaining friends as valued social ties but less so than key family members, these family members were the most important sources of support and resources (see also Chapter 6: typologies of social networks). Neighbours also most closely fitted within this second category of simpler relationships because they were potential support defined by proximity.

This section will explore the role of complex relationships and the underlying mechanisms which influenced participants through both the ability to manage and their level of engagement with related practices, such as food management or exercise. Bearman and
Parigi (2004) suggest that individuals talk to different people about different types of important topics. For example, individuals might selectively talk to partners about finances, other family members about health, and those classed as acquaintances about work. In other words, different network members are selectively chosen for different functions by an individual depending on their relationship. As demonstrated previously in this chapter, partners can have complex and multiple roles in relation to long term condition management, to which friendships, in particular close friends, can be considered supplemental or as an external source of support and reassurance. For close friendships, it was a defining element of the relationship that they would be able to discuss their condition related problems. Equally, there was an expectation that their close friends would listen with compassion and understanding without being judgemental.

A: They're like best friends... since school...
Q: And would you talk to them sort about different things or...?
A: Oh, yes, definitely... I speak to them about everything. Obviously they know about my stomach and things like that... they're always suggesting different stuff ...I talk to them about everything and anything...
Q: And what sort of things would they suggest?
A:...Just food and things. I mean, [friend a’s name] is quite into all like...alternative like medicine and things and she takes Echinacea and stuff for colds and bits and pieces, and she'll drink... like peppermint tea and chamomile tea and things like that... Just health things and vitamins and stuff... I've obviously just put my two best friends in there, I've got other friends and they like know about everything and I suppose your best friends you divulge most to

Sarah’s final interview (IBS, female, Age: 31)

5.4.1 Selectivity in seeking friendship support

All respondents described selectivity in where, when and how often they would seek support and assistance. Similarly, Wenger (1996) noted that help comes from a minority of network members and that not all are supportive. This was particularly evident when the respondents described their relationships with different friends. Similarly, Bearman and Parigi (2004) proposed that individuals are systematic when they talk to different people about various important matters. There was a clear distinction made by respondents with whom they could seek practical, emotional or informational support. More peripheral network members were sought out for information on a given topic or instrumental support at a specific time rather than any expectation of ongoing support and were thus considered less important.
Q: What makes you talk to some people and not others and how’s it different to people you talk to sort of normally or at outside of it like...
A: oh yeah them are just the two best friends that I’ve had all my life them...you trust your life with them but I’ve got a lot, a lot of friends ...them are close friends... you’d die for them but the other people are just, good friends ...
Q: ...what makes you talk to sort of those people over the other people?...
A: ...(friend a) and (friend b) I’ve been friends with for so long we know what one another’s thinking so well...there’s not a lot that you don’t know about one another really

Natalie’s final interview (IBS, high cholesterol, COPD and high blood pressure, female, age: 57)

Q: ...thinking about how this...wider, sort of social circle, do you, is there much differences or would these sort of, the same sort of people that you’d...
A: I suppose they’re similar sort of people...I suppose if you still if you have a wide circle of friends, they’re still just a core that you actually talk more intimately with...

ID 190a final interview (IBS, female, age: 62)

Wellman (2000) proposed that people tend to talk to their closest advisors about health. For some respondents, close friends were readily identified as close confidantes and had a greater influence than health care professionals, as they could relate to the everyday constraints and contexts that affected management.

Q: ...he (friend) won’t let us do anything that’s going to harm my health and that. So he takes... he takes it all on... (friend a’s name), he’s another one that came living down here same... just after we came living in this house, and he’s been a good (neighbour)...  
Q: And they’re people that you talk to. Do you talk to some people more than others?  
A: Yes.  
Q: Who would you talk to sort of the most?  
A: The most is that centre really here. 
Q: And are they all quite equal? 
A: Yes...we help each other with tools and cars and all of it, if we’re in’t back garden and that, but I don’t know about anybody else, that outer ring there, I don’t know. 
Q: So more distant people, maybe like a nurse or...other health care people you talk to?  
A: I talk to a lot but they’re not... 
Q: They’re not as important? 
A: No. It’s just passing time of day. I’ve known them for years, but, er, just like... well this last three or four years, we’re all getting on. Some dying, others going living somewhere else, out of place and that. 
Q: That’s your sort of friends and neighbours and things? 
A: Yes. But as far as anybody else talking about... I’m trying to place... placing anybody in that outer ring.

Adam’s final interview (diabetes, knee problems & kidney problems, Male, Age, unknown)
5.4.2 Friends as substitutes for familial relationships

Friendships were an important source of support for participants who did not feel they had any familial support. These participants described family-like relationships with close friends. These chosen-ties were highly valued and had a high level of reciprocal trust.

I haven’t got a mother or father so, brothers or sisters haven’t any brothers or sisters um I told you about the friends and we haven’t got a pet. I wouldn’t burden the neighbours although my next door neighbour’s a G.P. she’s very nice

Nancy’s final interview (COPD, arthritis, female, age: 76)

Q: Who would you discuss it with?
A: (friend a’s name) and (friend b’s name)… The inner circle if you like.
Q: So what sort of, things would you talk to them about? If you weren't feeling well or...
A: Well they, (friend a) and (friend b)… (friend c) who's there, they are the four beneficiaries of my will because I have no family...and also they have copies of my will ... if there were anything about my health which, I would discuss it with them anyway.
Q: Do you feel that you can talk to them all equally?
A: Oh, yeah.
Q: And if you were upset who would you talk to?
A: Those three…She’s in the will. Why not the others? Because we breed friendships, to give the answer, whilst we are friendly with people we don’t know them that intimately I think…Whereas other people, the inner circle, you can't and equally they could come to me.

Matthew’s final interview (COPD, oesophageal problems, feet problems, male, age: 69)

5.4.3 Barriers to support

However, for some participants close friendship were not a marker of disclosure and understanding. The following participant included four friends in the network whom she considered close. Yet despite this closeness, because they did not have IBS, she felt that they could not relate to her daily experiences, which left her feeling isolated and compounded a sense of emotional distance from those in her social network, which she depicted throughout her narratives. She had sought support instead from a counsellor, whom she described as being able to talk to and had also included in ‘the most important’ category of her social network.

Q: Do you talk to them? Do you have many, do you have any, sort of, do you have, sort of, a few close friends?
A: A few close friends...
Q: And would you talk to them about IBS?
A: No... if people haven't had it then, it's like everything else, it's just...they're not quite sure where you're coming from yet.
Q: ...is there anyone that you would talk to about it?
A: No. In all honesty.

Debbie’s initial interview (IBS, female, age: 62)

The types of support and the expectation of resources available varied across different network members. Relationships had multiple functions, although the respondents described seeking out specific individuals for specific types of support. This diversity of friendship roles which influence illness management were predominantly categorised as emotional support and, to a lesser degree practical or informational support, as respondents sought this type of provision from either close family or health care professionals. For participants who did seek practical support from their friends, it was for specific resources to which the friends had access:

Q: So the crutches came from your G.P.?
A: Actually a friend of mine gave them me...I was using a walking stick at first, you see, ‘If I could get crutches I’m sure I’m going to be better.’ And as it happened my window cleaner was here, he said ‘Crutches, ?’ I said, ‘Yeah, have you got any?’ He said, ‘Yeah.’ Oh he said, ‘You can have mine.’ So I’ve got a pair of crutches, and they were a Godsend.

Chris’ initial interview (male, diabetes, age: 65)

A key role that friends had was in providing emotional support. This was either the main source of emotional support either as supplemental to support from partners or close family, or alternatively if that support was absent from those relationships.

A: she [friend] tells me all her troubles and I tell her mine.
Q: But you say you wouldn’t talk to your husband as much?
A: Not as much as um, not as much as me sisters and me friends about different things really, because he’s only gets, he gets worried and stressed he gets really stressed so.

Danielle’s final interview (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

5.4.4 The influence of network density

Although much research suggests that the more highly connected the network members are with each other (i.e. the greater the density of the network) the greater the support and influence on health (Smith & Christakis, 2008). However, the respondents described the importance of having some network members who were not connected to all other
network members, who could act as a ‘sounding board’ to discuss problems with in confidence.

...if it were about (partner' name) I would go to a friend just because I wouldn't want my Mum to worry I think. Then if it was about anything else um, just different things like...you just go to your friends more don't you for things rather than; unless it's; if it's about family I'd go to my friends; if it's about friends I'd go to my Mum and just like different things like that I suppose

Sarah’s final interview (IBS, female, Age: 31)

Granovetter (1973) argues that it is through weak ties that important information is diffused throughout the network. Information was similarly sought in the respondents’ networks from more distant friends, or weaker ties, when conditions exacerbated and they sought new information. However, the experiences of close friends who have stronger ties may more actively influence management practices and choices. For instance the following participant described a reluctance to take the antidepressants her G.P. wanted to prescribe as a close friend had become addicted to them in the past.

A: Not yet, but I'm thinking if it; because I'm still suffering. I'm not as bad now as I was, but I am still suffering, but a friends told me you can get ones that are more like; they're not actually antidepressants, I think they're more like herbal kind of, tablets, I'd rather go down that route than get onto antidepressants. I don't really want to go there... It's not about being labelled or anything like that, but I've heard of people getting addicted to them and things like that. My friend got addicted to them and I think that's what kind of, puts me off. I just don't want to become reliant on them really. Even though I'm not really depressed, it's more for my anxiety, but still I don't want to.

Rita’s final interview (female, IBS, anxiety problems, Age: 25)

5.4.5 Reciprocity of support

Reciprocity of support in close friends was a key element of these relationships. The support and resources that participants sought from their friends was equally expected to be sought from participants.

A: Life’s what comes your way... and it's what you make it half the time. If you haven't got friends it's your fault, it's not being a friend yourself. That's my way of thinking of things anyhow. You don't make friends, you can't buy friends...you work for friendship.
Q: And do you think that's important, that give and take?...
A: Absolutely.
Q: ...listening to other people’s problems as much as being able to say your own is important?
A: Yeah.

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)
The level of expectation of support was also reciprocal. For example, simpler, more task-specific friendships such as social, ‘fun’ friends were maintained due to an anticipation that both individuals would meet with the same expectation. For more complex, multi-layered relationships this could also be a burden, as some participants described trying to manage everyday work and illness work (Corbin & Strauss, 1985). For some respondents maintaining relationships with partners, family and work colleagues, with the additional expectations of friends, was described at times as a burden and health management (e.g. exercise) would become de-prioritised.

_A:_ I’ve been to the doctors and they said like, keep a food diary, and to be honest, I’ve done that and nothing seems to jump… it’s only in stressful situations or when I get quite anxious or nervous about something, that’s when my stomach starts, so I’m presuming it’s stress related rather than food like related…

_Q:_ Have you tried doing anything…any yoga or kind of different things to try?

_A:_ Yeah.. I’ve thought about it… I just don’t get the time… That’s one of those things I don’t get enough time… I don’t really get time to do that sort of thing, because when I’m home… tidying the house, seeing friends and family… I don’t really get time to be honest.

Sarah’s initial interview (IBS, female, Age: 31)

Similar to Wellman and Wortley’s (1989) findings that emotional support is not significantly dependent on the frequency of contact, respondents described the importance of the meaning of the relationship as more significant than the amount of contact they had with friends. The amount of contact was not static and increased around events where more support was needed, for instance loss of a family member or hospital admission.

_Q:_ And then with your friends would you talk to about…

_A:_ Well because they’re a bit further away…I mean years ago when we used to get together more often… we used to phone each other like… four or five, six times a week even… and go on holiday together, we used to talk about our worries…I don’t tell them anything now, not that I keep it secret from them… if you’ve got something like you’ve got a death or something… you speak to them then. My friend lost her father and we spoke together a few nights on the trot… sort of thing and I was phoning her up regularly…every few nights to see how she was but now it’s gone back to normal… if there’s an incident happening… like I say her dad died, then her partner got run over…So for incidents like that you do speak more…Regularly

Jane’s final interview (Diabetes and epilepsy, female, age 55)

Friendships influence not only engagement with management practices, but also symptoms and restrictions to diet as a result of having a long term condition which could influence the degree to which participants would engage socially. Furthermore, it could
restrict places that participants could visit and breakdown everyday routines such as going to the pub when they could no longer drink alcohol.

Q: ...has having IBS changed how you view yourself...
A: ...I think it kind of makes me feel, I try not to get excited about stuff. I know it sounds stupid, because I don't want to get too excited, because I know it will set my stomach off...I'll say, stop it, being stupid... enjoy yourself, but I'm just scared of it flaring up... I suppose it has, really, because I do tend to fade into the background a little bit because I'm trying to be, just calm myself.

Sarah’s initial interview (IBS, female, Age: 31)
Q: ...what’s been the most significant change for you, as a result of it?
A: ...getting around, and at one time I used to go to the Tory Club up here, and a friend of mine... knew each other for donkeys’ years... he’s still going. But, of course, not been there for a few years, because the stuff you’re having, you can’t drink and I used to go just for the sake of...company and so on, to socialise, very nice club, and all I was drinking, I had to have this pop and stuff...I got fed up with that, and then when I started on the other stuff, the methotrexate and all this, that, and the other, advised not to have alcohol. I gave it up.

Adrian’s initial interview (Diabetes, rheumatoid arthritis, high blood pressure, Male, Age: 82)

Friends who also had long term conditions were an important source of ongoing support. Peer support was described by participants as mutually reassuring and further strengthened these relationships because they had shared similar experiences.

Don’s initial interview (male, diabetes, cataracts & eye problems, tendonitis, age: 48)

5.4.6 Breaking, bonding and reconnecting ties of friendship

Furthermore, friends whose partners had a long term condition also had access to information from their partner’s condition and acted as a bridge to this information. Participants compared the relative severity of their condition to that of friends, or their partners, and if they considered themselves to be less ill then this could directly influenced engagement with management to prevent them from progressing to the same stage. For
instance, the participant below, who described a friend’s husband as more severely diabetic, said “he’s looked after at the hospital so I’m hoping that day doesn’t come, I’m quite happy to go to my G.P.”. She later continued to describe the information that her friend passes to her from her husband’s experiences and identified that this was the only friend that she talked to about her condition because of these shared experiences. Peer support was qualifiedly differently to ‘normal’ friendship because of the ability to share relevant experiences that were harder to relate to with friends who did not have the condition as they did not have the shared experience.

A: ... I do have a friend who is quite badly diabetic... he went straight onto insulin... which was quite a shock in his forties; he was very fit, very active, went to the gym four times a week, but was drinking gallons and gallons and gallons of pop...he is quite bad with it. So he's a member of the Diabetic Association, so if anything comes up his wife will say, did you read this, did you read that and did you read the other, I am not a member of the, 'cos I don't want to make myself a member of a club... I don't feel that I am diabetic, I'm just somebody who's got to keep an eye on my sugar, end of... He's a proper diabetic; he has to take insulin out with him; he injects before a meal he'll disappear into the toilet and sort himself out... and then eat his meal and carry on as normal. But anything that she thinks I would find interesting, (friend’s name) passes on...

Q: So do you talk to people about being diabetic?
A: No, not particularly.

Donna’s initial interview (Diabetes, high blood pressure, high cholesterol, Female, age: 54)

The role of friends was part of an acknowledged but fundamentally taken-for-granted aspect of social networks. The roles that each person occupied within the dyadic relationship were well established. The relevance of friendships was most evident for participants when they reconected with former network members where ties had been broken, for instance through moving or changing jobs. These relationships do not have the implicit norms of established relationships. For the following respondent, a chance meeting with someone she had lost contact with highlighted the limitations of previous friendships which she subsequently considered ‘acquaintances.’

A: ...I know like my friends, well, I’ve got one best friend, one very good friend...

Q: Do you have a lot of friends round here?...
A: I have, I do, I have a few people. Like my friend... She has her problems, of course, like everyone in life, but sometimes she’ll say... she’s trying to lose weight, she goes swimming at this health club, she pays for it and all that, she has her nails done and all that, and she’ll come, she can be cutting towards me and I don’t have to do anything. I’m there for her, she’s texted me when she’s fought with her husband or her daughters and I send back. ‘I do understand you.’ And I do, and I genuinely mean that when I send a text back. And then she’ll say to me... ‘It’s all right for you.’ And I think, why, what the hell have I done now? And I accept that, and my, I’ve come to the conclusion now I’m not gonna
accept all that any more from people, why? I’m not gonna let them hurt me anymore. I can’t…that is not my friend, that’s why I call them acquaintances. And I mean that. Yes, I’m very, very, I’ll talk, I’m a very open person cos I’ve worked in retail most of my life. I’m very good with people…

Abbie’s initial interview (COPD, IBS, depression, female, Age: 53)

5.4.7 Absence of friendships in social networks

Nine respondents did not identify any friends that they could seek support or assistance from for a number of reasons such as death of friends or prioritising family and work ahead of maintaining friendships. Although nine participants did not include any friends in their network diagram, this was not necessarily detrimental because family was considered most important, and this was reflected in where they sought support and the impact this had on their illness management (also see Chapter 6: typologies of social networks).

Q: Is there anyone else that you call? Have you got any friends or sort of the neighbours or anything?
A:...Well, there’s no need, you see. Cos my son, well, my son lives at (location) but my daughter ...if it’s a time of the day, say in the afternoon, that’s the awkward time because my daughter’s at (location), and my son in law is, one of these dogs they’ve got, rescue dog, it’s only got..., it’s totally deaf, now it’s a bit awkward to leave it, so what we’ll do then, my son will come up then and take us wherever we want to go.

Adrian’s initial interview (Diabetes, rheumatoid arthritis, high blood pressure, Male, Age: 82)

For some participants health was considered private and they did not want to bring it into the public domain of their friends. These respondents’ friendships were mainly social and they valued maintaining that social role and separation between their social self and their self with a long term condition (this will be examined further in Chapter 6).

Q: ...have you got a lot of friends that you might sort of bring it up or is it something you don’t really talk about?
A: Summat I really don’t talk about if I can help it... if you mention it to whoever, like, ‘Oh yeah, I’ve got diabetes.’ ‘Oh, have you?’ And it’s a case of, well, I’m not really ill so it’s not that bad, but ...If I needed to I would, but I don’t like being the centre of attention, talking about what’s wrong with me

Beatrice’s initial interview (diabetes, female, Age: 46)

Conversely, expectations of support may not reflect the reality of the resources that friends can offer. Friends also have their own physical or emotional limitations that may restrict the amount and regularity of contact. This was most notable when participants described
not being able to substitute the types of support or resources typically sought from other sources.

Q: ...You talk about it being affected by sort of, anxiety and things, talking to the counsellor do you think that has helped?
A: It might have done [interviewer’s name], it very well might have done...when you think about it, if you have no partner or no brothers and sisters... friends don't understand. Well I have one friend that does...but when I do she can be here 'til one o'clock and then I take her back, because we have so much to talk about I can be on that complete wave length, I can say to her, 'You don't pass judgement’ ...(friend’s name) is one of these very sensitive people ... she soon gets tired (friend’s name), but she is a lovely person...I think we ought to do it more often. We keep saying that, but it is like everything else, all of a sudden a week has turned into a few weeks and what have you.

Debbie’s final interview (IBS, Female, Age: 62)

Neighbours were represented as a related group of simple friendships defined by locality, although the relationship may translate into friendship over time because some respondents described friends who they had initially met as neighbours but remained in contact when one had moved. Seven participants included their neighbours in their social networks, which could be considered an indicator of how connected the participant was with the area. This was one dimension of the context of management and was important because social networks can influence healthy, as well as unhealthy, behaviours through a variety of ways including providing a sense of belonging and reassurance (Berkman, 1984). Relationships with neighbours were typically described as supplemental or potential support to that of closer family and friends.

I strongly agree that I love living here.. it’s not oh well, I live here because I can’t go anywhere else. I’ve looked around different places and I’ve thought, well, I’ve got my friends here, that’s a very big, it’s central to my, the family...both neighbours and at the church, and it’s central to my other friends... friends that I’ve had all my life, because you do tend... all your acquaintances are pivotal to where you are. I went to the local college, I’ve still got people I contact even from then... this is where I am, this is where I belong really. And I can go out of the door and talk to people. I don’t know how I would cope if I was in a complete strange place...But I soon make friends but … it’s not the same, and a lot of my friends are long-standing friends.

Tina’s initial interview (diabetes, stress incontinence, eating and sleeping problems, hair loss, eye infections, skin and gum infections, female, Age: 69)

Neighbours were identified by respondents as a source of potential support because of proximity and expectations of emergency support. Although they were not necessarily labelled as ‘friends’ they could act as a valued connection to the local area and can directly help in times of emergency, such as by doing shopping or collecting prescriptions.
Q: So do you enjoy living around here?
A: Well yes... I like all my neighbours and we know everybody...When I think really I suppose we could do with a smaller place because I mean I've got four bedrooms and that, but then you say where do you go?... your neighbours and everybody's friendly... if we moved where would you move to, you don't know anybody so.

Danielle’s initial interview (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

5.5 Health care professionals

Twenty-three out of twenty-six participants included at least one health care professional within their personal community irrespective of the amount of contact that they had with them. Participants reported having less frequent contact with them than other network members. Despite this limited contact, it could have significant meaning in shaping management practice and priorities. One participant had only health care professionals in their network, two participants had more health care professionals than family members and two participants had equal numbers of health care professionals and family members. These five networks did not include any individuals categorised as friends. Three participants did not include any health professionals in their social networks. Of the twenty three participants who included a health care professional in their social network, for eleven participants this was the G.P. only. If the G.P. was the only health care professional included in the network, they were more likely to be in the ‘most important’ category (n=7). For eleven participants both the G.P. and practice nurse were included in the network with the G.P. either in the inner (n=6) or middle circle (n=5), whereas the significance of the nurse was more distributed with four nurses considered ‘most significant,’ three nurses were ‘important’ and four nurses were ‘less important.’ Five participants included hospital consultants in their network, three participants included podiatrists and two participants included pharmacists.

5.5.1 The interpersonal relationship between patient and clinician

Health care professionals had an important role in shaping meaning and engagement with self-management practices. Although the majority of chronic illness management occurs outside of formal health care, the management of symptoms for the majority of people with chronic illness involves a degree of interaction with health care professionals (Gately et al., 2007). All respondents’ narratives described their relationship with the G.P. or nurse, but did not acknowledge any changes in the clinician’s approach. Although the
impact of changes in UK health policies, such as the introduction of the Quality and Outcomes Framework (QOF), have constrained clinical practice from a clinician’s perspective (May, 2007), the participants’ narratives framed these relationships as being between individuals. This enabled participants to develop their role as a patient with different clinicians as individuals rather than with a generic ‘doctor’. These relationships were not interchangeable with other equally qualified clinicians, as the boundaries of trust were developed with the individual and respondents’ expectations of consultations. The respondents described only seeking help for specific symptoms outside of routine monitoring, as they had a clear understanding of ‘legitimate’ help-seeking from their G.P. or nurse through expectations established over years. Despite contact being sought around identifiable problems and not more generalised forms of support, relationships with the G.P. and nurse could be considered important.

These relationships are shaped by previous contact with health professionals, along with expectations of their role as a patient and their expectation of the clinical role. These dyadic relationships develop over a number of years and continuity of care is important to patients as clinicians knew their history, not only medical but also biographical, which contextually situated advice. Respondents described preferring to consult with their normal G.P. about their long term condition, as their shared history allowed for the description of their history to be truncated and allow the consultation to focus on the presenting issue. The following participant described how she felt comfortable talking to her G.P. about distressing problems and that he supported her in seeking counselling and telling her to draw on her ‘inner strength’. However, when she had to see a locum because of an exacerbation of IBS, the locum could only provide generic information that she had already been given and adapted into everyday life:

A: it's down to the gas again...I remember saying to one doctor... she said, "Oh, that means you're just eating all the right things. You're eating the brocoli and the da, da, de, da". Yes we are, I thought oh that really didn't help... "it's all the fibre in your gut", and I'm thinking well...I didn't pursue it.
Q: Did you go back? ...
A: No...she was a locum doctor.
Q: ... Did you feel she understood what you, where you were coming from?
A: No.

Debbie’s initial interview (IBS, female, age: 62)
5.5.2 Defining legitimacy of illness and health service use

Pilgrim, Tomasini and Vassilev (2011) describe an “implied contract” between professional and patient that enables efficiency in diagnosis and treatment. They propose that this entails a patient consulting voluntarily in a manner in which the professional considers appropriate. It is these expectations that shape relationships and define the types of support available. Patients learn this assessment of legitimacy and help-seeking from prior experience with health services (Rogers et al., 1999). Similarly, May et al. (2004) identified that G.P.s in part frame their relationship and evaluate patients on a moral evaluation of the patient in judging the legitimacy of the symptoms. For the following respondent, the G.P. explicitly voiced this process of legitimisation, which the respondent internalised so future consultations would focus on ‘medical things’ identified by the G.P. and the participant learnt from previous interactions.

... The nurses are fine...I cannot go into the doctor and say, "I've got a dose of flu doctor," which you would normally... I mean I'm sixty five year old now, I have had that many doses of flu, I know what a dose of flu is, you can taste the difference now. But he is the type of doctor, I really like him, I wouldn't change him for anything, but he'll say, "Let me decide whether you've got flu."....I know what's coming, so I go in and I say, "I am coughing up phlegm and I've got a chest infection," and he'll say, "Oh, you've got flu," but um, it is just how he is and um...he's a really, really good doctor...I tend to keep to medical things

Frank’s initial interview (Male, COPD, hypertension, age: 65)

The relationship between patients, families, health care providers and systems of care develops reciprocal trust and expectations by each party (Gilson, 2003; Lynns McHale & Deatrick, 2000; Pilgrim et al., 2011). The development of trust within the relationship was reflected in how protective respondents were over their relationships, particularly their G.P.. This was evident when the participants had multiple conditions (this will be explored further in Chapter 7) or if they wanted to discuss a sensitive issue.

Q: Do you prefer to see the same G.P...
A: When it's personal I don't mind, I'm not being funny but I've got thrush this week, I've had it, well I've had it for the last twice, three times since I come back from what’s it, well she said I can put another G.P. on, I said I don’t want to see another G.P. I'd like to see my own doctor. He was alright no problem. He gave me the right ointment you've got to rub on it sorted it out, it's doing well ...He knows what I'm, well I don't like giving other doctors information, I don't know whether he gets the information back.

James’ final interview (Diabetes, high blood pressure and high cholesterol, male, Age: 59)

Despite respondents describing having a discussion about health concerns with their G.P., such as the number or type of medication, if participants had doubts which challenged the
recommendations and the G.P was inflexible then they would predominantly rely on the G.P.’s clinical judgement based on the trust they had developed for them. This compromise would ensure that they did not threaten their relationship or challenge the G.P.s training and knowledge.

A: ..I wanted him to take me off the tablets and he wouldn't do it, but we had a, we had a heated debate.
Q: And what happened there?
A: ...I bowed to his greater judgement, 'cos he's the doctor, I'm not...
Q: Why did you want to come off them?
A: Well, it's not, I don't like the idea of puttin g chemicals in me. If you can do without it, then, obviously it's better...No, but he was... adamant that it was the way that the diabetics are treated... at the end of the day, everybody that's diabetic is now automatically put on those sort of, tablets...it's just something that you shut up and put up with, really. That's what I did, but it wasn't without a discussion... I'm not frightened to open my mouth and say if I don't think it's right.

Donna’s final interview (diabetes, high blood pressure, high cholesterol, Female, age: 54)

Respondents are aware that the health service is a limited resource and as such will selectively limit their use as they compare themselves to others who they view as in greater need of the service. Participants described their main contact being routine check-ups initiated by the clinician and not the patient. Returning to the general practice was viewed by some as the last option when all other sources of information had been exhausted, particularly for participants who had lived with their chronic condition for a number of years and had learnt the limitations of the information and support available from professionals.

... Well there is nothing now they can really give me, they've told me that. I mean I see the nurse at doctors every so many months, to see how I'm going on with all me sprays and that so... I don't bother the doctor unless I've got to; I've got to be desperate.

Lyn’s initial interview (COPD & IBS, female, Age: 57)

5.5.3 Visibility of condition

The main contact that participants had with nurses was through the routine monitoring of their long term conditions. A number of participants had described how previously they ‘slipped’ in questions about their condition at the end of the consultation, when they had been consulting over another ‘legitimate’ condition such as the ‘flu. The nurse consultation was considered a more open and valid space where participants could raise concerns about the management of their condition that had become routine for patients without threatening their role as an expert. However, an increase in the amount of appointments made their condition more visible to them as well as the nurse (which could
place an additional burden on some patients with multiple conditions, see Chapter 7). This was generally considered as a positive change in their contact with primary care, particularly for participants who had been managing their condition for a number of years and may have reached a limit of novel information or treatments that could be provided. This change was not linked by respondents to the changing structure of primary care but rather viewed more locally as something that the practice was engaging in for patient care:

*A:* ...certainly years ago you didn't get to see a nurse... the doctor...would do it all, but now the doctors can delegate...it's good because they can see from one year to the other... where before it never even used to get written down I don't think, or, "Your blood pressure now is..." *I mean you used to go to the doctor it used to be when you needed to go, when you had flu or something or you'd sprained your wrist and, "Oh by the way me breathing is not so good,"")...now it's more, it's an appointment for your breathing or whatever, well in my case with me breathing.

*Q:* So that's better or do you get?

*A:* Yeah, I feel I get a good check

Frank’s initial interview (Male, COPD, hypertension, age: 65)

*I had actually gone because I was very gurgly and windy and I, kind of, you tend to go with something and, and ease that in*

Debbie’s initial interview (IBS, female, age: 62)

When appointments are initiated by the patient who had a number of unexplained problems they described feeling like a hypochondriac. One participant described this feeling like a hypochondriac being further reinforced when the relationship with the G.P. became strained over the respondent’s insistence that he was not well. Respondents reported a tension between knowing that something was not right and not wanting to become a burden to the clinicians. The legitimacy of a condition was framed partly by expectations of how clinicians would respond based on previous experiences, as well as the participant’s value judgement about the perceived severity of the condition in relation to other people’s health. This was particularly evident for participants with IBS who, despite their condition being symptomatic, did not perceive professionals as considering it legitimate. On the other hand some participants with diabetes described themselves as not having a condition because of a lack of symptoms yet it was taken seriously and made legitimate through their contact with health services, medication and routine check-ups.

*I think it's something that's regarded as, because it, it's, kind of, stress related...it can almost make you feel as though this is self-inflicted...So, it's not quite taken all that seriously, I think, in all honesty...By the medical profession... that sounds awful because, obviously, you're here and there are people that do it, but I think it's just, um, I suppose people do have quite serious ailments and you're waffling on about your gut...*

Debbie’s initial interview (IBS, female, age: 62)
Similarly to Stevenson, Britten, Barry, Bradley and Barber (2002), if respondents depicted a lack of acceptance of the legitimacy of the diagnosis then the treatment was also perceived as illegitimate. One participant described not considering himself as diabetic which had been reinforced by other network members and those around him at work who influenced his perception of diabetes. This culminated in the final interview in him disclosing that he had stopped taking his medication. He did not experience any negative effects, which seemed to reinforce his perception of not being diabetic. Similarly, Siegel, Schrimshaw and Raveis (2000) referred to patients with HIV as ‘naïve scientists’ as they formulated hypotheses, monitored, altered and stopped medications in order to observe the effects.

Q: So how are you finding managing your conditions?
A: No problem, I've had nothing wrong with me. I feel as though there's nothing wrong with me.
Q: Because last time we spoke it was diabetes, but you didn't feel like you could tell you were diabetic...
A: That's exactly how I'm feeling now...I don't feel as though I'm a diabetic, but he keeps trying to give me these pills for my heart and blood pressure and all this lot...The diabetics, heart tablets, blood pressure and don't know, cholesterol. I have seven tablets a day...I know there is that has one's got a heart on is one for heart trouble...One's for cholesterol... can't say the word. And metformin that's the tablets I've been taking.
Q: Mmm, and how you finding taking them?
A: No problem. I will admit to you I've not been taking them for a bit, but like I said I've not took them for a couple of days, but I'm alright, having no problems...I'll probably start taking them when I get nearer to going to ... blood test...I have no problem with drinking, not drinking beer every night... sitting drinking beer...No effects, nothing... I know I used to raise my blood pressure, but I've not had that since I was working, but now I don't...My blood pressure is high I go blood red in my face...They used to say I'd been sunbathing and I say I haven't my cheeks are red it's my blood pressure... Last time I went [to G.P.] my cholesterol was high. He gave me some more tablets, well he gave me these other tablets to try them and then I said I keep getting cramp in my fingers every time I take one of these tablets...so I cut it in half, so that works alright... Like I said I've not had them for a couple of days at the moment, I just see how I feel in the morning...
Q: Did the G.P. just kind of, explain things to you, or just you them and told you to take them?
A: Just give them to me and told me to take them.
James’ final interview (diabetes, high blood pressure and high cholesterol, male, Age: 59)

5.5.4 Continuity of care

Respondents valued continuity of care achieved by consulting the same G.P., particularly when they were concerned about something serious or sensitive which was based on the trust they had in their relationship. However, when this trust was lost with the G.P. or nurse, the participants described seeking support or resources through other mechanisms, such as a pharmacist, different nurse or G.P.. This occurred because the breakdown of
trust in one relationship did not necessarily threaten the trust participants had in their relationship with clinicians as they are constructed as dyadic relationships rather than with the health system as a whole. The following respondent described a life threatening misdiagnosis by her G.P. which had changed her relationship with health services as she became more active in her care such as actively following correspondence between the G.P. and consultants as well as test results. She described subsequently trying to change her G.P. but was unable to do so. Consequently, she sought informal routes of accessing different care by actively choosing to see a locum G.P. instead of her assigned G.P.. The development of trust with other care providers had taken time to develop and she identified that it had taken six months for her to be able to raise concerns about medication with the practice nurse.

A: The smoking has caused it... we all know the smoking causes emphysema. ‘We will work through this.’ He said, he will work through it, ‘And we will help you.’ Which he has, with the proper medication, COPD nurse, (nurse’s name), and then it was (nurse), not my doctor, that put me onto the rehabilitation ... which is just down the road. It wasn’t (G.P. name) ... referred me to see a psychologist. And the antidepressants, he did not prescribe, (locum G.P.), his ... stand-in, she prescribed the antidepressants. She gave me a leaflet first to read cos I was against them,

Q: Do you feel that you can talk to them about, I mean about your medication, if you’re happy?
A: Now I can. Now I can, yes. It’s took six months.
Q: What’s changed?
A: I think the condition has made me change and made me ask questions ... (nurse’s name) she’s done a diagram for me ... I’ve got information on it myself from the hospital when I’ve been there. I’ve taken information, I’ve sat and read about it... I know now it’s being more recognised, but it never used to be, it’s only these past, they do more and more research into it.

Abbie’s initial interview (COPD, IBS, depression, female, Age: 53)

The largest constraint of the system was access, in particular to the G.P.. As there was restricted numbers of appointments and the process of making them was considered problematic, receptionists who were viewed as an initial hurdle. The participants described resenting having to demonstrate their need for an appointment.

That's the only problem that is, you can't do that appointment service...I honestly thought I had that cold that flu...Swine flu and I phoned up, she says, 'Have you got a temperature?' 'No.' 'Well you haven't got it then.' That's all she said, it's nothing to do with her [receptionist] ...So I was fuming over that. I said, 'Well, then what is it' I'm full of cold and not got a temperature, normal cold.' 'So you've got a normal cold, don't worry about it.' Other than that it is still bad news...when you've got to be up at half past eight to phone doctors, then you can't get through, then they tell you he's not there anyway, he's on holiday.

James’ final interview (Diabetes, high blood pressure and high cholesterol, male, Age: 59)
5.5.5 Medication and condition control

Medication was a key resource whereby participants could actively take control of their management through challenging their traditional patient role as they were able to introduce information from other sources, e.g. from pharmacists. In one review, medications were found to be with passively or actively accepted into everyday routines or conversely rejected (Pound, Britten, Morgan, Yardley, Pope, Daker-White & Campbell, 2005). These categories were reflected across the narratives and were not static categories. Participants described points where they were more likely to accept or reject medicines to varying degrees depending on a number of factors such as anticipation of medication because of age or additional conditions (see Chapter 7: co-morbidity), and emotional or physical reactions to medications. For instance, the following participant described resistance to medication as a mechanism through which he took control of his illness management in response to changing health that was distressing.

A: I’ll be straight up with you, and I’m gonna tell you this now, I try a lot of the time to push it to the back of my mind, that this isn’t happening to me. So some days I don’t bother doing anything, and there’s times I’ve thought, it’s not me, this, it’s not me. And I won’t take a tablet and then I’ll be, then I’ll feel ill. And then I’ll start back on my tablets. But if I tell my doctor that he’ll go absolutely ballistic at me.

Q: So you wouldn’t tell him when you’ve not taken tablets?
A: No. I wouldn’t, no...he’s only doing it for my benefit... I know why he’s doing it. It does upset me as well, what’s wrong with me.

Q: ...Have you been offered sort of any sort of counselling or any kind of ...?
A: No, no. I’ve never. But I need support, I need counselling, I really feel as though I do. I’m getting upset now about it, talking about it...It’s just that I’ve never had anything wrong with me in my life.

Don’s initial interview (male, diabetes, cataracts & eye problems, tendonitis, age: 48)

Usher (2001) described the pressure to take neuroleptic medicine for schizophrenia, which was exerted by relatives or health professionals, as ‘imposed compliance’. Some respondents described being persuaded by their G.P. or nurse to take the medication, even if they were very reluctant. One mechanism through which this was done was by highlighting the relative stage of the condition and what would happen if they did not conform and follow instructions.

So in the morning I've got six pills but it's one metformin, an aspirin for me blood...I've got a cod liver oil, I do evening primrose oil, I do an iron tablet because I am prone to be a little bit iron deficient, and that's it and I just take that and I take a packet to work with me and I have one after me lunch and tea in the evening, me evening high blood pressure one...it's just automatic, so it's just a routine that you get into... It's a bit of pain having to keep going for them 'cos they only give you, they give you a couple of months at a time, so
every couple of months I've got to go and get all my tablets and the fact that I'm on it forever more is a little bit daunting maybe... Cos I've never taken as much as an aspirin up until I was diagnosed so... I think it's an age thing and I think it's something you've got to accept. I did fight, I fight against it at first; I didn't want to take the tablets and I did say that I am not taking these tablets; I want to carry on with diet control, um, but they talked me into it and that's what I do. I just do it... I do worry about the long term, I mean, how's it going to go on long term; I'm hoping somewhere down the line that they'll find a cure for it... I don't want to go on insulin obviously; that would be the last thing that I would want to do, but at the moment with the tablets it's not an issue.

Donna’s initial interview (Diabetes, high blood pressure, high cholesterol, Female, Age: 54)

5.6 Summary

In this chapter, I have described the structure of illness support networks for this study participants. The qualities of these relationships cyclically influence the meaning of management at different levels and to varying degrees over time through a variety of mechanisms which shape the context of management. These relationships influenced the timing and place where help is sought, the legitimacy of the problem and its relative severity. These relationships have negative as well as positive influences yet remain included in the social network despite these negative components because of the value of other types of support they provide and the substitution of support by other network members. However, when the flexibility in networks was limited by the loss of network ties, for instance because of the death of a key figure, this challenged existing notions of management and the resources available (discussed further in Chapters 6 and 8). The functional size of the network depicted in the narratives was smaller than the actual elicited social network. This highlighted differences in the mutual expectations of roles and the social acknowledgement and management of their long term conditions. Complex relationships, for instance with partners or close friends, could influence individual management on multiple levels and to varying degrees. Simpler, ‘fun’ friendships are more implicated in wellbeing dimensions of support, as they did not provide a tangible form of support but help create a context in which management is more achievable or engaged with. These simpler relationships have an important but under recognised role in long term condition management as much research has focused on the more obvious forms of support that a social network can explore because ‘it makes no particular assumption about the type of relationships in which people are involved’ (Phillipson et al., 2001:26) and allows for the nuances of relationships as well as more peripheral relationships to be identified. The importance of relationships was characteristically defined by reciprocity of support and levels of trust developed over time. The narratives depicted how the
expectations of reciprocal support shaped where individuals selectively sought support and what type would be expected.

In the next chapter I will go on to explore the typologies of social networks and the influence they have on shaping long term condition management.
Chapter 6

Types of health related social networks

In this chapter I begin by identifying the types of social networks that are important in the management of long term conditions. I then examine the influence of these network characteristics on condition management and vice versa using case study examples to highlight the role of key features in shaping engagement with illness management. Finally, I will highlight the degree to which professional and lay networks interact to shape the individual’s management.

6.1 Introduction

The management of any health problem is a combination of both personal and social processes shaped by the context in which it occurs (Pescosolido, 2001; Serlachius & Sutton, 2009; Gallant, 2003). Additionally, the interaction between lay and professional networks is an important element of understanding how engagement with illness management is shaped. Viewing the network as a whole framed within the narrative context of illness accounts enables us to explore the complex interactions of multiple types of relationships which influence and shape illness management (see Figure 6.1). The composition, or type of social networks, has been related to physical and mental health outcomes rather than the size of the network (Stephens, Alpass, Towers & Stevenson, 2011). Resources available through social networks can help to mediate the accessing of health services and the normalisation of practices in everyday life (Dixon-Woods, Kirk, Agarwal, Annandale, Arthur, Harvey et al., 2005). Different types of networks may reflect differing access and availability to resources supporting illness management. Across different network types, Fiori et al. (2007) found variation in relation to subjective well-being, depressive symptoms and morbidity. In particular, they identified six network types which could predict well-being differentially: family focused, diverse-supported, friend focused-supported, friend focused-unsupported, restricted-nonfamily-unsupported and restricted-nonfriends-unsatisfied. For instance, individuals in a friend-focused supported network type had lower subjective well-being and higher levels of depressive symptoms than those located in diverse-supported, family-focused or friend-focused unsupported network types (Fiori et al., 2007). They found that this difference in subjective well-being
Across different types of social networks was not moderated by age but rather by the strength of the network type in which a person is embedded (Fiori et al., 2007).

Figure 6.1: A summary of the specific ways that social networks influence long-term condition management

**Negative influences of social networks on illness management**
- Access to unhealthy foods (e.g. being offered chocolate by husband when diabetic)
- Denial/lack of recognition of condition
- Lack of emotional support
- Isolation
- Expectations of social roles (e.g. grandparents babysitting and getting tired which exacerbates symptoms)

**Positive influences of social networks on illness management**
- Peer learning and social comparisons (i.e. learning from the experiences of, and comparing themselves with, network members with the condition - e.g. friend going blind because of complications with diabetes)
- Cooking food within dietary restrictions (e.g. wife cooking for husband with diabetes)
- Information provision
- Access to resources (e.g. lifts to appointments, shopping, advocates during consultations)
- Expectations of social roles (e.g. being a parent and wanting to prevent children developing diabetes)
- Everyday work (e.g. partner of participant with COPD cleaning to reduce dust)
- Work colleagues organising alternative healthy snacks in the office

**Social network characteristics**
- Size
- Density
- Trust
- Amount of contact
- Distance living from participant
- Type and relative meaning of relationships
- Type of social network

**Consequences of social network influences on illness management: engagement with management practices**
- Eating more healthily
- Losing weight
- Increased exercise
- Reduced symptom exacerbation

**Consequences of social network influences on illness management: disengagement with management practices**
- Not changing or controlling diet
- Not maintaining exercise
- Increased intake of alcohol
- Reducing or stopping completely medication taking
- Symptom exacerbation

**Amount of contact**
- Distance living from participant
Fiori et al. (2007) found that structure and function of social networks are not always correlated and can be affected by factors such as age which can affect how active the participants were and the reliance on network members for instrumental aid. Wenger (1991) also proposed five social network types of older service users which influenced aspects of health social service provision based on the proximity of close kin, the proportion of family, friends and neighbours involved in care as well as the level of interaction between the family, friends and neighbours with the community. These network types did not include health care professionals, yet for some respondents in this study these relationships are considered of greater relevance than familial or friend ties (see below). However, within the existing literature there is limited, often cursory, understanding of the types of networks which support or undermine self-care and its associated practices (Vassilev et al., 2011). By exploring the types of networks for people with long term conditions, the impact of the wider contextual influences on illness management can be situated alongside an understanding of how self-management practices are adopted and adapted into everyday settings.

6.2 Three types of networks

Three types of social networks, or personal communities (Pahl & Spencer, 2004), were identified from the data analysis of network diagrams and narrative representations of the meaning of the relationships. By identifying the number and types of relationships and their relative importance to the ego (i.e. the individual with a chronic illness) and their health management, networks could be categorised as:

1. Family focused network
2. Friend focused network
3. Health care professional focused network

The three types of networks are characterised by different combinations of features that could influence priorities for health, the various roles that network members occupy and the degree to which they might support and facilitate the normalisation of illness management into everyday life (see Table 6.1). The networks can be considered social networks related to health, or health networks, as the focus of the study was to consider
the significance of network members to the management of the participants’ long term conditions and health.

However, participants described there being little difference between who they would place in the network if it was more broadly defined as important people generally in their lives, particularly in the first two types of networks. Key differences between the networks were, firstly, the function of, or type of support provided by different network members and the relative importance ascribed to them by the ego, and secondly, whether different members could act as substitutes for other network members. Yet equally relevant were the similarities present to varying degrees across the types of networks that influenced the source and timing of support as well as to how changes in health or changing composition of the networks were adapted. The key features of network types derived from the data collected in this study were:

1. The structural size of an individual’s social network does not necessarily reflect its actual functional size. Networks were typically small and selective embedded within a larger network structure.
2. Within all of the network types, descriptions indicate the presence of key individuals that provide instrumental or emotional support who can be readily identified irrespective of the size of the network. This is usually a partner, significant friend, pet or child who can be relied upon in the event of a serious problem. Thus, the presumption within the wider literature on social networks that the strength of weak ties (Granovetter, 1973, 1983) which have been identified as being more functional in other areas of social life (e.g. access to children’s education (Li, 2007)), might not apply to chronic illness management. The stronger ties for illness management may lie in the ties that bind and bond network members.
3. Network members can be substituted, but the degree to which this occurs in practice varies, with some participants describing more limited substitutability depending on the perceived flexibility of established relationships to redefine entrenched roles (for example see the case of Catherine in Chapter 8 who lost her father and brother during this study and the difference in the ability to substitute support provided from them).
4. Descriptions of meaningful relationships in management were predominantly static across the period of study. Those who had been identified as being important in the initial interview mainly remained important in the final interview. When networks
or health did change over the course of this study, this was often preceded by or reflected a major shift in core intimate relationships in a way which undermined expectations of, and actual, support.

6.2.1 Defining critical moments

Critical shifts in relationships acted as turning points whereby existing management was disrupted thereby impacting on everyday practices and management. Examples of critical moments included divorce, loaning money, declining health, re-establishing broken ties with former network members, bereavement and the subsequent reactions of other network members and the loss of a driving license. These moments were also reflected in the development of the individuals’ narratives about their chronic illness. The way in which these events influenced management reflected Denzin’s (1989a, b) description of epiphanies, which he defined as “interactional moments and experiences which leaves marks on people’s lives (Denzin, 1989a, chapters 1 and 7). In them personal character is manifested. They are often moments of crisis. They alter the fundamental meaning structures in a person’s life. Their effects may be positive or negative.” (Denzin, 1989b, p 70, lines 31-35). He further identified four types of epiphanies:

1. Major epiphany, i.e. an experience which affects every part of a person’s life.
2. Cumulative epiphany, i.e. reacting to experiences which have been ongoing for a prolonged period of time.
3. Illuminative, minor epiphany, i.e. a symbolic representation of a serious, critical event in a relationship or individual’s life.
4. Relived epiphany, i.e. meaning is given retrospectively to events through the re-playing of the event.

In the current study, the phrase ‘critical moments’ has been used to similarly reflect the development of a critical mass of multiple factors that can accumulate, or singular events which act as turning points, to cause a shift in management priorities. This allows for the accounts of illness management to be situated within the context in which they occur. It is these turning points that can lead to reports of a change in the situation in which illness management occurs.
6.2.2 Comparing the three types of social networks

In a family focused network, participants tend to be older, and married, with the main source of support and information being provided by multiple family members with various roles in supporting the individual. There are usually multiple ties between network members. For networks that can be defined as family focused networks, health care professionals are viewed as important but are not regularly seen. In a friend focused network, there is greater variance in the types of relationships present; friends appear to have a more significant role for the individual than in either the family focused network or the health care professional focused network. For younger participants with a friend focused network, parents and partners are also important, yet their role is subject to change, i.e. becoming more restricted because of specific events which have altered their relationship. For the participants whose social networks are characterised as friend focused who are older, family members were less relevant. The importance of family and friends has also been highlighted in social network studies of well-being and social support (Fiori et al., 2006; Stephens et al., 2011). For these first two types of networks, management is normalised into existing practices and routines through negotiation and discussion with other network members, but despite multiple conditions, participants in this study identified only a single G.P. or nurse as significant. The networks described in these first two categories frame health management within existing dimensions of everyday life, which is not separate but integrated as routines and practices in daily life. In other words, there is no distinction between a health network and wider social networks. The friend focused network seems to emerge when there is an absence or loss of adequate family support and alternative lay support is sought instead.

Conversely, the third type of network, the health care professional focused network, more distinctly represented a network in which health was considered to be something managed more separately from the wider social network. Health and its management are framed as private, which can be a burden to others and so seeking support was avoided, or limited, as much as possible. The health care professional focused network is characterised by a dominance of health professionals in shaping management priorities and is characterised by multiple health care providers and few family members or friends. Yet in other studies which have examined social networks and health, health care professionals have not been considered more important than family and friend ties unlike for respondents in this study. The importance of clinicians in this study may be because it has focused on social networks related to self-management rather than general well-being or ageing (Fiori et al.,
Participants whose health networks were dominated by health care professionals were more narrowly focused around their contact with health professionals and a partner.

Each type of network will be described in more detail below, by using case studies to demonstrate the meanings and connections of the networks to illness management. These categories are not meant to imply that other relationships do not have a role or influence in supporting illness management (e.g. in the family focused network friends do play an important role); however, they have a more minor role. Although Wenger (1991) found that mostly network types remain stable, in this thesis I have used typologies as a means of enhancing analysis to summarise how relationships were described in the narrative context. However, the provision of support can be considered more as a continuum of a range of relationships with varying degrees of influence that can change and be redefined over the life course rather than be viewed as discrete, static categories which occur to the exclusion of other types of support.
Table 6.1: The criteria for selection and characteristics of the three types of social networks for condition management

<table>
<thead>
<tr>
<th>Type of social network</th>
<th>Criteria for inclusion</th>
<th>Centrality of ties</th>
<th>Family role in health management</th>
<th>Health professional role in health management</th>
<th>Friend role in health management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family focused health network</td>
<td>Family members outnumbered friends and health care professionals</td>
<td>Predominantly multiple family members. For some participants their G.P. was also central.</td>
<td>Multiple family members had significant roles in supporting the individual</td>
<td>Health professionals were important but family members were normally consulted first</td>
<td>Friends were less important in management. Were a source of potential support</td>
</tr>
<tr>
<td>(n=17)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend focused health network</td>
<td>Friends outnumbered family and health care professionals</td>
<td>Friends, family and G.P.</td>
<td>Important for instrumental support for younger participants, in particular parents and siblings. For older participants, family was less relevant because of emotional and physical distance. Yet these networks were characterised by a physical, instrumental or emotional absence of family support</td>
<td>G.P. has a significant role but other health care professionals do not.</td>
<td>Friends are important in providing support. Differs to family focused health network as friends are a central source of support.</td>
</tr>
<tr>
<td>(n=4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care professional focused health network</td>
<td>Health care professionals outnumbered other network members</td>
<td>Multiple health professionals. Few family members identified.</td>
<td>Few family members identified. Primarily partner.</td>
<td>Very significant role. The participants referred to multiple health care providers including G.P.s, nurses and specialists</td>
<td>Friends were not identified as significant.</td>
</tr>
<tr>
<td>(n=5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6.3 Family focused network

The family focused network was described by seventeen out of twenty six participants, with the personal community being characterised by the main sources of support from multiple family members. Health care professionals were sought out for specific, task-focused support, such as prescriptions or routine check-ups. Health was framed as an integrated, although relatively minor, part of their everyday life and was something which they “just got on with”.

The family focused networks were characterised by multiple family members who were described as having specific roles such as emotional support. Rather than expecting all their support needs to be met from one network member, participants sought support from various network members (Perry & Pescosolido, 2010). These relationships were reciprocal, for instance, in one case a daughter provided emotional support when her mother was upset and her mother looked after her daughter’s daughter, i.e. her grandchild. The support that the participants provided to others was equally as meaningful, motivating and fundamentally defining who they were and their role in life (Corbin & Strauss, 1985). As such, these reciprocal relationships had great value and meaning to the participants and were typically a significant part of their daily routines. The expected roles that individuals took to support their family members was of greater significance in family focused networks than in other types of networks. Nevertheless, when these roles were threatened or placed under pressure, such as supporting a child who had separated from their husband, it forced respondents to seek substitutes for support which they could no longer access through their family (see example below of Tina). A key characteristic of the family focused network was multiple sources of support and perceived potential support which in itself was reassuring. However, around the occurrence of critical moments these multiple sources of support did not always result in the expected consequences. Thus, for routine support, such as lifts to doctor’s appointments, there was a greater substitutability between network members (Perry & Pescosolido, 2010). Respondents’ accounts depicted that it was important to maintain one’s position within the family which limited where they would seek support in times of emotional crisis as they wanted to preserve how they were perceived by family members. Similarly, Townsend et al. (2006) found that maintaining valued social roles, such as being a worker or a parent, was sometimes prioritised over symptom control in individuals with multiple conditions. Overall, these relationships were a significant source of motivation and potential support.
Figure 6.2 The personal health related social network of Don

KEY
Size of circle for each network member represents the distance they live away from the participant:
- Co-habiting
- Short walk/drive away
- Up to 1 hour away
- Over 1 hour away

Lines in black represent the amount of contact the participant has with network member:
- unknown
- less often than every couple of months (a)
- at least once every couple of months (d)
- at least once a month (c)
- at least once a week (b)
- daily (a)

Blue line represents:
- Network member connection defined by ego
through the negotiation of roles within limitations posed by chronic illness. Relationships with those closest, such as parents or partner, could also be a source of tension (see case study of Don below). The loss, or reconnection, of broken ties with family members had a significant effect on individual’s wellbeing and was explicitly reflected in participants’ degree of engagement with illness management.

To illustrate the characteristics and functioning of the family focused network, two case studies are used here. Firstly, the case of Don, who was a 49 year old, white male who lived with his wife, Gail, and pets and worked as an engineer at a local hospital. He was categorised as having a family focused network. He had diabetes, cataracts, eye problems and tendonitis. In the initial interview the participant spoke of struggling to come to terms with his condition and increasingly becoming ill. In the initial interview he described his wife, Gail, and mother, Anne, as his closest support. However, as he was very upset about being diagnosed with diabetes, he felt he could not get the emotional support that he needed from Gail, although she was able to help him get doctor’s appointments because she worked for another general practice locally. Thus, she was important in gaining access to resources from formal services, but provided limited emotional support. The main source of support Don had was from Anne, his mother, who also had diabetes; however, he felt that her understanding of the condition was out dated and did not reflect, or was not relevant, to his experiences. This remained an important source of tension in the final interview as he described this lack of emotional support and empathy from Gail, his wife, as having a negative effect on his management. He preferred not to talk to Anne about the condition because he did not feel that she acknowledged the differences between their experiences. Although Don was able to get instrumental support, he described being “very upset” and over the course of this study he had started seeing a counsellor. Despite describing in both the initial and final interviews the importance of the activities he did with friends, he did not consider them sources of support for his health:

A:... But my mum, she won’t know what a carbohydrate is if it hit her in the face like a potato...we do talk about it [diabetes]... I do feel as though the only support I’ve got, because my wife really doesn’t, even though she works in a surgery, she doesn’t really understand the feelings and things, she does say things like, ‘Oh, what’s, what’s wrong with you today?’... and I say, ‘I just don’t feel good, Gail.’ ‘Oh, you’re always saying things like that.’ And she doesn’t understand that I do feel like that...
Q: How does that make you feel, when she says things like that?
A: Upset. Upset ... I can talk to her but she’s not one for talking to like that, she’s more, ‘You go and do something about it.’ Rather than help me.
Q: Okay. So what sort of things would she say to you to do?
A: Go and see your doctor. Go and make an appointment with your podiatrist again. Push them to get in. Don’t, well, my surgery’s [surgery name] so it’s hard to get an appointment, so you’ve got to phone up days before... But when you mention you’re diabetic they get you in pretty quick... And then when I mention where my wife works it makes a difference... Cos I give her a due, she has phoned up [his G.P. practice], cos I’m [practice name], she’s [a different G.P. practice], and she has said, ‘Can you get him in.’ And they have phoned me up and said, ‘We can get you in this afternoon.’ ... she doesn’t understand too much about it

Don’s initial interview (Male, Diabetes, Cataracts & Eye problems, Tendonitis, Age: 48)

The personal health community identified during the final interview with Don (see figure 6.2) included: his wife, step daughter, mother, grandson, three friends, grandson, daughter, G.P and a work colleague. His friends he had known all his life and were considered like family. Although Don did not identify their importance in the initial interview when he was struggling to come to terms with his condition, in the final interview he described the value of sharing experiences of health and illness with them. He had recently re-established his relationship with his daughter, Shelly, after years of not being in contact, and described that relationship in terms of it developing. Yet, as this relationship had progressed Shelly’s importance had increased which he showed visually as Don moved Shelly from the outer circle to the middle circle. However, his grandson, Lee, who Don had also only recently started developing a relationship with, was placed in the centre of the circle. Lee had had a great impact on Don’s motivation to manage his health (see below). A further meaningful role which was Don described was that he was an informal carer for his work colleague, and described taking his lunch in for him daily as he was not able to do himself.

Q: Okay. Just sort of, from that, what makes these people say more important (in the inner circle) than the next circle out?
A: Because I've grown up with these people all my life. Obviously my mum, the people I've named in there besides my step daughter obviously, because she's my wife's daughter who's been part of my family since she was four, we’ve been married twenty-one years. Collin and Alan are friends for forty years. Adam a friend of forty years. My mum's me mum.
Q: And your wife.
A: My daughter just, I don't trust her at the moment. She would have been in the outer ring, but slowly she's coming into it...
Q: Building up trust.
A: Building up, yeah. (G.P.), he's my practitioner obviously. Bob on the outer ring because I see him at work and I look after him at work and stuff like that and make sure he's okay and...
Q: And would you talk to them about your health as well?
A: Yeah, me and (work colleague) talk about our health because we call it the 'cripple shift'. Me with my problems and him with his.

Don’s final interview (Male, Diabetes, Cataracts & Eye problems, Tendonitis, Age: 48)
The changing structure of the network could have an impact on management practices such as motivating individual’s to manage their health. This occurs not only through the formation of new connections, but also through the re-connection of lost or broken ties. Through re-establishing contact with his daughter, from whom Don had been estranged for a number of years, this respondent had been able to meet and develop a relationship with his grandson. Don described how much he had enjoyed babysitting, taking his grandson to the park and out on his bicycle. Reconnecting with his daughter and establishing a relationship with his grandson had provided a focus for a new and valued role as grandfather to his only grandchild. This had helped Don to manage the depression he had experienced as a result of his ill health.

Q: Okay. And the last thing when we were doing the circles, what's been the most significant change for you sort of, in the last twelve months? There can be more than one if there is.
A: Well it's got to be my grandson. It really has got to be my grandson. Again to my daughter again and not see my grandson for his first year of his life and then seeing him in the last twelve months, awesome. Awesome. And every time he sees me he bursts out laughing and shouts 'Grannadad' and he melts me. Just totally melts me.
Q: And has that impacted on how you feel about your health or making you want to sort of, take on the diet more and sort of...?
A: Yeah, it makes me want to live longer...It really does...You start thinking things like, well I'm forty-nine now and he's two, in twenty years I'll be sixty-nine and he'll be twenty-two. I won't have that much time with him will I. I want to live longer... you think things like that

Don’s final interview (Male, Diabetes, Cataracts & Eye problems, Tendonitis, Age: 48)

Critical moments in management can arise not only through the re-establishment of connections (see above), but also through events which can shape priorities and management, whether intentionally or otherwise. Having lost his licence two years previously, Don adapted to living without being able to drive. This had a number of negative effects, such as a decrease in pay because he was unable to be on call for work, but also had made him start using a bicycle to ride to work and get exercise, which helped him to lose weight. This had been coupled with a change in diet and Don’s narrative had changed from a sense of despair in the initial interview to one of control and acceptance

A: ... I'm coping with me diabetes now. The last 12 months I'm coping with diet more than anything and...me diet's changed a lot.
Q: Oh, in what kind of way?
A: Er, in I eat a lot more fruits. I’ll leave the skins off. Don’t take the skins cos I struggle with those. Um, everything’s like either steamed or boiled or...the frying pan only comes into it when I decide to make a sweet and sour...I treat meself..., cake stodge has gone out
“Maybe I do too much. Somebody might tell me I do...I feel I can never have too many people in my life... Mm. And maybe sometimes maybe it does do me harm, because sometimes I do worry.”
Figure 6.3 The personal health related social network of Tina
Although Tina was restricted in the support she received from her family, this was of little importance to her in terms of her strong identification with the valued role of family “matriarch”. The latter meant that she expected all those in her family to confide in her without this being reciprocated. Tina identified and placed thirty-three people into her network, (whom she considered of equal importance, from a baby great niece or nephew to her husband) suggesting there was a sense of potential support. Although Tina included four friends in the network diagram, their role was depicted as more peripheral, such as sending flowers when she was ill, as she did not describe seeking support from them when she was unable to seek it from her family. The functional size of her network was more restricted to her immediate family, an equal family matriarch in America, her G.P. and nurse. Similarly, Wenger (1996) noted that the majority of help comes from a minority of network members. From the initial interview this role of matriarch was evident as important, which she maintained over this study and would have been threatened if she had confided in her wider family with her own health concerns. The only member of her family that she felt able to raise her own health problems with was her American cousin (Claire, in the network diagram, see Figure 6.3) who Tina considered her equal as the “matriarch for USA” and did not threaten her position within the family. Further, Claire was seen as a legitimate source of knowledge because she was a retired nurse.

A: I’ve got such a big family… I’m, I’m like the elder one in the family that they all turn to when things go wrong. Me sister’s just been on now…
Q: How do you find that when they sort of turn to you for help?
A: put it this way, I feel I’m the matriarch in the family and I’ve got such, such a big family. Not just in this country, er, in America…in Australia…
Q: How do you find sort of being the matriarch? …do you find that difficult or do you like that role?
A: Sometimes I love it but sometimes I find it very difficult… I mean just now me sister’s phoned me and, and she’s having a problem… It’s wonderful, but at the same time you feel oh goodness if, if things…they ring me up if they’re, if they’re not well and, and things like that, which is a bit, um…you feel responsible…
Q: Do you find that then adds to pressure for you?
A: Yeah. Sometimes… And I’m trying to give advice… on the outer circle I suppose it’s me sisters…
Q: And are they all equally kind of as important to you and your health, in terms of your health?
A: … All me family’s important… I’ve got so many it’s hard to put them in order. There’s no order of importance really because, um, they’re all…They’re all very special to me..
Q: And you talk to all of them equally about your health. So if you had to say if there was a problem…
Tina’s final interview (Female, Diabetes, Stress incontinence, Eating and Sleeping problems, Hair loss, Eye infections, Skin and Gum infections. Age: 69)

For Tina, the experiences of her family members were so important that when something happens to them it was almost like it occurred to her, as she internalises these experiences. During the period of this study her daughter, Joan, separated from her husband under difficult circumstances, which affected her greatly. Joan would normally be her main source of emotional support and despite initially describing that she had ample support and a large social network, this critical event highlighted that the support she received was limited to her immediate family with whom she was unable to discuss her emotions about the situation in order to maintain the matriarch role. However, in this situation, through a lack of emotional support, Tina had an extreme physical reaction. Tina was forced to seek substitutes for emotional support and as such went to her G.P. “as a last resort”:

Q: ... you can’t say to them. So you said you talk to the doctor was it?
A: Yeah.
Q: ... he’d be sort of the most important person.
A: Yeah, because he, he said oh well you’ve done seven years training in psychotherapy, Tina... And this last year I’ve said oh, goodness, you don’t know where I’m coming from, I said, because me health has just gone absolutely AWOL. It really has...You see, I mean I suppose I talk to Joan a lot...I talk to Greg and he talks to me...
Q: ...so you talk to your G.P. and you talk to your G.P. when you’re upset as well as about sort of health problems.
A: Yeah.
Q: And what sort of things would you tell...recommend?
A: Should I put down here what I...I’ve turned to the G.P. about this, yeah... Well, when I found out (about Joan’s separation from her husband)...it really affected me and, put it this way, I couldn’t eat. So it was about eating, it was about sleeping [pause], it was...me hair coming out...Which is all about stress... I only went to the G.P. as a last resort really.
Q: What had you tried before?
A: ... I’ve done seven years training as a psychotherapist. I try to help other people... Well, these are the...me problems: eating, sleeping, hair loss, and also I was having viral infections...since Christmas. Since I found out ... it’s really affected me, and I thought don’t let him hurt you, don’t let him hurt your grandsons. But you see at the end of it you can’t help it.

Participants with a family focused network tended to consider their health to be a minor part of their everyday life, irrespective of the severity of their conditions (assuming that it was not critical or life threatening). For Tina, despite the multiple effects of stress on her
health because of her daughter’s situation, which was subjectively a more immediate concern, Tina did not consider her own health a priority. She remained more concerned for her daughter and grandchildren, framing her own health concerns as of little importance despite her having to seek support from the G.P..

Q: So, we’ve talked about, sort of, problems around, um, stress incontinence and the loss of appetite, hair loss and diet, we haven’t really mentioned diabetes as much, in that it's under control. Is it something that, kind of, is at the fore of your mind or are the other issues more important?  
A: I never think about it. I just take my tablets and, no, it's not, it's not really a priority for me.  
Q: And why, why is that?  
A: There are so many other things to think about.  
Q: What sort, what sort of, things?  
A: My family, and..., many other issues that I need to, no, it's just pushed at the back of my mind... I honestly can't think about anything like that. I've so many other issues. I think, oh, diabetes, fwiwh.

Tina’s final interview (Female, Diabetes, Stress incontinence, Eating and Sleeping problems, Hair loss, Eye infections, Skin and Gum infections. Age: 69)

6.4 Friend focused network

The friend focused network is distinguished by the presence of a greater number of friends than other network types, with few family members being named. If health professionals are considered significant, this is usually only the G.P.. This type of network represents four out of twenty-six networks, and the participants were characterised by trying to maintain a greater separation of their health concerns from their network members than the family focused network, although not to the same degree as the health professional focused network types. This network is distinct from the family focused network by the apparent absence of family support. Support was either physically absent, as a result of no relatives in the network, or emotionally absent, because the type of support available from family members was constrained and limited by other factors which had a comparable effect to having lost that family member and their previously valued support. For example, Catherine described being no longer able to discuss health problems with her mother, Carol, who she had described in the initial interview as a major source of support (see Chapter 8 for further exploration of Catherine’s case). This change in their relationship had come about following the loss of her brother and father within six months of each other. Despite Catherine’s condition being exacerbated by the stress of the loss, she did not want to burden her mother with something which was relatively less important despite it causing her multiple related health problems such as weight loss, exacerbation of occipital neuralgia and depression. Absence of emotional support framed around critical
moments fundamentally changed the nature of the relationship (in particular see below with the example of Rita).

Similarly to the family focused network, health in the friend focused network was framed as a minor part of everyday life. However, when help or advice was sought it was more selectively targeted from individuals who were most able to provide the resources for that specific issue. Although this network type represents only four participants, the networks and narratives had distinctive features separating them from a family focused health network. The essential difference between these two network types was the emphasis placed on the increased role of friends as more centrally important, along with a greater distinction between the types of support sought from different individuals. Lack of familial support may be substituted with friends who adopt the role of these missing family members as a type of ‘fictive kin’ (Rae, 1992; Allen, Blieszner & Roberto, 2011). This was in contrast to the greater substitutability of network members in the family focused network, where participants described being able to talk more equally to the network members about problems that concern them. The participants who were identified as having a friend focused network tended to identify greater conflict between different network members, which made the participant selectively choose where support was sought. Subsequently, there was a more limited substitutability of individuals to different types of support across different network members. Health professionals had a minor role in the shaping of the management of health as they were considered to have limited, task specific roles and were visited for explicit reasons such as medication.

To illustrate a friend focused network in more detail, two case studies will be used to demonstrate characteristics of this type of network. The first case study of Ron who has limited family to seek support, rather seeking support and information from friends. A further case study of Rita will also be used to demonstrate how a participant can lose support they have traditionally sought from family members, as well as friends, as she chose a partner they did not approve of. Changes in friendship occur around events such as divorce, or disillusionment in the relationship (Pahl & Pevalin, 2005). Such pivotal points change people’s ability to manage their conditions because of the changing nature of the support they can access. This decision affected where the participant could seek support because of the loss of valued emotional support provided by close family and friends. This eventually led to conflict within the network, ultimately changing what constitutes a social network as a result of these critical moments or “major epiphanies” (Denzin, 1989b:129).
Figure 6.4: The personal health related social network of participant Ron

The diagram shows a social network centered on participant Ron. The network includes connections with Bob (friend), Carol (friend), Victoria (friend), Tony (grandson), Steve (friend), and Jan (reiki associate).

**KEY**
- Size of circle for each network member represents the distance they live away from the participant.
- Co-habiting
- Short walk/drive away
- Up to 1 hour away
- Over 1 hour away

Lines in black represent the amount of contact the participant has with network members:
- Unknown
- Less often than every couple of months (e)
- At least once every couple of months (d)
- At least once a month (c)
- At least once a week (b)
- Daily (a)

Blue line represents:
- Network member connection defined by ego
I first address the case of Ron, who is an eighty-four year old, man who had diabetes, ischemic heart disease and arthritis. Ron lived alone, following the death of his wife thirteen years previously. More recently his brothers, and during the period of this study his only daughter, had passed away. The absence of family in this network is characterised by the physical loss of family members. Ron’s grandson, Tony, was his only remaining living close relative. Overall, Ron described himself as being able to talk to any of his network members about health concerns and despite having recently stayed in hospital for a number of weeks he did not include any health professionals in his network (see Figure 6.4). Although Ron had been going to the practice for over forty years, he described their very limited role in his health as they were only able to provide reassurance and the relationship was impersonal which was in contrast to his experiences when going to the pharmacist who he felt he knew better:

Q: So you didn't put the doctors on as important in your health, how come?...
A: Well they're only important in as much as they give you reassurance...
Q: Not in giving you advice...
A: You can't say much more than that about them really.
Q: So they're not important in helping you manage your health?
A: I wouldn't say so, no. Well I suppose they think they are, but... that's their job isn't it really?
Q: ...What do these people [on the network diagram] do that the doctors don't do? What makes these people important?
A: Talk to you sensibly. Sit down and talk quietly to you, reassure you...
Q: And you wouldn't feel that the G.P. or the nurse would, you'd be able to talk to about sort of...?
A: I have very, very, very little contact with any of these people. Normally if I visit a doctor it is no more than three times a year.
Q: ... For sort of, annual check-ups?
A: Or when I've got a chest infection or something like that. It's the only time... it's, no I very rarely talk to the doctors for anything really.
Q: So you wouldn't really ask them for practical help or emotional support?
A: No, I think I would ask the pharmacist sooner than the rest.
Q: Because?
A: Well I know her very well. Both pharmacists at the practice, they're both excellent.

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

These types of networks are characterised by health being framed as a minor part of everyday life in amongst a number of other priorities such as work, looking after children or doing voluntary entertainment at local care homes. This was despite all participants having multiple health concerns. Health was not a focus, and unless absolutely necessary it was not discussed with anyone. This was similar to accounts which highlight individuals attempt to maintain normal lives despite their condition (Charmaz, 1990). For instance,
Ron since the initial interview a year previously had undergone a knee operation and whilst in recovery had two heart attacks which resulted in him being in hospital for three weeks. However, despite these health problems it was not something about which he would talk. This was similar to Kelleher’s (1988) description of normalisation which suggested that individuals who normalise the condition change their routines to adapt to it but do not complain about its effect on their life:

*And I mean, I don't, kind of; my health isn't a major topic for me really... Only when something like this is, you've got a chest infection, but generally I class myself as a normal healthy person really...I don't, I'm certainly no hypochondriac.*

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

Information was sought from other sources, predominantly the internet. In particular the internet was used to look up information on symptoms and ways of self-managing problems so as to have timely information rather than visiting his doctor, as Ron often had to wait three or four days for an appointment. Further, friends, and to a lesser degree relatives, were an important source of meaning for his daily life. In the initial interview, Ron spoke about the importance of his friends as almost a selected family, in particular one close friend who he described in familial terms as “like another daughter”:

*Q: Um, and, so you'd speak to your daughter. Would she be the main, kind of, person you'd talk to about it?... A: No. No, actually the main person I talk to about it is a friend whose wedding cake I made thirty four years ago, and I taught her one-to-one in cake decorating about five, six years ago, and she's got her own business now... She's like another daughter to me. She comes to see me every week, once a week.*

Ron’s initial interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

This friendship maintained its importance and increased with regular contact as Ron’s health declined over the year. In the final interview, Ron placed Carol in the central circle. Most significantly for this participant was the emotional support and regular contact from the friendship; Carol was the most significant person he had contact with:

*My closest friend, Carol. This is a young lady, I made her wedding cake thirty-seven years ago, we've been friends for a long time. She's a wonderful person. She lives at [location]. We talk every night on the phone about a quarter to ten, ten o'clock, we have ten minutes on the phone...Checking each other’s alright ... It's her checking up on me mainly.*

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

Another meaningful element to Ron’s health management was through the maintenance of existing roles such as being a Reiki healer which he used to treat himself as well as other
people with a range of ailments. Helping others was an important part of his self-image and motivation, as it provided comfort to him, not only through Reiki healing, but also through entertaining others by playing the keyboard twice weekly for people in care homes. Friendship was also viewed as another type of work, i.e. that they did not just occur but were an important investment of time which reflected Ron’s outlook both on life generally and more specifically on health:

...you've got to look on the right side of things all the time really...Life's what comes your way... it's what you make it half the time. If you haven't got friends it's your fault, it's not being a friend yourself. That's my way of thinking of things anyhow. You don't make friends, you can't buy friends...you work for friendship.

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

Reciprocal relationships in friendships were developed over many years. Different friends had different roles in not only supporting, but also in what they expected from respondents (Spencer & Pahl, 2006). Ron described a much closer relationship with his friends than his family. Although Ron considered Jan, a Reiki associate, and his grandson as most important to him, he turned to Carol for financial and emotional support and Jan for instrumental support to help him write a will before he went for an operation. Ron spoke to his grandson more out of obligation and he had a much more limited role in his daily life or around critical moments:

A: I remember one time, I'm going back a long time ago now and something happened and I needed money rather quickly and Carol lent me three thousand pounds without batting an eyelid...I paid her back within a fortnight... because I knew I could do, but that's Carol. She didn't question it.
Q: ... And then with Tony, would you talk to him if you were upset?
A: Oh, yes... Out of duty more than anything really.
Q: What do you mean?
A: I mean, with Tony, what I've done I've made a will before I went in for this operation, not that I thought it was going to be anything final but I thought I should do it anyhow. And again, oh, no it was Jan this time, Jan works for a legal firm in Manchester and she said, 'Have you made a will Ron?' so I said, 'No' and she said, 'Well you should do.' So she said go to Boots, WH Smith and get a will form and she was telling her boss at work about these will forms from WH Smiths and he said don't get one he said they're not complete... they're not a proper legal will form. So he said, 'What's it all about?' So she told him. She said it's my friend, she said, he's just got one grandson. He doesn't want anything complicated, he just wants to leave everything to his grandson, everything, and then write his grandson a letter for what gifts he wants to give to his friends.

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

However, despite recounting the adequate support which Ron valued greatly, this support was limited. He spoke often about not wanting to burden Tony, his grandson. At the time
of the interview Swine ‘Flu had become epidemic and was prevalent across the country. For Ron this acted as a minor epiphany (Denzin, 1989b), as he acknowledged the limitation of the support he had and identified how isolated he would be from his current support mechanisms. Had his daughter been alive this would not have been the case, suggesting the limited substitutability of friends over family in supporting someone when greater needs arise:

Q: Um, and do you think that you could talk to your G.P. if you needed sort of social support or practical help?
A: Well, I’m not a panic person. Definitely not a panic person…I take things as it comes. But one thing that does slightly, very slightly worry me is, um, if I went down with this swine ‘flu. I mean I’ve…I’m on me own…What do you do? [Laughs].
Q: What would you do?
A: I don’t really know. Um, I’d let me grandson know, but I mean I, I, I don’t want to impose on their lives by expecting them to come and look after me…I mean if [daughter] had been alive she’d have come and lived with me for a week and sort me out… but that isn’t so now… I mean I, I don’t know really. I’d take it as it came.
Q: Do you think that the G.P. could provide some sort of help, maybe practical help if that happens, if you did get flu?
A: Well I’m sure they would. If you were bad enough they’d take you to a hospital wouldn’t they?

Ron’s final interview (Diabetes, ischemic heart disease & arthritis, male, age 84)

The above example of Ron represents a friend focused network shaped by the physical loss of familial support through bereavement. However, for two of the participants whose networks were characterised by the significance of friends over other relationships, the change to their familial relationship was loss of emotional support around critical moments (Denzin, 1989b). For example, Rita who was twenty-five years old who has IBS and anxiety problems and lived at home with her mother, stepfather and younger sister (see figure 6.4). She described in the initial interview that having IBS was a minor part of her everyday life which she had adapted to through eating regular meals and drinking Activia yoghurt daily. However, by the final interview Rita had developed an anxiety problem, and the help she had sought from her G.P. had had limited success and the IBS had flared up. Friends were an important part of her everyday life, and in particular Rita had a group of close friends who she had known for a long time, and three out of the four also had IBS. Although in the network diagram (see Figure 6.5) Rita’s mother, boyfriend and sister are placed centrally as the most significant members of her network, this network was characterised as a friend focused network because of the significance of her friends in the narrative. In the initial interview, Rita described seeing her friends regularly to go out with them, looking after their children and joining exercise classes together.
Figure 6.5: The personal health related social network of Rita
They were a mutual source of motivation, advice and general support (Gallant et al., 2007). At the beginning of this study Rita had just started a relationship with her boyfriend and over the period of this project this relationship had become a cause of conflict between the participant, her mother, sister and friends to the extent that she had already lost a long term friend. Rita described being alienated from her traditional support because of their disapproval and so was unable to discuss problems in the relationship, which she linked to her increasing ill health because of anxiety and exacerbation of IBS. Rita described how the loss of support from her mother and friends was the main source of anxiety, as she was unable to be honest about being in the relationship with her boyfriend because of their dislike for him. She described feeling like she was “being torn between them”.

Q: …Do you think there are people in that group who may make it a little bit harder to manage your IBS?
A: Boyfriend…Definitely. Oh, I've just had non-stop trouble with me to be honest. I'm actually hiding the fact that I'm even back with him at the minute from everybody because he's cheated on me with his ex, there's been some violence as well, so I've just gone through; I've changed from being like a confident person to just being a bit of a mess. I'm not as bad now as I was, but I was a really bad mess. I've lost a friend because of him and it's just been, just been one thing after another with him. He was living here for a while with my mum, so he got close to my family and everything and kind of, let them down, so it's just not been good, but I just, through my stress, I didn't stop eating because I wanted to stop eating, but through stress I just couldn't eat. I mean, I've lost a lot of weight since then as well. But it's weird now from not eating and being so stressed has caused my IBS to be really, really bad, it's gone really bad…The pain's aren't as bad, but as far as like going to the toilet and things like that, I just can't, but I think it's because I've not been eating properly and obviously I'm stressed out. It's weird how one little things can just affect your whole body really... I mean, I hope that in a few months time I can tell people I'm with him and things will be alright. I don't think they will be because basically everyone says if you get back with him now, that's it kind of, thing, but I don't know. It's kind of, it's very hard as well when you're trying to keep everybody happy and I understand that people just care about me and they don't want to see me get hurt and all the rest of it, but it's hard when you're trying to keep everybody happy and it's like stressful. But I'm hoping, I am trying to get a different job as well at the moment, I just need something with a bit more routine, so hopefully once I can get a new job as well I can start eating properly again.

Rita’s final interview (Female, IBS, Anxiety problems, Age: 25)

This loss of support was reflected in how Rita described the effect of stress on IBS; in the initial interview she described her friends as not being able to control their condition because they were unable to control the stress in their lives, which was something to which she had managed to adapt. However, by the final interview the anxiety caused by the relationship was being manifested through her health. Rita would normally have
accessed lay support, but instead had to seek professional support from her G.P.. Yet the information and treatment options offered by the G.P. were still verified by friends’ knowledge and experiences, filtering the treatments through the context and experiences of those closest and placing illness within their knowledge of the participant’s individual situation:

Q: Have you spoken to them [G.P.] at all about it [IBS] over the last year?
A: Not my IBS, no.
Q: But other; the sort of, anxiety issues?
A: Yes.
Q: How do you find talking to them?
A: The doctor that I went to last time was really good actually, he was really understanding, but the only thing was he basically wanted to put me on pills for my anxiety, but even though it's not; they were antidepressants and even though they're for anxiety and not depressed people, I didn't even want to go down that road, so I kind of, said I'll have to think about it and see how I go with it.
Q: And have you gone back to him?
A: Not yet, but I'm thinking if it; because I'm still suffering. I'm not as bad now as I was, but I am still suffering, but a friends told me you can get ones that are more like; they're not actually antidepressants, I think they're more like herbal kind of, tablets, I'd rather go down that route than get onto antidepressants. I don't really want to go there...It's not about being labelled or anything like that, but I've heard of people getting addicted to them and things like that. My friend got addicted to them and I think that's what kind of, puts me off. I just don't want to become reliant on them really. Even though I'm not really depressed, it's more for my anxiety, but still I don't want to.

Rita’s final interview (Female, IBS, Anxiety problems, Age: 25)

6.5 Health care professional focused network

Health care professional focused networks are characterised by the identification of multiple health care professionals including G.P.s, nurses, specialists, pharmacists and podiatrists who provide support. The amount of contact with health services may only represent a small amount of the time that a patient manages their long term condition but can have a disproportionate impact on illness management because of the significance of the contact (Gately et al., 2007). They have a central role in influencing management, are consulted regularly and are seen as a legitimate place where health was discussed. For participants with a health care professional network, this contact was particularly important. This type of network was represented in five out of twenty-six final interviews and was not associated with the degree of severity of a condition, i.e. these participants are no more likely than those in other types of networks to have multiple, complex conditions which are functionally limiting. Health care professional focused networks contain few family members or friends (see fig. 6.6). Rather, they have a distinctive characteristic in
the way in which health was framed as more individualistic, with a preference for managing predominantly on their own with specific focused support from professional care.

*All you’ve got to do is just keep going at it... Fifty per cent mental attitude isn’t it?... I will get up there, I will go up a step, I will go down... I just regularly kept my tablets, I don’t miss the tablets.*

Tom’s final interview (Diabetes, high cholesterol, male, age: 52)

Nevertheless, all participants identified one key lay person who was important to their health management. Usually their partner, or if they did not have a partner a single family member or friend, was identified as significant whom they could discuss health matters and seek instrumental support:

*Q: Thinking about say this network, diagram in relation to your sort of, normal social circles... would there be people that you don’t talk to about your health sort of, who, so obviously on here?*  
*A: No um... I don’t see diabetic; diabetes as a drawback it’s just what it is and I take the food and I go on... the only people I would talk directly about diabetes are those three people.*

Tom’s final interview (Diabetes, high cholesterol, male, age: 52)
Figure 6.6: The personal health related social network of Tom

KEY
- Size of circle for each network member represents the distance they live away from the participant:
  - Co-habiting
  - Short walk/drive away
  - Up to 1 hour away
  - Over 1 hour away

- Lines in black represent the amount of contact the participant has with network member:
  - unknown
  - less often than every couple of months (e)
  - at least once every couple of months (d)
  - at least once a month (c)
  - at least once a week (b)
  - daily (a)

- Blue line represents:
  - Network member connection defined by ego
This type of personal community was characterised by health being viewed as a private and distinct dimension of the participant’s life which they did not want to place within the sphere of their everyday social network as something to be discussed and negotiated. People at the centre of this type of network sought their ongoing support from formal sources and their partner or a significant family member. Management was seen as an internal, private process, despite three of the five participants’ accounts involving declining health over the previous year, which made it more publically noticeable. The following participant, Kate, described initially how she did not raise her health problems with her family: “No, no, no I try not to worry them [nephew and sister]. I try to be as independent as I can” (Kate’s final interview (COPD, high blood pressure, blackouts, female, age 84). However, in the final interview Kate described having unexplained blackouts after which she would wake up on the floor, unaware of what had happened. These blackouts had occurred when she had been shopping, which she used to do independently of her sister. In the final interview she explained how she had increasingly come to rely on her sister to take her shopping, for advice and support as well as to prompt her to go to the doctor’s. Kate did not speak to her nephew, whom she had described previously as being someone she could call on. Despite this initial description of having a lot of support from her extended family, as her health increasingly deteriorated the focus of lay support was from her sister only. There was a limited substitutability of network members to do other types of work, as there was conflict between her desire to remain independent yet increasingly needing greater support:

Oh yes, you see what they did give me was just something to take some of the pain away. Now over the weekend my sister said, 'Has it, has the pain gone?' I said, 'No it's not it's been worse.' So she said um, she said, 'Well ring them up and tell them that none of the pains gone’... Anyway um, I spoke to the doctor on the phone
Kate’s final interview (COPD, high blood pressure, blackouts, Female, Age 84)

Participants whose networks were characterised as health care professional focused tended to provide accounts of single significant episodes with family and friends which influenced how they managed their condition rather than ongoing reciprocal relationships. Although in respondents’ accounts there was support that was ‘invisible’, i.e. was not considered important enough to place in the network diagram yet had a significant influence over illness management priorities (see below), this was more evident with health care professional focused health networks. Their accounts depicted the importance of their ongoing relationships with health care professionals and individual family members, usually their partner. This was in contrast with the other two types of networks,
where relationships with family and friends were described as ongoing and had greater significance for normalising health practices within the context of other significant daily routines.

To illustrate the characteristics of the health care professional focused network, a case study will be used. The case study is of Frank who was a sixty-five year old, white male with COPD, hypertension and was born with one lung. He had retired and lived with his wife. Frank had had ongoing breathing problems all his life as a result of having one lung. He was self-employed and described having taken few days off sick, only taking six holidays in forty years and having worked through Christmas’ and Easters. Being independent and taking on the role of provider for his family were important dimensions of Frank’s self-image, which was gradually being challenged because he was becoming increasingly functionally limited. Yet maintaining independence was a source of tension with his wife, Elaine, who would avoid asking him to do tasks, although Frank identified them as needing doing, such as painting the house. Frank described wanting to do these tasks but would get tired and Elaine would “nag” him not to do things which was a reversal of her asking him to do these jobs. In trying to protect him she highlighted his illness. This changing role threatened Frank’s identity and perceived usefulness in the family, and as such he preferred to be alone when he was upset or ill.

Q: How would you describe your current state of health?
A: Huh, it’s probably ... I can get about, but it's declining, I am feeling, especially this last week or two I have not felt this bad ever, which isn't to say that I can't cope with it ... I've just got to slow down. I can’t now, I find it hard walking and talking,...
Q: ...how does that make you feel kind of that change?
A: Well it's just a bit, it is more annoying than depressing... I mean there's lots, I'm getting old now, I am nearly sixty six, so you’ve got to expect this... with having been born with one lung there was times when people didn't even think I would get to twenty one, let alone sixty-six... I am fortunate to be this far...and don't expect to keep the same level up... It's just if now I was to get another really bad dose of the flu I would be on me knees I think. I can cope as it is but there's not much spare capacity there... I am normally positive it's not...I never stop in bed and that sort of thing.
Q: When you are not feeling quite as positive do you talk to anyone or do you; how do you deal with it?
A: Yeah... I just I go quiet, very, no I can't say that I talk to people, but the wife knows immediately if I am not so well, because I am quiet... But I just tend to work myself through it

Frank’s first interview (COPD, hypertension, Male, Age: 65)
Figure 6.7: The personal health-related social network of Frank

KEY
- Size of circle for each network member represents the distance they live away from the participant.
- Lines in black represent the amount of contact the participant has with network member:
  - unknown
  - less often than every couple of months (a)
  - at least once every couple of months (b)
  - at least once a month (c)
  - at least once a week (d)
  - daily (e)

Blue line represents:
- Network member connection defined by ego
The personal health community for Frank (see Figure 6.7) included: his G.P. and nurse as most important; a COPD rehabilitation clinic he had started attending over the course of this study, which had been recommended by the nurse and his wife, Gail, was considered secondarily important; and his eldest son, James, was considered as less important, although he fulfilled roles which his mother could not do, such as drive him to hospital. Nonetheless, he placed his youngest son, Paul, outside of the circle with the caveat “I'll put him on the outside, so he knows about me but...I don't trouble him much” (see Figure 6.6). A key feature of the centrality of network members in this type of network was in the functional and instrumental support they provided. Emotional support and reciprocity of relationships are less important as the individual tried to maintain independence.

Frank’s role and relationship with his G.P. was well established, whilst operating within the limitations of care available, such as the negotiation of antibiotics for a chest infection. To challenge such a hierarchical relationship without threatening his role in the relationship, Frank described the way in which he sought another network member to act as a bridge to medications that he needed. His description was of not being able to challenge the G.P. despite knowing that the system could offer him more assistance and that the G.P. was the bridge to those resources. Instead, Frank described how he used the connections between professionals to get the prescription that he needed and to which he should have access. This process of seeking alternative routes to access resources was highlighted when Frank had reoccurring chest infections. The infections increasingly weakened him and led to his wife becoming temporarily more assertive because of the severity of his health problems pushing him to challenge the accepted treatment. This was further combined with knowledge from the COPD clinic that he could have antibiotics to leave in the fridge and begin a course when he was beginning with a chest infection. When Frank’s attempt to organise a prescription of antibiotics from his G.P. failed, it forced him to seek other network members (i.e. the nurse) to act as a bridge to the medication:

It's because I've had a lot, a lot of chest infections. Last year and I mentioned to the doctor and everybody's been worried about me because um, I was going every six, seven weeks, and then the chest infection, and then another lot of antibiotics. So I counted within fourteen months I had ten courses of antibiotics, so. I went to see the doctor, she Gail said, 'For God sake, tell them you shouldn't be like this.' So I went... and he [G.P.] said, 'Oh, well, it's that time of the year, everybody's getting um, chest infections and colds and flu.' I said, 'Don't you...?' 'No, no, no, what you worrying about?' I said, 'Well, I'm getting paranoid' I said, 'every time I take my inhaler I'm washing it and disinfecting it in case I'm carrying germs from one to another.' No anyway, he sort of, dismissed it and I come home, and he [G.P.] said, 'Oh, stop worrying about it... then I went on this ...COPD course and went to the see the nurse and told her... that I should have antibiotics and she went to see the doctor...since then they clear up a lot quicker. I don't think I ever got them
cleared up before ... because often it was four or five days before I could get to see [the G.P.].... if you start with a chest infection on Friday and you phone up, and it's oh, he's not in Monday.. you've gone four or five days and it's really got hold of you.

Frank’s final interview (COPD, hypertension, Male, Age: 65)

Frank’s sons were peripheral to his health management and, although he placed the eldest, James, within the diagram and the youngest, Paul, outside, he described not talking to them about his health. Rather, Frank’s wife acted as a bridge to let them know how he was as he preferred not to “mither” them as they had their own families. Despite seeing them regularly he did not seek support as he tried to maintain his valued role as father, grandfather and babysitter to his grandchildren, despite recognising that he could easily become ill because of their colds:

A: Jame's very sensible... but he, he's the one that my wife chats to about... have a word with your dad and stuff like that...he knows how I am and he keeps an eye on me from a distance, without interfering...

Q: Do you prefer that?

A: Yeah... then my youngest son, if he says 'How are you?' I say, 'Oh I've got a sore throat,' something like, we rarely go into details... he knows I have a bad; everybody knows I have a bad chest and some days we can't look after the kids because I'm not so well, so obviously he knows how I am...

Q: So why wouldn't you sort of, talk ... 

A: Well, he's er, he's a bit younger... James er, youngest one's fourteen, but Paul's got a three year old, six year old and nine year old...But Paul, when he comes home he's got to sort the kids out and bath them and make the meals and get them up in the morning, so he's got enough to do without me mithering him, so we don't mither Paul, do we?... And er, he lives in a dream world anyway.

Frank’s final interview (male, COPD, hypertension, age: 65)

Thus, the importance of maintaining these valued social roles, such as ‘being a wife’ or ‘being a parent’ (Townsend et al., 2006), was maintained by his wife acting as a bridge for his children to find out about his health. His children could offer more practical support, such as helping with his computer, which did not threaten his position. However, the roles of network members were not static and when they changed, such as his wife becoming more assertive about him seeking care, this acted as an impetus to make him challenge the established relationship with his children as it highlighted the seriousness of his condition. Further, he sought alternative routes by using other network members to indirectly act as bridges to the resources he required.
6.6 Summary

In this chapter, I have shown that three ideal types of networks are relevant to understanding the management of long term conditions: family focused networks, friend focused networks and health care professional networks. Each type of network differentially reflects the degree to which self-management practices are supported or undermined by those in a social network. However, even negative influences remain an important dimension of the narratives, as network members have multi-faceted roles with both positive and negative elements. There is limited substitutability of network members because support is typically sought from core network members and the opportunities for extending or developing more weak ties are limited. Peripheral network members had a minor role, often described in terms of potential support, although at times of need they had limited substitutability for core network members. The resources that were wanted and available from those in the network varied over time and was also influenced by the social roles identified themselves as having (e.g. being a parent). Critical moments played an important role in shaping engagement with illness practices (as defined in Chapter 2) through placing them within the context of other existing demands and priorities of everyday life, consequently emphasising the importance of social network analysis to the work of being ill (discussed in Chapter 5). The impact of this in particular for the family and friend networks, is greater because an individual’s health and motivation for management are greatly interconnected with their everyday roles, self-image and the desire to retain normalcy. Critical moments, both positive and negative, that occurred as a result of the influence of network members tended to have a greater influence on health in the family and friend focused networks than the other types of networks. The impact of these events is internalised and ruminated upon and has a seemingly more enduring impact compared to the health professional based network types where intimate relationality is less and individuals are viewed as external to intimate life and less connected into the other roles and aspects of everyday domestic life, and so inevitably have a more limited impact. Other types of critical moments which directly health related (such as the onset of additional conditions-as discussed in Chapter 7) could also cause this re-evaluation of management but tended to occur across the different types of social networks.

In the next chapter I will explore the role of multiple conditions on illness management and consider the effect this has on redefining relationship with network members.
Chapter 7

The role of multiple conditions on illness management and social networks

In this chapter I begin by explaining the role of multiple conditions on illness management. I will then examine the influence of multimorbidity on the resources available through an individual’s social network. Finally, I will explore how multiple conditions challenge relationships, influence the roles of different network members, and alter established reciprocal relationships.

7.1 Introduction

An important dimension of illness management is the presence of multiple long term conditions. Yet, the literature on the experiences of people living with long term illness has focused predominantly on single conditions (Bury, 1982; Faircloth et al., 2004; Corbin & Strauss, 1985). Current practice for long term condition management tends to reflect a static, disease-specific model of management. The aim of this thesis was to examine the interaction between lay and professional networks in shaping management priorities, yet the presence of multiple conditions created a further layer of complexity to management, such as an increase in the number of medications and dietary restrictions, which may stretch the limited support available. The way in which individuals adapt to, and manage, long term conditions and the resources utilised through social networks can be influenced by the management of multiple conditions as they place an additional burden on the limited resources available from the network. The burden of chronic illness is increased in the presence of multiple conditions as it can increase the complexity of management which accumulates over time (e.g. physical limitations, lack of knowledge, problems with medications) and there is a greater need for social and emotional support (Bayliss, et al., 2003). As there are limited resources available for deploying self-management activities, individuals must prioritise conditions relatively, based on how manageable with medications and predictable they are (Lindsay, 2009). Although, as Piette and Kerr (2006) identify, not all comorbidities have the same impact and thus may not need the same amount of management. This may in turn influence the impact of the number and type of conditions on the practices and resources needed to support self-management.
There are compounded challenges in managing multiple conditions including a lack of care co-ordination (May, Montorri & Mair, 2009), a need to develop multiple techniques to manage symptoms in daily life (Townsend, Hunt & Wyke, 2003) and the influence of type and severity of comorbid conditions (Kerr, Heisler, Krein, Kabeto, Langa, Weir & Piette, 2007). Continuity of care with multimorbidity also has an influence over the broader experience of health care (Cowie, Morgan, White & Guillford 2009). These challenges, such as care co-ordination and symptom management, have particular relevance when considering the role of network members as they place a greater responsibility of management on the individual outside of formal health care. In turn, this influences the negotiation of management in the daily context of existing roles and responsibilities. The focus of analysis in this chapter was on establishing the role of multiple conditions in influencing illness management through accommodating, or not, additional conditions into existing practices. Attention is also given to the influence over resources needed from, and roles of, different network members and in turn how this affects the significance and reciprocity of relationships.

7.2 Multiple conditions and illness management

Multiple conditions affect illness management through the way in which conditions are prioritised and strategies developed to integrate and manage information and practices. This was evident when multiple conditions were either accommodated or caused disruption (as defined in Chapter 2 as: the re-evaluation of personal, familial and work-related factors which are associated with the onset and management of a long term condition (Bury, 2001)) to existing practices for participants. Twenty-one of the thirty participants had at least one co-morbid condition (see table 4.2 for a list of all comorbid conditions reported). For some respondents, additional conditions had a disruptive effect on existing practices leading to confusion and ambiguity as they tried to disentangle conditions and symptoms in an attempt to alleviate them and reduce the work caused for other people:

I don't know whether it's I am carrying too much weight or I'm having too much sugar, I am having, I know one thing I am having too much salt, because I like my food salty and that, but I'm trying to find out why I'm; of a night, every night, get up of a morning and all me, I am all wet through...with sweat....I have been trying to find out what's caused it, and all I get from, it is your diabetics, they give it a different name all together...that's one main thing and the other is, I have had my eyes done cataract done and that, that were
alright but um, it's just niggly things ... the bed is simply wet through in morning when I get up, the wife has to change the sheets and everything.
Adam’s initial interview (Diabetes, knee problems & kidney problems, Male, Age, unknown)

If conditions were ‘biographically anticipated’ (Pound et al., 1998) and practices were framed within existing notions of management they required fewer resources. However, if new conditions challenged existing practices they could become disruptive (i.e. the structures of everyday life and its’ taken-for-granted features are challenged and resources (such as physical, social, financial or medical) are mobilised to adapt to the altered state (Williams, 2000)). When multiple disruptions occurred there were fewer resources available for the individual to manage the conditions and this led to some participants feeling overwhelmed which consequently made their conditions worse. An accumulation of conditions and events leads to an increasing disruption of illness within everyday life.

I have... just get on with it. It's a chronic condition, there's not a lot I can do about it other than, except I’d like to take more exercise, walking, but at the moment as I say because of my feet problems I can't, so it's a double whammy as they say.
Matthew’s initial interview (COPD, oesophageal problems, feet problems, male, age: 69)

7.2.1 The influence of social roles on multiple condition management

The other roles, such as being a husband or worker, that an individual performed could also be prioritised above the needs for their own health (Townsend et al., 2006). Some participants’ accounts depicted placing their health in the background as negotiated and influenced by other network members priorities (as described in detail in Chapter 5). Alternatively, new management strategies were readily engaged with if they were congruent or complimentary with existing illness practices, such as dietary changes. The impact of having multiple conditions was not always reported as having an additive effect (Piette, & Kerr, 2006). Learning from one condition allowed participants to adapt to an increasing work load brought about by diagnosis of additional conditions. Yet there is a presumption in the literature that multimorbidity requires increasingly complex clinical management strategies, as a new set of practices was required for each ‘new’ condition acquired (Valderas, Starfield, Sibbald, Salisbury & Roland 2009). The following respondent described how routines adopted for epilepsy management were similar to those for diabetes control.
like I say other than drinking a lot and weeing a lot... I feel okay. As long as, I mean I have to sort of eat regularly for the epilepsy, eat regularly, not get over tired, not drink too much alcohol, I mean I do have the odd glass, but I don't drink basically it's just the odd glass here and there. So we have to make sure ...don't get over tired, don't skip meals, so that is what I do for me epilepsy anyway, so that's what helps with the diabetes as well

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

However, despite recognising the links across the conditions and management practices, participants’ actions could be undermined by the actions of those surrounding the individual (for instance the role of partners examined in Chapter 5). The continuity of illness behaviour was referred to in relation to dietary and exercise advice. Network members, in particular practice nurses, G.P.s, spouses and support groups, played an important role in providing the information that was accommodated into management practices (Pescosolido, 1991). If information fitted within existing routines there was a transfer of learnt practices across conditions:

A: Well she talked about diet and um, yes really it was diet really... just be careful what I eat.
Q: And has that been a big change?
A: No not really 'cos I was already on quite a healthy diet...before that I'd um, I'd decided to lose a bit of weight if I could because with having MS it's better not to carry a lot of weight with it.

Danielle’s initial interview (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

One participant referred to a history of deliberate efforts to lose weight because of knee problems. He sought out resources to enable him to reach his health goal and transferred them across conditions. Having recently gained some weight and having had a reoccurrence of the knee problems, he joined WeightWatchers where he learnt about saturated fats. He used this additional knowledge as a rationale for reducing his cholesterol as well as continuing with his prior objective of losing weight:

A: ... I used to carry, when I was carrying those [heavy sacks] my knee did hurt, when I wasn't carrying them my knee didn't, so I knew it was downward pressure on the joints.
Q: Okay, so that's kind of prompted you?
A: Yeah to get some weight off. I can walk up and down stairs easier now than I could before I lost that ten pound weight... But I want to lose another half stone if I can...
Q: Okay, so do you monitor your food now do you read the labels better or...?
A: Oh, I always read the labels now when I am buying food...
A: Yeah since [WeightWatchers], anything over four... in the saturated fats I won't touch it at all.

Ron’s initial interview (Diabetes, ischemic heart disease & arthritis, male, age 84)
Yet accommodation of management practices was not always consistent across narratives; rather, descriptions depicted change over time, with accounts of disruption and flow (Bury, 2001; Pound et al, 1998). Accounts depicted a set of actions, reactions and self-preservation strategies that are considered to work for one condition and then are applied to newer conditions. This was evident in the links that the participants made between strategies, as the descriptions were of change over time leading to an accumulation of coping strategies because the respondents necessarily needed to prioritise due to the limited availability of management resources.

7.3 The dynamic prioritisation of conditions

Respondents described a dynamic process of prioritisation, i.e. bringing to the fore, or shifting to the background (Patterson, 2001), one condition over another in response to a variety of factors (described below), over time which the required re-negotiation of available resources that influenced management in a positive or negative manner. This shifting prioritisation was key to the way in which management was framed and practices were engaged with. In order to manage the complexity of multiple conditions, participants responded by accommodating (see above), as well as prioritising (Lindsay, 2009). The relative significance of conditions was accomplished according to: which condition they considered most severe, how restrictive the condition was, their prior knowledge of the condition and the timing of the onset and flare-ups of different conditions and how new conditions fitted within existing routines with pre-existing conditions:

.. watching out for tiredness and diet basically, that’s, that’s my concern...it doesn’t really worry me too much the diabetes... I think because it is overshadowed by the epilepsy....whereas if it had been a sort of a new diagnosis and it was like oh...

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

7.3.1 The role of expectations of illness on condition prioritisation

Prioritisation was based on a complex interaction of personal factors, such as how relatively limiting each condition was and also through previous experiences of illness, whether personally or through the experiences of significant others. For the following respondent, the addition of feet problems to a pre-existing COPD condition had a physically limiting effect in reducing the amount of exercise he could get from walking. However, he was more concerned about his oesophageal problems as he had a family
history cancer and thus anticipated relatively more serious health problems which resonates with Williams (2000) description of ‘biographical anticipation.

A....It's a chronic condition, there's not a lot I can do about it other than, except I'd like to take more exercise, walking, but at the moment as I say because of my feet problems I can't, so it's a double whammy as they say... the conditions don't inhibit my lifestyle... the main worries if I do have worries, my father died of bowel cancer at fifty; oh, I had polyps on my bowel, don't know if that matters...my sister died five years ago with cancer of the oesophagus and they leave an indelible impression on you.

Matthew’s initial interview (COPD, oesophageal problems & feet problems, male, age: 69)

The significance of conditions was usually initially made by respondents based on judgements about the seriousness nature of the condition or on prior experiences:

Q: What's kind of, your main priority at the moment with [G.P]?...
A: Probably blood pressure, probably and cholesterol...I'm more worried about those because they are more serious things. IBS didn't kill anybody...but blood pressure is serious and cholesterol is serious so IBS has gone into the background

Natalie’s initial interviews (IBS, high cholesterol, CPD, hypertension, high blood pressure, female, age: 57)

7.3.2 Relative visibility of conditions

More visible conditions, such as breathing problems because of COPD, were more readily prioritised over conditions that did not have visible indicators, such as diabetes (also see Chapter 5). Participants with diabetes raised the fact that it was a condition which was not visible so it was not as much of a concern because it did not functionally restrict them. For the following respondent, she was initially diagnosed with epilepsy which she had described in detail about her concerns and need to rebuild her confidence in particular for routine events such as going out alone. She was later diagnosed with diabetes which she described as something that she could manage without others having to know about unlike epilepsy which was visible (Thorne, Paterson & Russell, 2003). Although she was increasingly learning about her epilepsy she had less control over it especially when it would affect her whereas for diabetes she could recognise when she needed to act, giving her a greater sense of control. As such, she viewed it as less of a priority in her daily life:

A: ...the worry is if you are on your own... if it happens... I panic about that. Sometimes I have felt myself go strange, like one day I was at the hospital and I felt myself going and I have a couple of minutes before I know it's going to come on, I mean when I first started with epilepsy I didn't get any warning it came on......but like the second time it started up I
got that sort of bit déjà as I was starting slowly as if things are slowing down before I go into it …...

Q: And is it the same with diabetes that you are kind of learning how to manage it, or is it quite different...?
A: Well it doesn’t sort of have any sort of outwards signs of diabetes does it... especially with type two, although then saying like if I've been out saying, "I need to get something, I am starting trembling."

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

Complications from medications could also bring to the fore conditions which were normally less of a priority. Throughout the interview with the following respondent, Lyn described how COPD was her main condition and IBS was something that had relatively little impact as she needed to take tablets to control it. However, when Lyn had a bad chest infection the stronger antibiotics that she had to take irritated her stomach and her IBS flared making it of greater priority than in her normal everyday experience of the condition:

No because I have never bothered, because I've always supported meself ...because it's like when I am ill, he [G.P.] will say to me, "...you will come when you are desperate don't you?" because he knows I try and deal with it meself...because I think to meself, "Oh I don't want more tablet's." Because it's like they told me the antibiotics I take, now I take them every day, because I have an infection in the bottom of me left lung all the time... All that they do is stop it flaring they ...But when I do get these chest infections I have to come off them and then go on stronger tablets ... that then starts messing with me digestion, but then I've got to put up with them pains then to get rid of the infection, so that I don't get rid of the infection.

Lyn’s initial interview (COPD & IBS, female, Age: 57)

Respondents’ descriptions depicted the changing relative significance of conditions. This was influenced by a number of factors including interactions with health professionals, medication management which changed around key transition points, or critical moments (Denzin, 1989b, also see Chapter 6).

7.3.3 Interactions with health professionals

Respondents’ accounts of management practices were viewed across conditions with links in practices and tensions made between conditions that required active choices to be made across various options. Management was not divided into separate conditions. An assumption by health professionals that their knowledge is the most valuable in terms of guiding self-management, disregards an individual’s daily experience of management
which may have a more organic approach as it incorporates a variety of information sources and personal experiences (Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011). Respondents described a process of self-management which was dynamic and variable with little separation between conditions in how they managed across conditions. This contrasted with a description of health professionals ‘sequential model’ in managing multiple conditions during consultations with limited consideration given to interactions between conditions (Bower, MacDonald, Harkness, Gask, Kendrick, Valderas et al., 2011). Respondents’ accounts of management practices depicted a more holistic approach to management where the practices involved were not divide by condition, i.e. dietary changes, such as for diabetes, needed for one condition may supplement dietary for another, such as IBS. However, if the recommended management practices between conditions conflicted this made the decision process explicit and at these points information was sought from health professionals (which was influenced by the trust developed within the relationship, see Chapter 5). However, because of these different approaches to management (i.e. sequential or holistic) this challenged participants’ established relationships as respondents sought information and management strategies across conditions but were given little or no appropriate information. Information did not necessarily translate across conditions meaning that accommodation into existing regimes was necessarily limited:

*Again, if you start to research it you come across dietary and nutrition, so that one kills all the sugars off and that kills all the fat off and the two of them just clash all the way down… You end up with you would be eating absolutely nothing except fruit and the odd slice of bread.*

Tom’s initial interview (Diabetes, high cholesterol, male, age: 52)

The degree of congruence or conflict between views of health professionals and patients regarding management priorities impacted upon subsequent management practices and therapeutic relationships. For participants who described management goals similar to their health professionals, contact reinforced and maintained priorities. Communication and negotiation were key factors in interactions with health professionals (also see Chapter 5).

*A: But basically that's what it is, but I take a lot of tablets now, every time I go and see him, "Don't give me another tablet."*  
*Q: Does your doctor actually go through different sort of things?*  
*A: He tries me on different things and what… doesn’t agree with me, he doesn't give me.*
Q: Do you feel quite comfortable talking to him about sort the different tablets and different sorts of suggestions?

A: Oh yeah...he knows that...Same as pain killers, I won't take pain killers, I only take paracetamol.

Lyn’s initial interview (COPD and IBS, Female, age 57)

However, for those whose illness management priorities conflicted with those of health professionals, established relationships were challenged. If the general practitioner was unable to provide useful information and their priorities conflicted with the patient’s this could negatively impact on engagement with management. This challenges the assumption by health professionals that they are the most valuable source of information for patients (Kendall et al., 2011) as respondents’ accounts of conflicting approaches to illness management limited the utility of information from clinicians. One participant with diabetes and chronic depression described being upset and “angry” when her G.P. told her that she “just had to have willpower” to control her diet for diabetes. However, the respondent’s priority was depression, and not being able to control her eating, which although she recognised affected her diabetes control, was something she had actively tried to change over a number of years but struggled because of it being a complex problem. When she tried to obtain information about managing both conditions “they couldn’t offer any help”. The G.P.’s response conflicted with her priorities and had a negative impact on how she would engage in managing her health.

“I mean I've got to say when the doctor, when the G.P. said it to me, I actually came home and felt er, why should I stick to this diet? Because I was depressed I felt, I've nothing to live for anyway, the diabetes will kill me anyway”

Isabella’s initial interview (Diabetes & chronic depression, female, age: 50)

7.3.4 Critical moments and their influence on multiple condition management

To manage the complexity of multiple conditions, the participants responded by not only accommodating management practices (see above) but also through adopting a process of prioritisation which changed over time. A critical moment, as defined in Chapter 6, was a phrase used to reflect the development of a critical mass of multiple factors that can accumulate, or singular events which acted as turning points (Denzin, 1989b), to cause a shift in management priorities (also see Chapter 6 for the influence of where support is sought at critical moments). This shift was based on a complex interaction of factors such as: timing between diagnoses, prior experiences, recommended self-management activities, bereavement (as discussed in Chapter 8), contact with health services, the relative severity of illnesses and flare-ups of different conditions. This was an ongoing
process and reflected the changing nature of the significance of conditions. At these transition points management activities were reordered, support and reassurance were actively sought and could influence whether individuals became overwhelmed and disengaged with illness management. Alternatively critical moments acted as an impetus for respondents to take control over their health.

The ongoing process of reprioritisation was particularly evident in tensions that arose between the various conditions’ management strategies. These arose around key transition points which shifted the relative importance of different management practices and had either a negative or positive effect on engagement with illness management. The following respondent described how weight management was his main concern as he had been unable to lose any since becoming diabetic. However, as the interview was in Autumn and as the weather was getting colder his breathing would become more of a problem and make his COPD a priority over the diabetes:

A: But it's hard I don't know...I put it down me personally to the tablet’s, whether that's putting weight on I don't know... I've been trying to look in the book the tablets like, see if there is any...sugar contents in them and reading all the effects of them like...whether there's... you put weight on and that... but not really, but just watching what I eat now...with diabetes really more than anything like... But this breathing, this COPD that's what will affect me in another few weeks when it starts getting cold; it's the cold that affects me.

Jack’s initial interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

The following respondent, who initially was diagnosed with epilepsy and had controlled it for three years, described an exacerbation as a result of the death of her father, as well as being diagnosed with diabetes and high blood pressure. She considered the loss of an important member of her social network as negatively affecting her health:

... there's been a lot of things going on, because I started with epilepsy in two thousand...I had like a cluster and then they settled down, so I was like, I was driving for three years... I had twelve months free of them and so it had been like five years, and then out of the blue I started with another cluster, but I think it’s hormonal because that started up, I started with diabetes and blood pressure ... I had gone through a period of depression because of my dad, and I put it down to like the emotional state and the strain ... with everything that was going on

Jane’s initial interview (Diabetes, epilepsy, female, age: 55)

This shift in the relative significance of conditions could also challenge participants’ existing roles in supporting significant members of their network. This was particularly evident for one participant, who in the initial interview talked about the importance of her
health in being able to babysit for her daughter. In the follow-up interviews and final interview, the participant’s narrative was of the disruption to her life and a significant effect of the breakdown of her daughter’s marriage on the respondent’s health. This represented a significant break in her normal ordering of conditions, as the associated stress in supporting her daughter led to the respondent developing a number of further health problems which she had unable to overcome (see the case of Tina in Chapter 8). This change in her health was not only influenced by what had happened to her daughter, but also in turn changed where she could access support and represented a significant transition in illness management.

7.3.5 Medication management

All respondents described the influence of medication on their management of health. Medications caused some of the greatest confusion and ambiguity around management, and within accounts medications represented an object through which participants took control or alternatively described a loss of control of their health management (Rogers et al., 2005). Medications were described as either an external event which was ‘being done to them’, that they had little control over (Makoul, Arntson & Schofield, 1995), or alternatively as an internal process whereby they gained control of their illness management by establishing routines and personalising their medication management.

I don't really know ... I am quite vigilant about taking my medication...and if I've missed it I do know that I do start feeling tired ...so I am quite compliant with me medication, but I have to take my epilepsy medication anyway ...I take me medication morning and take my medication at night, like I say I am quite complaint about that.

Jane’s initial interview (Diabetes and epilepsy, female, age 55)

However, other accounts medication use portrayed a sense of an ever increasing number of tablets, which caused confusion and increased work load that was compounded by the relationships with health professionals:

... for different ailments and that like and I've got bags of tablets there and now I've got that many tablets ...swapping and changing tablets, getting tablets from the hospital and I don’t know where I’m up to with them

Jack’s initial interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

If narratives depicted respondents being in control of the multiple conditions then management of the conditions was framed as an everyday task that could be easily completed. However, similar to Townsend et al. (2003) accounts of medicines, portrayed
as an ever increasing burden, the participants resisted being prescribed additional tablets. Medicines were described as objects and a process to which they were subject but had little direction over. Medications could be overwhelming with the addition of more tablets causing confusion as to what tablets were for and respondents described feeling of them accumulating which led to a resistance to being given more tablets:

*He (G.P) suggested taking... tablets every day... to control it, but my answer to that was... it's all right taking tablets but there is a penalty to pay for every tablet you take. There is a down side.*

Natalie’s initial interview (IBS, high cholesterol, hypertension, COPD and high blood pressure, female, age: 57)

Medications were also a point whereby change in an individual’s role in illness management could be negotiated. For respondents additional conditions acted as impetus in making them seek additional sources of information and verification around medicines. This was beyond the information that was provided by general practitioners or specialists, as they did not feel confident that the latter were aware of all medicines being taken by the individual for all conditions, or their interactions. The main sources of verification came from the internet, pharmacist and others with similar conditions. These acted as points of legitimation whereby the participants could alter their routines and were able to engage in more focused dialogue with health professionals and direct illness management. Narratives depicted a change to becoming active self-managers and taking control as respondents sought out enough information to enable them to make decisions about medications:

*I asked the pharmacy yesterday, I rang them up, cos I’m taking so many different drugs, you’ve gotta be careful. And they were saying, I was saying could you take them at the same time, cos you’re supposed to take these with food but you can’t take ‘em all with food... Well, I could’ve asked the pharmacy...the pharmacist at [local hospital], forgot about it, cos you don’t think of all these... there’s one or two more,... you’ve gotta keep a track*

Adrian’s initial interview (Diabetes, rheumatoid arthritis, high blood pressure, male, age: 82)

### 7.4 Understanding of conditions

Managing multiple conditions required the respondents to interpret the various conditions present and relate information that had been received from different individuals. This directly influenced how practices were engaged with and where and how much information and support was sought. For respondents there was uncertainty over which
condition was causing which symptoms, with individuals dealing with uncertain or ambiguous feelings of ill-health by relating back to their self-defined priority condition. Members of an individual’s social network played an important role in supporting an individual through their own experiences but information was rated on its quality and relevance, impacting on whether they would be sought out in future for guidance.

7.4.1 Accessing information resources

The type of information that respondents were given, as well as existing knowledge of their conditions gained from families or the media also played an important role in condition management (Kendall et al., 2011). Furthermore, these sources of information influenced the prioritisation of management practices in the presence of multiple conditions. The following respondent was initially diagnosed with diabetes and then had a heart bypass, which he described as something that he had and then could return to work; however, after the operation his diabetes ‘kicked-in’ and became the main priority. He described how he knew very little about diabetes, comparing it to cancer:

Q: Did you know much about diabetes then?
A: Nothing at all.
Q: You hadn't known anyone with it or anything?
A: No, well it was what? It was a bit like cancer at one time; nobody spoke about it... I was a diabetic... I mean, like in ninety-four it's what nearly...I think it's come a lot more to the forefront that what it ever was at the time...the first person I'd really heard about being a diabetic was Mario Lanza ... the singer, the famous opera singer at the time... he killed himself by over eating chocolate as he was a diabetic... thought, mmm... you can't do anything when you're a diabetic type of thing. So, no, I didn't know none of my family that I knew of was diabetic or anything like that.

Zac’s initial interview (Diabetes, heart bypass & ulcers on bottom of feet male, age: 65)

Information was described as conflicting by respondents, in particular about diet, and did not necessarily translate across conditions or fit within pre-existing regimes. Advice would then be considered generic and of little relevance to them as individuals (this was particularly evident with interactions with health care professionals, see section 7.3.1). This represented a key transition point whereby links made across conditions supported participants in making changes, but when this did not occur it led to confusion. Health care professionals did not always consider the impact of other conditions on the information they were giving to patients. If information given was conflicting, the respondents were left to navigate the most appropriate course of action or seek further information by making additional appointments.
Well she [practice nurse] gave me... information on diet which you could read in any woman’s magazine, there was nothing specific. I did say to her that my problem was binge eating and she had nothing to offer at all. She could not comment...she knew nothing about it, so she wasn't able to help... it was a complete and utter waste of time.

Isabella’s initial interview (Diabetes & chronic depression, female, age: 50)

Existing knowledge and direct experience of conditions from other sources played a role in patients’ illness prioritisation and interpretation of information. The participants described integrating information from a number of sources, which could be contradictory and lead to confusion and a need to seek clarification from alternative sources, such as pharmacists. This downwards delegation of responsibility for care coordination, which traditionally would have been a role of the G.P., changed the patient’s role and increased the disruptive effect of additional conditions. Thus, information and advice given had to be re-interpreted and verified to be useable. For all participants, based on the significance they placed on their conditions and the appropriateness of information they could obtain, pragmatic routines that fitted within existing work roles were developed.

7.4.2 Information on exercise

Exercise was considered an important part of self-management by participants although this was not realistic because of limitations, such as tiredness or mobility restrictions caused by other conditions. When conditions placed a physical limitation on an individual, this was talked about as having the greatest impact on their lives and caused tension between which self-care activities they should prioritise. Physical limitations would have a greater impact on certain types of illness work, as they would restrict daily activities, such as going to the local shopping centre or G.P. surgery:

A: Breathing. Um, only that I can't do the things I used to, but whether that's breathing or whether that's old age I'm not sure. In truth, I suppose I used to walk up to [town centre], now I get a taxi...Or somebody takes me, but seventy per cent of that is because of my feet, maybe thirty per cent [because of COPD]. If my feet were fine, I'd still walk up to [town].

Matthew’s initial interview (COPD, oesophageal problems & feet problems, male, age: 69)

Restrictions by one condition limited the ability of individuals to engage in recommended practices for other conditions. This could be exacerbated by other events occurring in respondents’ lives. The following respondent described how he had previously been a member of gym but had stopped when his wife had become terminally ill. He now wanted to return as it was a good place for meeting other people, as he had limited opportunities
to do so in his daily life, and was important as he described increasingly feeling isolated, but problems with breathing and arthritis stopped him:

...and then I re-joined [gym] again last year, and I've not been well and I left it again... They just sent me a thing the other day about rejoining again, they do all different um, there's swimming, and a sauna and Jacuzzi and everything like that, there's a lot of people, and you get it cheaper being over sixty.... but then I was having this trouble with me breathing and trouble with this arthritis and just down I just couldn’t draw myself to going

Jack’s initial interview (Diabetes, high blood pressure, high cholesterol, male, age: 65)

Limitations of conditions could lead to individuals becoming isolated from existing contacts, which could lead to further social exclusions and reductions to normal daily routines such as shopping or going to the gym. Restrictions could accumulate and presented themselves as further problems, which influenced what could be attempted and the relative significance of management practices.

7.5 Summary

In this chapter I have shown that multiple conditions recursively influences resources available through an individual’s social network, as well as impacts on the priorities of illness management. This is not a linear process: rather, social networks influence illness management and vice versa. Chronic illness management priorities changed over time. The findings presented in this chapter indicate that specifically social networks impacted on multiple condition management by influencing the relative meaning of multiple conditions. These in turn, were found to shape individual prioritisation of management practices (e.g. diet control, exercise) and the extent to which they were engaged. In particular, social network members impacted on condition management prioritisation through their experiences, personal accounts and information provided which shaped the accommodation or disengagement of these practices. This was particularly evident when information provided by clinicians about a condition conflicted with the individual’s bodily experience of the illnesses (e.g. being recommended to increase exercise to help control diabetes when they had knee problems that restricted movement). Social network members provided clarification and in some cases, identified links across management of multiple conditions leading to better control and management (e.g. through reducing ambiguity about medication interactions which increases concordance with medication management). Conversely, social network members did sometimes undermine self-management by creating confusion via conflicting information for multiple conditions. Social networks could also have a negative impact on management due to the reciprocal nature of support. If network members experienced problems, respondents’ accounts
depicted this placing an additional emotional burden on them (such as one participant’s daughter getting divorced) that created a stressful environment which threatened engagement with management and was further amplified in the presence of multiple conditions. Respondents reflected a more integrated stance in their illness management at key transition points health priorities shifted and was influenced by health care providers as well as partners, family and friends through a process of information and support provision. However, this is not necessarily positive because negative events occurring to significant members of the social networks can negatively influence an individual’s health. This is further heightened in the presence of multiple conditions. It is through the links made across management practices from one condition to additional conditions that the disruptive effect of multiple conditions can be reduced. In particular, health professionals can play an important role in facilitating this and, as I examined in the previous chapter, the interpersonal nature of relationships developed with clinicians as individuals could be challenged. Yet health care professionals utilise a ‘sequential’ model when addressing multiple conditions in consultations (Bower et al., 2011), which maintains separation between conditions that do not facilitate discussion of such links in management. This is important for the coordination of care, as individuals’ management priorities are a balance of personal experience, the recursive relationship with health care providers and other priorities in life, which impact on the roles an individual can adopt and the degree to which self-management practices will be engaged with.

A shortened version of this chapter was published in Chronic Illness (Morris, Sanders, Kennedy & Rogers, 2011). A copy of the paper can be found in Appendix 12.

In the next chapter I will examine the reciprocal effect of the changing nature of social networks and health status over the period of the study.
Chapter 8

Changing networks, changing health management

In this chapter I will focus on the changing nature of social networks alongside changes in health status over time. By examining the participants’ accounts over the one year period of the study, I will explore the influence that breaking or losing valued network ties, or establishing or reconnecting network ties, have on health management. Finally, I will explore whether these direct changes have a subsequent reassessment on the value and meaning of the remaining network members.

8.1 Introduction

The processes of illness management change over time. Some changes may be subtle whereas others may be more evident, highlighting the need for a longer temporal perspective (Corbin & Strauss, 1985). Corbin and Strauss (1985) identified that even small changes in everyday routines can have important influence on trajectory management. Furthermore, Kahn and Antonucci (1986) proposed a convoy model of social relations which highlights the role of close social relationships across the life span as personal and situational characteristics change the nature of social relationships (for further detail see Chapter 3.5.2). Lawton, Peel, Parry and Douglas (2008) examined the fluidity or stability of diabetes causation accounts overtime and how these accounts were implicated in negotiation and legitimisation of the choice of lifestyle and treatment practices. However, these choices do not occur in isolation and are reciprocally influenced by social network members. Social networks are comprised of a complex interplay between a variety of network members who provide access to a range of support and information, as well as potentially connecting individuals to people outside their personal network. Similarly, Pescosolido (1991, 2006, 2011) proposed a Network Episode model which had two core characteristics: firstly, that the illness career was dynamic and secondly that social networks had a role in shaping health care outcomes (for further detail of the model see Chapter 3.5.2). In this chapter by exploring the change in network structure over a year period through using case studies, I will demonstrate how changes in network structures and changes in health can be mutually influential. This reciprocal influence of social networks on health has remained an under explored element in considering health as a social process. Change in network membership may have wider ranging effects than
simply the loss, or reestablishment, of a dyadic relationship as it can prompt the reassessment of trust and meaning of existing relationships. In other chapters this changing role has been highlighted, for instance in Chapter 5 the ongoing influence of types of relationships in specific contexts and the influence this broadly has on the degree of engagement with management practices. Further, in Chapter 6 and 7 the influence of the types of networks was explored to demonstrate how individuals adapt to changes in circumstances and health through seeking information and resources from different network members. Support was sought through processes of substitution and supplementation across the network and was highlighted around critical moments that lead to participants depicting a re-evaluation of available support. As discussed in Chapter 3, the help available from network members varies over time and support can be sought from a range of ties (Plickert et al., 2007). Further in this chapter, I will demonstrate that for some participants, despite changes in health or social networks, the meaning of management remains either unchanged or insignificantly so. This is not meant to imply discrete, static categories; rather, it should be considered on a continuum whereby individuals can fluidly adapt over time as their illnesses flare-up or become problematic. Progression of their illness trajectory was not linear and was influenced by factors, such as clinical or contextual factors, including their social networks. Certain members of the network were more important at certain times and changes were found to influence how respondents managed their condition and whether or not they sought other sources of support (Perry & Pescosolido, 2010). Throughout the previous chapters in this thesis, the accounts have depicted this change in relationships and health management. In this chapter, I will highlight how changes in individual relationships can have a wider effect on the way that support was sought throughout the social networks and the influence of health.

8.2 Positive change to health management

Positive changes in health management identified in the respondents’ narratives were noted for six participants. Corbin and Strauss (1985) proposed that the conditions and context in which illness management occurred are in a constant state of flux which placed increased pressure on the limited resources an individual has available in order to complete a variety of everyday and illness related tasks. The participants described changes to factors which had inhibited their management and valued social roles such as ‘being a worker’ that had a positive influence on their health management. They described how deteriorating health meant they reached a critical moment prompting action in terms
of self-management and utilisation of resources within the network which improved their health management (see Chapter 6 for a discussion of the role of critical moments in condition management). Alternatively, the reconnection of broken ties with former network members provided access to further support and resources. Firstly, the reconnection of broken ties will be explored using a case study. Secondly, the dynamic reciprocal relationship between family members, health professionals and the respondents’ self-management will be examined.

The data indicated that breaking of close ties through life events such as divorce and death caused distress and a re-evaluation of valued social roles, such as ‘being a parent’ or ‘being a friend’. Conversely, reconnecting with valued network members through redefining and reframing expectations of the relationship can have a positive effect on health (also see Chapter 6 for the description of Don on reconnecting with his daughter and grandson). For the following participant, Leo, who had IBS, in the initial interview he described being able to talk to ‘my close family like my parents, not anybody else really’. The ending of Leo’s marriage and breaking of the tie with his wife, Dawn, through the divorce was good for his health because he identified the relationship as a source of stress which exacerbated his symptoms. Over the course of the study, Leo described his relationship becoming increasingly more amicable. In the final interview the importance of re-establishing a relationship with Dawn, which involved redefining the meaning, roles, expectations and resources that were available from each other had resulted in a level of trust where he placed his ex-wife in the most important category (see fig 8.1) and he would seek her advice about health concerns before going to the G.P

Q: Okay. So who then would be the most important to you in terms of your health?
A: ... probably Dawn. I'd probably talk to her about something before I went to see... see the doctor... probably Dawn.
Q: Do you have a good relationship with her now?
A: Yeah...
Q: So would you feel that you could bring up anything with her?
A: Yeah...
Q: And why would you talk to her before, say, the doctor?
A: ...well she's a nurse...for, what, twenty odd years...as long as we were married for... probably for that reason. I know there's the fact that we've know each other for the best part of thirty odd years...
Q: ...she knows you really well...
A: Yeah...
Q: ... would you have ever of spoken to her about IBS?
A: ...probably after it was diagnosed, because the lead up to it being diagnosed was, sort of, the breakdown of the marriage...obviously we weren't talking about things that are, well, not about health issues at that time, so...
Q: How did, so did that make it harder, sort of, if you couldn't talk, obviously she's the main person you talked to...if you haven't got her to talk to, whom would you talk to instead?
A: Probably my mum, or either my mum or the doctor then.
Q: ... who did you talk to?
A: .. it would have been the doctor...
Q: Okay, so what's changed? Why have you not had to take it?
A: ...it's probably just the fact that it's under control now...bit less stressed probably as well...
Q: Because everything's settled down with...the divorce.

Leo’s final interview (IBS, male, age: 51)

Positive changes to health management were also reinforced by key network members and enhanced engagement with self-management. This shift in the framing and engagement of management was preceded by an event which acted as a tipping point (Denzin, 1989b) to this change. For example, the following respondent, Lyn, described in the first interview that she was increasingly being restricted by multiple conditions, and especially COPD because she suffered from ongoing chest infections.
Figure 8.1 The personal health related social network of Leo

Key:
- Size of circle for each network member represents the distance they live away from the participant:
  - Co-habiting
  - Short walk/drive away
  - Up to 1 hour away
  - Over 1 hour away

- Lines in black represent the amount of contact the participant has with network member:
  - Unknown
  - Less often than every couple of months (e)
  - At least once every couple of months (d)
  - At least once a month (c)
  - At least once a week (b)
  - Daily (a)

- Blue line represents:
  - Network member connection defined by ego
Although over the course of the year Lyn’s health had deteriorated, indicated by markers such as the number of medications she was taking, in the initial interview she took seven tablets daily and by the final interview she was taking fourteen tablets. However, how she framed her conditions and her wellbeing had changed. In the final interview due to a number of infections Lyn’s health had deteriorated, however, she described increasing family support and the role of the G.P. in acting as a bridge to refer her to a nutritionist. This connection to the nutritionist had improved her quality of life through dietary changes and Lyn was more engaged with managing her conditions although she did not see improvements in her health, such as a reduction of tablets. In the final interview the participant recalled using a PRISMS form (see appendix 7) which was a tool developed by the WISE team to enable patients and clinicians to discuss appropriate self-care support during consultations. Although twenty five respondents did not recall having used the form with their G.P., for this participant using the tool had enabled her to address ongoing health problems which were not condition specific, such as increased tiredness which had become normalised (as defined in Chapter 2 as: the incorporation of illness into a patient’s life so as to become ‘normal’ (Bury, 2001)) over several years. This enabled the G.P. to identify that he should refer her to a nutritionist. The introduction of this form coincided with the participant being so tired and lacking energy that she believed she was going to die and this critical realisation acted as a tipping point (Denzin, 1989b) to make her seek help and the tool enabled her to act on this.

A: ..I filled in what I could...like sleep problems, well I always have, I’ve always had big sleep problems... support from the family, yeah I get, I get plenty of support...
Q: and for the things that it was a problem did this help you sort of start talk, bringing up things with the doctor?
A: yeah this is when I said to him I’m going to get myself motivated... get myself cracking, I don’t, I, I kept saying I’ll die in the chair if I carry on that cause that’s what I’m saying
Q: so this sort of helped ...  
A: yeah because that’s what he said, that’s what he’s doin tests for cause this tiredness but it can be due to the cal-, the calories that I’m burning away... that makes you, that can make you tired and all
Q: oh okay so this sort of prompted that discussion
A: yeah

Lyn’s final interview (COPD and IBS, Female, age 57)
Figure 8.2: The personal health-related social network of Lyn

KEY
Size of circle for each network member represents the distance they live away from the participant:
- Co-habiting
- Short walk/drive away
- Up to 1 hour away
- Over 1 hour away

Lines in black represent the amount of contact the participant has with network members:
- Unknown
- Less often than every couple of months (a)
- At least once every couple of months (d)
- At least once a month (c)
- At least once a week (b)
- Daily (a)

Blue line represents:
- Network member connection defined by ego
The dietary changes recommended by the nutritionist were supported by her husband and son through buying higher calorie food and encouraging her to eat, which reinforced the message from the nutritionist and her own actions. This was in contrast to the first interview where her account depicted an increasingly negative framing of her ability to manage the condition as she was increasingly becoming weaker from multiple chest infections (for a further discussion of the impact of multiple conditions on management see Chapter 7).

A: ... there's only me and my husband here now and he likes entirely different stuff than me. But he always make sure I've got what I like in...Because he said he can put a tin of beans on a piece of toast, he's not bothered...he always makes sure he gets my pies for so many days or my quiches in the freezer...Now if our (son's name) down or ... the kids are down at the weekend with me, I'll have a pizza with them...So he said to me, 'That's fine. More pastries the better off you are going to be'. And like I eat digestive biscuits so she said 'Every time you have a cup of tea, have one or two digestives'. Because what she said 'You are doing with the breathing I am now, even when I'm asleep, with my breathing heavy, it's burning my calories off...more than what I am putting in. So she wants me to put a few more calories in my body ready for when I'm asleep and stuff like that, that they are there to burn off and there's not next to none to burn off...she said, 'That's what's doing it, it's burning your calories off, the breathing now, the way you are breathing it's fighting and it's burning the calories off your body'. So I said 'Fine'. So I've tried to do that. Piece of toast in the morning with jam on and stuff like that. Well I like anything like that.

Lyn’s final interview (COPD and IBS, Female, age 57)

Lyn was able to implement the recommendations made by her G.P. to increase movement in order to reduce the progression of arthritis and COPD through the provision of resources from different family members. For example, Lyn received a Nintendo Wii from her son and a Wii fit board from her daughter which her grandchildren encouraged her to use it. All of this was also reinforced by the meaning attributed to being an active grandparent. This was in contrast to during the previous year, where Lyn described lying on the sofa and believing that she was going to die. The PRISMS form acted as an initial prompt to the discussion with her G.P. about these general symptoms of tiredness which were not condition specific but were restricting her quality of life. The recommendations made by the G.P. and nutritionist were then maintained by the ongoing familial support, which reinforced her motivation and engagement with management practices. The changes in health discussion led Lyn making changes to her management with the support of her family members, which in turn continued to improve her health and reduce her symptoms.
A: Yes. Because I'm finding out now that if I'm not doing anything, I have a lot of arthritis now, so my knees are locking, my feet are swelling a lot... But my doctor said that it's due to my condition [arthritis] now... All this breathing is connected with that'. So I've just got to get used to it. But if I start doing more and getting a bit more active... sitting in the chair, keep telling him that thingy, because I need to start, I don't mean going ballistic... I mean my son, my husband bought me, a Wii because you see these old folks home, ... I nearly had a heart break by the time I'd finished with this thing...

Q: So, have you been using the Wii?
A: ...Only when the kids have been here.

Q: How have you been finding it? What sort of things have you been doing on it?...
A: Yes, the sports one with the hand thing... So, they decided, clever lass here, buy me this Wii Fit Board. 'Well you kept saying you wanted a Wii Fit Board, you wanted to do this skating'. I said 'I was only pulling your leg'. And he said 'It will be alright to do it Mum but don't try the yoga'. So anyway, we got this Wii Fit Board, I've not been on it yet.

Once I've been on it on the skate... Anyway I'm watching them but I said, 'You show me and I'll watch it and then our lass said 'We've got this little dance Nana'. Which I can't do it as fast as them. So yes, I do have a go with it with them... just with my grandson and my granddaughter... Because it's funny. And I end up sitting on the bed. But it's getting me motivated again whereas for months I was just... not wanting to do anything. I was coming down the stairs two or three or four in the morning, taking me nebuliser and that was it, I wanted my puffer again. And then I went through a bad spell for over a week. I don't know what was wrong. But I didn't go, I'm terrible for not going to the doctors... I didn't literally know what I was doing. My husband was up and down all night with me... I couldn't lift my head up, I couldn't keep awake. He was giving me my tablets and then finding them on the floor. I wasn't taking them. I just didn't know, I didn't even know what day it was... he was taking me to the toilet, everything.

Lyn’s final interview (COPD and IBS, Female, age 57)

8.3 Negative changes to health management

Negative changes to health management over the course of the study were a characteristic of nine respondents’ accounts. This was particularly evident around major events linked either directly or indirectly to health, such as a heart attack, which caused a reassessment of roles and expectations of support. In the previous chapters the effect of changes on individual relationships was explored. Previous studies have shown that in response to decreasing health, the size of the network remains approximately the same but the amount of support provided by the network members increases (Wenger, 1990; Miller & McFall, 1991; Stoller & Pugliesi, 1991). For instance participant Jack identified how his relationship had changed with his brother as a result of him staying with him soon after the participant had had a heart attack. Yet the loss of key network members subsequently influenced the expectations of remaining network members and caused a shift in the reciprocal roles and responsibilities in response to these changing circumstances, which in turn could affect where the respondents could seek support. The following participant,
Catherine, initially identified her parents as her most important source of support for information and advice. In the first interview she described being comfortable managing her IBS, which was exacerbated in response to conflict with her ex-husband.

Q: Who would you say that you spoke to most about when you are upset and it has been kind of not a good day?
A: Probably my mum. Mum and dad.
Q: And do they, what do they kind of say to you or what kind of support do they, do they ...?
A: ...They are great. They don’t really say, they try and advise... ‘Make sure you have some vegetables.’ ... But yeah, my parents are like the most consistent people in my life really, so I speak to them, and they can always tell, cos they’ve seen it for thirty six years, they can always tell when I’ve not been to the loo...

Catherine’s initial interview (female, IBS, occipital neuralgia, reoccurring cystitis, age: 36)

However, over the course of the study, firstly Catherine’s brother died and subsequently her father died a few months later. Increasingly during the telephone follow-ups she described a series of illnesses which she linked to having not looked after herself through these periods of bereavement. The impact of these losses was relative, as Catherine had a close relationship with her father and would call on him for support. Conversely, the loss of her brother, John, whilst traumatic, was more expected because he had had a series of serious health problems. This had less impact on her health management as she had not sought support from him:

Q: ...is there anybody there that's not there that maybe makes it harder for you to manage your health?
A:...My dad should be next to me mum really because I could speak to him about anything. ... I wouldn't say my brother because we were never...never very close. I mean, I could talk to him but he had his own problems, but my dad, he was just one person that I could phone up and talk to about anything. And I wouldn't necessarily... get the answer I wanted...sometimes I kind of, felt that he was watching TV past me, but just the fact that he was there...he was so reassuring to me... since John died and since my dad died I've been ill about four times, not just irritable bowel, that comes and goes all the time. I can't even tell you when irritable bowel starts I had; last weekend I didn't go to the toilet all weekend...and the weekend before I didn't, so I can't...

Catherine’s final interview (female, IBS, occipital neuralgia, reoccurring cystitis, age: 36)
Figure 8.3 The personal health related social network of Catherine.
Changing roles also impacted on the availability of support, as well as altering responsibilities following the loss of key network members. With the loss of her father, Catherine described increasingly taking on responsibility such as shopping for her mother, as she was grieving for the loss of her husband. As well as more generally making sure her mother was well, which previously would have been her father’s role, tensions developed in their relationship:

A: ... I would talk to Sam, um, like I say, I would probably talk to um, any of them in the middle circle...I would talk to me mum, but my mum's not very in tune with like younger people's problems...because her problems were completely different when she was young... we've probably got closer in the fact that... I do feel that I need to go and make sure she's okay, because I would never forgive myself if I didn't and something happened...I do take a lot of her stresses on, like I will sort all the paperwork out for her... I do get very frustrated by her because she's kind of, given up as in she feels like she can't even get on a bus now, and if I'm not there to take her anywhere she doesn't go and she'll go without bread or milk, she has only just started walking to the; she's not in very good health and she has only just started walking to the shop herself, but then it kind of, I get told how tired she feels and how ill she feels. So it's in some ways it's changed for the better because I'm more responsible for her now, but in some ways it's definitely not, because obviously we are both got our own grief over my dad...  
Catherine’s final interview (female, IBS, occipital neuralgia, reoccurring cystitis, age: 36)

The loss of her father and brother made Catherine re-evaluate the support that she had available through her network. She described ‘I don’t have friends that I just phone’. Instead she identified that her friendships were not based on a reciprocal level of support through her friends’ actions around the loss of her brother and father.

A: It's sad because my cousin, who is in the outer circle is a nurse and she's lovely but she is very wrapped up in her own life, whereas I think I'm here for anyone...like no one comes here, no one visits... if I didn't have Sam I would have no one... Like my friend Mary I've known for thirty-seven years, we were born together literally, her parents are; their house is adjoined to my mum's, so we have grown up from being eggs...and Mary is very, very wrapped up in her own life...They don't have the time. Mary is getting married to a Turkish guy in March and it is all going horribly wrong...I phone her like every other day and make sure she is okay, ‘Have you heard anything?’ But when my brother died ... she didn't really get on with John but she grew up with him, and I am still waiting for my visit...She never came. I mean, she's been since for Christmas, she called for an hour with her partner ... but I still never got that visit over John, and then when she came round over me dad she sat and talked about her partner.  
Q: Not about your dad or how you were?  
A: Not once, no. ...But she's there because we've got the length of time between us... Vera is someone I have known since about '96. Very self-indulgent... never saw her ... through my two bereavements... and then recently; I am putting a bad light on her mean she is lovely or else I wouldn't be friends with her, but she's put me through it over the years...she's fallen out with me for things that she's done...But I am quite a tolerant
person...I sound really bitter, I know I do and probably am now I'm talking about it... the difference is that I would always be there for them, do you know, what I mean and I can't say that about anyone else...It's helped me, because you know what, I've got Same now and you know, I look after me mum I'm always there for her and me daughter, and to be honest it's made me concentrate a lot on me now because I was always there for them... I've got to admit that maybe the likes of Vera and Mary have got me so riled in the past that it has made me ill...I've been to the point where I've been having conversations with myself... what I'm going to say to her. I never do because I am so non-confrontational, but... like they've upset me that much in the past...

Catherine’s final interview (female, IBS, occipital neuralgia, reoccurring cystitis, age: 36)

8.4 Health management stayed the same

Eleven respondents described their health management and social networks in relatively stable terms. For some participants this meant there was little or no reported change to their health or social network over the year. This did not mean that there were no health problems or changes in their health, but rather it did not cause disruption (as described in Chapter 2) to their ongoing management as changes were concordant with how existing practices or health was framed. Furthermore, this stability was reflected in the way in which the key social network members responded through maintaining and consolidating links, despite changing health circumstances. These accounts closely resonated with the Shifting Perspective model of chronic illness (Paterson, 2003), whereby people living with chronic illness placed in the foreground wellness or illness depending on the circumstances. When the respondents’ narratives depicted health management as staying the same, it was depicted in terms of illness in the background, with other everyday priorities being in the foreground. These respondents had learnt to manage their condition and normalise practices into their everyday lives and during the study the way they framed their condition had not been threatened or existing notions of management challenged.

...I know that if you spoke to them they would help... I'm sure they would, but I get on with it and I'm a practical person, I just, this is what I've got and you get on with it and get on with it...

Chris’s final interview (Diabetes, Male, Age: 65)
Figure 8.4 The personal health related social network of Chris
The following respondent, Donna, is an example of how changes in health, through a knee problem, stopped her from working for 6 months, led to a reconstruction of her narrative (Williams, 1984). In the initial interview, Donna described how she had normalised her management into her everyday routines through support mainly from her partner, close friends and people from work. In particular, from work she could seek practical advice and with weight loss and described it as ‘we’re all part of a team...extended family outside I’m with the girls at work longer than I’m with my family’. She was confident managing the diabetes through diet and exercise.

A: …No, I'm fine... I get on with it I'm not one of these that takes to me bed... I just carry on with my day-to-day life it's not changed any, I just carry on...I've not made a big deal of it at all so...after the initial diagnosis, I just got on with it; did what I had to do...when I was on purely dietary, I was very, very strict with myself as to what I ate and what I didn't...I lost quite a bit of weight overnight, this obviously an indicator of the diabetes when I actually kept that weight off for maybe three years, four years... ...I upped me exercise, I mean, I'm fairly active person anyway, I'm on my feet anyway, I have the dogs, I walk the dogs, we walk at weekends... I'm not one for organised sport or anything like this, I go out and dig the garden, for me I like an end result...I clean the house; I don't go to a gym or anything like this, but I am fairly healthy...
Donna’s initial interview (diabetes, high blood pressure, high cholesterol, Female, age: 54)

In the final interview, Donna’s narrative of where she could seek support and how she framed health management remained very similar. Her main source of support remained her partner, work colleagues and close friends despite having to have knee surgery and being bed-bound for six months.

...I tend to cope with myself. I don't talk about my health really. It's Peter mainly, and Doris... and the girls at work. If I see Grace and Betty, we're out socially...so I'm not going to talk about my illnesses socially, and that's probably it...It doesn't embarrass me in any way...I am what I am and that's it; take it, take it or leave it. It's an illness, I didn't ask for it, I was... it's not anything that I've done that's give it me, so consequently I don't have any... any thoughts about it... If I needed to speak to somebody about it, I would do...but on day-to-day support, it's your friends and family...we don't take life too seriously... no, if, if I'm down, he puts me up again, and vice versa. ... Doris will give me practical advice...the others, the others are just aware and, and don't let me do anything daft...they're all, they're all aware and they all... sort of, keep an eye on me...That's as far as it goes, really. It's not a major deal; it's not a big part of my life. I just carry on and do it...Just get on with it...
Donna’s final interview (diabetes, high blood pressure, high cholesterol, Female, age: 54)

Despite the change in accessing support from Donna’s work colleagues, who she described as her ‘extended family’, she was able to manage the emotional effect of the injury through the adaptability of the network members and the reciprocal value of their
relationships. Also, in the first interview Donna had talked about the effort that she had put in to losing weight and now, despite having put weight on, she did not see this as a reason to give up but something which she could overcome to get back to her normal management.

A: I've got to go and have a new knee... I've had a very strange year...I was walking, I, I've had arthritis for many years... I took the dogs for a walk, I fell over a brick... about a month later... I was upstairs and I was just leaning against the wall, looking at the computer...and I couldn't move it. So I was actually off work for six months, flat on my back...it ended up being a piece of floating cartilage that had stuck in a nerve...So, I went in, in June... had it taken out and my knee cleaned out...it was crumbling away and I needed a new one...So, that's all, that's all gone on in the twelve months... Q: So how did you find that, I mean, being off work for six months?... A: It drove me batty... they actually all kept in touch from work. They came on a regular basis to see me...I had 'phone calls; I was doing bits and pieces over the 'phone... everybody else...was good... I just was on crutches for a bit, just pottered about, and all I did was watch telly. So I was very bored. And I did, I have put weight on, for the simple reason that I can't exercise at the moment... the minute that I do, I will join a gym and shift it, but I can't do anything 'til it's done...it's not affected my diabetes in any way, other than the fact that I probably ate a bit more...I don't think I've eaten a bit more actually. Donna’s final interview (Diabetes, high blood pressure, high cholesterol, Female, age: 54)
Figure 8.5 The personal health related social network of Donna

Key:
- Size of circle for each network member represents the distance they live away from the participant:
  - Co-habiting
  - Short walk/drive away
  - Up to 1 hour away
  - Over 1 hour away

Lines in black represent the amount of contact the participant has with network members:
- Unknown
- Less often than every couple of months (a)
- At least once every couple of months (d)
- At least once a month (c)
- At least once a week (b)
- Daily (a)

Blue line represents:
- Network member connection defined by ego
8.5 Summary

In this chapter I have demonstrated that the social networks implicated in the management of long term conditions change over time and can be considered to exist on a continuum between positive and negative reciprocal influences with health management. There is an ongoing process of breaking or reconnection of ties within social networks which shaped the context of health management and the degree of individual engagement. In this chapter, I have demonstrated how changes in dyadic relationships can reciprocally influence the broader social network and where support and resources are sought which influences health management. Certain members of the network are more important at certain times and this change is not necessarily directly related to health but may be related to respondents’ roles and responsibilities which influences the degree that management may be engaged with. Conversely, changes in health may challenge assumptions about the nature of relationships and expectations of resource and support provision.
Chapter 9

Discussion

In the discussion chapter of this thesis I will firstly summarise the findings of this study and interpret them with reference to the associated literature. I will examine the implications of this study and relate them to future self-care policy. Finally, I will identify the limitations of this study and propose suggestions for future research.

9.1 Introduction

The context in which health management occurs involves embedding illness practices, such as medication management and diet control, into everyday settings through ongoing processes of negotiation and prioritisation. The empirical literature on self-management has emphasised the influence of personal factors whilst the broader ecological context in which it occurs has remained underexplored (Gallant et al., 2007). This thesis has empirically examined the social networks implicated in long term condition management and identified the positive and negative contextual factors which influence self-management and how this changes overtime. This also has implications in the wider social network literature as it challenges the presumption that as individuals age the size of the social networks decreased, for instance through retirement, illness and death network members (Pescosolido & Levy, 2002). Rather, respondents’ accounts across the range of ages of participants showed processes of breaking, reconnecting and establishing new ties with network members. Respondents depicted selectivity seeking support and resources from a smaller, functional network within the social network yet there was flexibility in this process if they were unable to get the support they needed from those sources. Furthermore, for respondents who depicted a larger social network this could increase their work load, such as keeping in contact or providing support to their friends, which could have a detrimental effect on their ability to manage their condition. This further has implications in considering the relevance of measuring social networks quantitatively, as relationships were complex, often with both positive and negative components, and the size of the network did not necessarily relate to its ability to provide support.

Self-care has been central to UK policy to support people with long term conditions (as discussed in Chapter 1). This individualistic approach has been maintained within self-management policies (as discussed in Chapter 2). Piette (2010) argued they necessarily
need to acknowledge the role of the family and broader social networks involved with care in an attempt to address the limitations of the existing individualistic approach. This thesis has addressed the limited individualistic focus of many self-management studies and interventions (Piette, 2010; Rogers, 2009) by identifying: firstly, what constitutes a network for individuals with a long term condition, which has not previously been empirically explored; secondly, the meaning of these relationships relative to other network members was examined; and thirdly, the social network has been examined as a unit to identify types of support identified and valued by individual’s. Additionally, this study has revealed the role of multiple conditions as placing an additional layer of complexity within a context of limited resources that challenges existing relationships. Finally, throughout the study narratives change over time was depicted as influencing understanding of, and engagement with, management practices.

This study has responded to gaps in the existing literature on illness experience and management (as stated in the conclusion of Chapter 3) by taking a more socialised perspective that considers how social networks influence orientation to management. This moves beyond existing research by examining the specific processes of support and resource provision, highlighting its complex and reciprocal interaction on influencing management. It demonstrates the variety of relationships and the work that those individuals actually do which is implicated in long term condition management and highlights the direct and indirect influences over management engagement.

This study has added to the knowledge of the broader research community on social networks and long term condition management. In particular, much of the literature on social networks has focused on the decline in the size of social networks as individuals age, yet this study has demonstrated that the size of social networks fluctuate over time and the processes of breaking and reconnecting of network ties occurs over the life course which influences access and provision of resources (both for illness management and everyday life).

Furthermore, this study has challenged the existing assumption of the individual focus of formal self-management support programs which have been the focus of commissioning and provision of services. By examining the types of social networks that individuals with long term condition management use, the study adds detailed insights regarding who helps with various aspects of illness management, from the minor and mundane tasks of
everyday management, to the major events (such as a hospital admission). Whilst many assumptions have been made regarding the influence of families on self-management support, this has rarely been investigated empirically. The current study has enabled insight into the negative as well as positive aspects of support and how these might change over time in relation to different members of individual networks. In turn, this study demonstrates that this approach can help to consider why certain people respond well to formal education programmes and others do not. Future commissioning needs to recognise the roles of network members and the potential of local voluntary and community groups for providing a range of services which could more appropriately reflect a more socialised perspective of illness management. The results have implications for the commissioning of services that are responsive to existing networks and help to move beyond an individualistic focus on long-term condition management.

Specifically, the overarching research question this study addressed was:

“How do lay and professional networks interact to influence self-management and use of health services for individuals with long term conditions?”

The interaction of lay and professional networks varies across respondents and influences management through a variety of pathways. By breaking down broad categories, such as ‘family’, into more discrete components, such as parents or children, this study demonstrates a spectrum of the types and amount of support available which varied over time within relationships (as shown in Chapters 5 and 8). In these chapters I have demonstrated that relationships could substitute or complement resources from a variety of network members to support health management and influence the utilisation of services. These relationships influence the extent to which management practices could be embedded within everyday experiences. This was an ongoing process of negotiation of management practices within everyday routines, and the respondents’ accounts depicted a continuum of relative influence of the variety of different network members. In Chapter 6, I identified three types of networks (the family focused network, the friend focused network, and the health care professional focused network) which reflected the interaction of lay and professional networks across respondents and influenced how information and support was sought.
The specific research questions addressed were firstly:

“What constitutes a social network for people with long term conditions?”

In Chapters 2 and 5, I examined the role of different social components and how relationships with family, friends, and health care professionals influence understanding prioritisation and engagement with management. Respondents’ accounts depicted a range of meanings they ascribed to various relationships that cyclically influenced the meaning of, and extent of engagement with, management. Included within the social networks were people who had a negative impact on management. Relationships which exhibited negative components were included because of the value of other types of support that they offer and limitations in the substitutability of other network members’ support. The functional size of a social network was typically smaller than the actual social network size. Relationships were complex with mutual expectations of roles and either sources of potential or actual support. In Chapters 3 and 6 the role of network typologies were examined. Three types of social networks (the family focused network, the friend focused network, and the health care professional focused network) were identified. The degree to which self-management practices were supported or undermined was influenced by those within the social network. Engagement with management practices was shaped by critical moments, which were either very significant events, e.g. bereavement, or an accumulation of smaller, less significant events. This is relevant when considering to how self-management programmes and initiatives are targeted (see below).

The second question was:

“How do social networks and health management reciprocally influence each other over time?”

The respondents’ accounts depicted the reciprocal influence of changing social network members and health over time. Consistently across narratives there was a stable core of important network members, however, this could, and did, change as a result of a significant event (for instance, through bereavement or a change in the expectations of network member roles). There was an ongoing process of breaking or reconnecting ties, which shaped the context of health management and the availability of support, as shown in Chapter 6 and 8. Conversely, changes in health highlighted the limitations and
assumptions of support from specific network members, which could cause a shift in how important they were considered or resulted in their removal entirely from the network diagram. In Chapter 7 this was further examined in relation to multiple long term conditions which recursively influenced the resources available through respondents’ social networks and management priorities.

The third specific research question was:

“What influence does having multiple long term conditions have on access to resources within the network?”

Individuals with multiple conditions have compounded challenges such as a lack of care coordination (May et al., 2009), a lack of knowledge and problems with medications and a need for greater practical and emotional support (Bayliss, et al., 2003). Further, this places additional demands on existing resources and a greater responsibility for management on the individual outside of formal health care. Chapter 7 shows that multiple conditions can challenge existing relationships with clinicians, by highlighting limitations and challenges in existing relationships, patient-clinician roles and expectations during consultations. Accounts depicted management priorities shifting at key transition points, which were influenced by health care providers, partners, family members and friends through information and support provision.

The final question was:

“How do changes in primary care influence how an individual accesses and uses resources from their wider social network?”

The respondents for this study were recruited through the pilot study of the WISE RCT, which aimed to improve self-care support by using a whole systems approach incorporating engagement at the level of the organisation, practice and patient (as detailed in Chapter 2). Chapter 5 highlights the framing of the consultation as an interpersonal relationship between the patient and clinician whereby changes in the support provided are considered individually and based on their relationship with broader policy and professional changes to primary care generally unnoticed. The specific tools designed to support self-care within the consultation were guidebooks and the PRISMS form (see Appendix 7). When respondents were asked if they had used or seen these tools only one
remembered having used the PRISMS form. The form had acted as a catalyst to raising problems with the G.P., who then connected her to a nutritionist whose information and advice was then utilised by her husband and children and supported a positive change in her quality of life and health management (see Chapter 8). From the pilot study necessary learning occurred and modifications were made as part of the iterative process of trial design. Subsequently, to support the use of these tools a PRISMs patient guide was developed (Protheroe, et al., 2010). The implementation of these findings will be discussed now in more detail.

9.2 Social networks: more than social support? Revisited

As described in Chapter 3, social support has been considered a mediating pathway through which social networks may influence self-management, but there are emergent properties of the social network which constitute more than only social support. Social capital is arguably one such property. Although this notion has been widely debated, the definition used throughout this study has been that social capital involves the resources in social networks to which an individual has access through ties within the network (Lin, 2001). Analysis of respondents’ accounts depicted that social support was the main relevant property of these relationships to an individual’s management whereby the emergent processes of the network of bridging ties and resource provision included not only the support offered, but also pathways which could enhance it. A social network approach provides a model of social actors embedded within the networks of support (Faber & Wasserman, 2002). Vassilev et al. (2011) argue that the distinction between social relationships and networks within existing studies of long term condition management can be categorised, firstly as network relationships focusing on dyadic relationships, for example, between patients and relatives. Secondly, they identified ‘social networks as affective communities’, i.e. networks can be formed from existing groups such as family, ethnic group, locality or virtual group membership. The final type of networks identified were ‘networks of networks’, or personal communities (Vassilev et al., 2011). The types of networks influenced the function of support which in turn shaped the nature of the interaction and the degree of disclosure (Vassilev et al., 2011). In this study, respondents’ accounts demonstrated these processes of selectively disclosing and seeking support for their long term condition, in particular with work colleagues and different types of friends. Friendships ranged from simple to complex and were reciprocally shaped by a mutual expectation of resources and support (Spencer & Pahl, 2006). In this study, respondents also spoke to different people about different types of
important events (Bearman & Parigi, 2004). The notion of affective communities in shaping identity and framing social roles, such as ‘being a worker’ or ‘being a parent’, was important to how respondents in this study identified themselves, particularly around being a worker. Yet when condition management and more highly valued social roles such as being a parent were in conflict with their roles within these groups, the respondents’ accounts depicted prioritising these close relationships and health over their membership in these communities. The relative importance of these affective communities was reported to be lower by respondents than the individual relationships which formed their access to these groups. Analysing the social networks in this study as individual personal communities enabled the key features of the network that influenced access to resources and support from the various network members, which occurred as a unit to supplement, substitute or complement each other to be identified. Although the respondents readily identified key network members, they also depicted being able to search through the network for specialised assistance (Wellman & Wortley, 1989).

Access to social support and material resources was influenced by the structure of networks, and could be influenced by network characteristics such as the range or size of network, the homogeneity of members, i.e. the degree of similarity of the various network members, the frequency of contact, reciprocity and the duration of the relationship (Berkman & Glass, 2000). These characteristics shaped respondents’ expectations of support and resources. For instance, when they described greater homogeneity within their network, such as networks which were mostly made up of family members, this reflected the value they placed on different sources of information and types of support. When networks were dominantly focused around health care professionals, respondents described their health as private, distinct dimension of their life and support was sought from formal services which would connect to other health care professionals. Social networks may influence decision making on a continuum of involvement (Rogers et al., 1999). Conversely, when respondents’ social networks were family or friend focused they tended to be less homogenous, including a range of family, friends, work colleagues and health care professionals. Moreover, when gaps in access to resources were identified by network members they would connect, or bridge, individuals to a wider range of personal, community or health professionals through lay referring which placed health within the broader context of wellbeing and quality of life. Respondents’ accounts depicted receiving routine information from key network members. When respondents needed novel or additional sources of information some participants described speaking to more peripheral
network members, as weaker ties have access to a larger breadth of information less familiar than that available from stronger ties (Granovetter, 1983).

Although many studies of long term condition management have identified relationships as having a positive impact on management, only a limited number identify any negative effects (Vassilev et al., 2010), respondents in this study described the complexity of relationships and the dynamic nature of networks and personal relationships which do not remain static. For some network members, the overall impact of some relationships were negative or so restricted by the limitations of the support that they had, on balance, a negative impact on management or wellbeing and therefore tended to be excluded from the network. Respondents identified seeking certain dimensions of support or resources from different individuals that they considered negative, and described limiting the resources or support they would seek from them. This resonates with Gallant et al. (2007) who found more positive than negative social network influences in relation to chronic illness management.

Social support is one key process through which social networks influence long term condition management. Expectations of support are emergent attributes of a social network as a combination of network properties such as the functional size and availability of other network members, length of time of the relationship and expectations of roles and responsibilities. Examining social network processes such as bridging, substitution and supplementation has enabled the complexity and contingent nature of support that can have both positive and negative dimensions to be examined within the context of a flexible system.

9.3 Multimorbidity and ‘self’-management

Managing multiple conditions can affect many aspects of condition management because of the increased complexity of treatment (Bayliss et al., 2003). Multiple conditions emerged as an important dimension of illness management during this study, as it shaped access to and the availability of resources and support, as well as challenging established relationships. Multiple conditions had practical implications in increased workload for members of the network, such as an increased number of appointments or the increased dietary restrictions which could alter food preparation, in particular if their partner cooked
their meals. The increasing demands and restrictions created by the presence of multiple conditions further challenges whether self-management programmes and policies should focus on the individual and the rhetoric of increasing individual responsibility without fully acknowledging the range of support and resources that are sought from others.

Furthermore, for some respondents the presence of multiple conditions caused a fundamental change or re-evaluations of individual relationships and the roles that they wanted or were able to take. Changes in the dynamics of relationships were particularly evident with the patient-clinician relationship, as the respondents’ accounts depicted seeking strategies across conditions for which they were given little or no information. This is in contrast with the description of health professionals’ ‘sequential’ model for managing multiple conditions in a linear manner (Bower et al., 2011). Respondents’ accounts depicted an active process of selectively searching through the network to identify appropriately those who were able to provide specialist support. These relationships would then temporarily be re-prioritised to enable them to support the participant around the diagnosis and the prioritisation of conditions (as described in Chapter 5.3.3). The degree of congruence or conflict between patients and health professionals regarding management priorities impacted upon subsequent management practices and therapeutic relationships. Thus, multiple conditions further challenge the individualistic notion of self-management because, if participants did not get the support or information they needed, this led to distress and confusion, which in turn prompted decreased engagement with management.

9.4 Evolving ‘self’-management?

Self-care has been the dominant focus of health policy for long term condition management in the UK since the 1990s as a fully engaged approach whereby individuals take greater control of their health by increasingly appropriate use of health services through ‘a range of activities that patients undertake for themselves in managing illness’. (Rogers, 2009). This approach focuses on the actions an individual takes to manage their condition with limited acknowledgement of the influence of the content and key figures in shaping management. Central to the programmes developed to support self-management has been the notion of ‘self-efficacy’ through courses aiming to develop the confidence and motivation of individuals to manage their condition (Newbold et al., 2006). Commentators have increasingly identified such an individualistic focus of these
programmes as a limitation to their effectiveness. The value in attending these programmes, such as the EPP, may be the potential for reducing social isolation and developing new or complementary social networks (Rogers, 2006). Further, there remains a gap between much existing research on the self-management and the everyday reality of living with a long term condition, which reinforces inequity in accessing and utilising self-management programmes and services (Furler et al., 2011). This thesis has focused on examining self-management as an element of an individual’s complex everyday life to understand the process through which it is negotiated and prioritised into everyday life. Fundamentally, these processes are the actions an individual has to take, yet this study has demonstrated that considering this as an individual practice is limited as it restricts the development of programmes and practices which can appropriately support individuals.

Self-management has been important in setting up the political agenda of chronic illness management, although in order to progress this it needs to move beyond its individual focus to understand the importance of social network members as support or advocates for respondents, but also as constraints to individual management engagement.

It is clear from the analysis presented in Chapter 6 that the respondents had different types of social networks which influenced self-management. The types of social networks that individuals depicted influenced how condition practices were embedded within everyday routines and the value that is placed on different types of support. Although types of networks have been linked to subjective experiences of well-being, depressive symptoms and morbidity (Fiori et al., 2007), respondents’ accounts depicted the relative importance of the various types and degree of support. This influenced where information and resources were sought; the degree to which support could be supplemented by other network members or substituted, as the availability of support and resources from different network members changed dynamically over time. Within the existing literature commentators have often given a cursory explanation of the types of networks which support or undermine management practices (Vassilev et al., 2011). Rather, they have focused predominantly on the responsibility of spouses (Smith & Christakis, 2008) or the patient-clinician relationship (Thorne & Robinson, 1989). Nevertheless, by taking a social network approach, emergent properties from the different types of networks were examined to explain management characteristics which remain intangible when focusing on the constituent parts of the networks (Smith & Christakis, 2008). This is particularly evident when considering the impact of the different types of networks on utilisation and effectiveness of education programmes. Some respondents valued more highly
information from health care professionals than from within their lay network. This was reflected in where they sought ‘legitimate’ information and they were reserved in relying on wider family and friends for support or information. Conversely where respondents’ accounts depicted family-focused networks, the main source of support came from multiple family members, and health care professionals were sought for specific, task orientated support. For these later respondents, programmes which mobilise family support through mechanisms such as training of family members or goal setting to support self-care behaviours might be appropriate (Rosland & Piette, 2010). Yet those respondents who value health care professionals and minimise the support of family members may not engage with such initiatives, as it would challenge their valued role within the family. Thus, identifying these different types of networks enables a possible understanding as to why a ‘one-size fits all approach’ to education programmes and policies has only limited utility and cannot address inequity in access to, and the utilisation of, these programmes (Newbould et al., 2006). Rather, considering the different meanings of support available from different types of networks may help to address the spectrum of support required through more appropriate targeting of programmes over time, as the type of support needed changes over time.

A cross-cutting theme that was demonstrated in the data chapters was that illness management is a dynamic process. This means that the amount and type of support that respondents sought varied. Furthermore, as this was a reciprocal process both respondents and network members provide support to each other, the availability of support from network members varied at different times and depicted flexibility in seeking support constrained within implicit boundaries based on mutual expectations of roles. Adaption to living with a long term condition is an ongoing process whereby fluctuations in the conditions and the context in which management occurs dynamically adapt (Corbin & Strauss, 1985; Patterson, 2001). This shifting process of condition management is reflected in the different types of help and support available and sought from health services (Lauver, Ward, Heidrich, Keller, Bowers, Brennan, et al., 2002). Respondents reported this change around critical moments. For some, this shift occurred around major events such as the death of a key network member or diagnosis of an additional condition while for others there was an accumulation of minor events which had reached a critical capacity and forced a re-evaluation of management priorities. This resonated with the role of epiphanies in changing the ‘fundamental meaning structures’ in an individual’s life (Denzin, 1989a). Respondents also reported changes in the expectations of relationships
developed over a lifetime, particularly with family members, which was key to understanding the resources, a form of social capital, available to them in later life (Antonucci & Ajrouch, 2007).

A remaining question is: does ‘self’-management as a notion needs to evolve to reflect these broader influences? I would argue that based on the evidence presented in this thesis that yes it must. Policies and programmes which have been developed on the notion of ‘self’ are necessarily limited and exclude important resources which may reinforce existing inequity in supporting long term condition management. Terms such as ‘health management’ may be more inclusive of multiple conditions and the wider influences on management, as well as acknowledging the roles of quality of life and wellbeing yet may also not adequately incorporate the problems associated with illness experience and health care needs. Fundamentally, self-management refers to the actions an individual completes in the management of their long term conditions. In other words, the term ‘self-management’ may be adequate in explaining individual behaviours, yet the broader policy focus and the design of programmes to support self-management must expand to include these complex and critical social components if it is to remain relevant and useful.

9.5 Strengths and limitations of this study

This study has provided an understanding of the quality of social networks by using a qualitative approach to examine the meaning of various network members and their interactions in influencing engagement with management practices and setting the context in which self-management occurs. Unlike quantitative methods that have examined social network effects and health outcomes that have the potential to correlate a range of health outcomes, qualitative methods can illuminate the value of those relationships. As Cohen-Cole and Fletcher (2008) identified, it is possible to correlate acne, headaches and height using social network methods and caution is needed when relying on the diffusion of health outcomes within whole networks. Qualitative methods enable the social reality of the relations considered within a social network to be considered beyond their existence to understand the meaning and processes involved in understanding their role in long term condition management. In other words, this study has moved beyond examining the structural components of the social network to understanding the mechanisms that underpin these relationships. However, it would be incorrect to assume that social networks are static or have definite boundaries, as Crow (2004) describes ‘social networks
are configurations of people rather than collectives with definite boundaries’ and they change over time. Heath, Fuller and Johnston (2009) argue that it is impossible to capture the social network in its entirety because of its fluid nature. This study has examined the role of social networks changing over a one year period and the fluid nature of the networks means that over a longer period of study processes other than substitution, supplementation and prioritisation might be depicted.

The strength of using a social network approach is that the network elicitation technique has illuminated the nuanced relationships which have tended to remain implicit and underexplored within previous research that has relied mostly on a traditional interviewing technique. By examining the structure and the meaning of the social networks in relation to management, this study has explicitly explored and highlighted the boundaries of practical and emotional support and resources such as information. Additionally, the examination of these nuanced relationships has shown the importance of reciprocal relationships where expectations of support are mutually defined and relationships could be multifunctional or focused around specific activities which have direct and indirect influences on management. A further strength of the study is how it has identified the functional size of the network is smaller than the actual network size and how this changes over time. The study has also enabled the examination of the relative importance of different network members and how this is revised over time. This has enabled me to identify the types of social networks implicated in long term condition management to enable a more socialised perspective on self-management which is important when considering the appropriateness and provision of formal self-management support programs. Furthermore, using a longitudinal approach has enabled me to identify how relationships and information use changes or remains the same over time.

Participants were purposefully sampled to include a range of ages and length of time since diagnosis, although the index conditions were restricted to those which were the focus of the RCT. These conditions were selected because the existing provision of support is variable. Diabetes is more prevalent within the population and there are a greater range of resources that have been developed to support its management, whereas for COPD and IBS there is more variable access to support and with IBS there is a variable process of diagnosis and legitimisation of the condition. Despite this, the processes of seeking support through the network were more dependent on the type of support available and that valued by the individual, which was irrespective of the index or presence of co-
morbid conditions. Also, the nature of longitudinal research allows for emergent topics to be explored and a degree of flexibility in data gathering (Saldana, 2003). The development of the methods from the initial interview led to adapting the Antonucci (1986) concentric circle social network elicitation technique for use in the final interview. The ensuing interview discussion helped to develop an understanding of the relative importance and role of various actual and potential sources of support. The central network members were discussed in both the initial and final interview but the nuanced relationships were difficult to elicit in the initial discussion without the use of the social network tool because of their relatively more minor role. The inclusion of these relationships was not recalled by discussion alone but rather included in network diagram and their significance discussed in the final interview, which highlighted the network process of substitution and supplementation. One limitation of the longitudinal study was the frequency of telephone follow-up calls because participants could not be reached once a month as originally planned, but were contacted intermittently depending on participant availability. This varied from reaching participants approximately every three months to being unable to reach some participants during the telephone follow-up period at all despite their former agreement to the follow-ups. This was a difficult process to balance between trying to contact participants regularly and not to appear too demanding that they may withdraw from the study altogether. When I did manage to reach participants they gave accounts of a variety of influences on their management, such as a chance meeting with a friend who also had diabetes, but these were transient and did not have a long term impact on their management priorities as in the final interview they were typically not remembered. However, for one participant whose father and brother died during the study, the effects that the associated bereavement had was different for each loss and was able to be captured during the telephone interviews, although because of the significance of the events their influence was remembered in the final interview. Attrition is also a common problem in longitudinal studies (Saldana, 2003), although for the final interview, through re-invitation to this study and a financial incentive, twenty-six of the original thirty respondents participated. This may suggest that these participants preferred face-to-face interviews, or that financial compensation for participation may reflect the value of the participant’s time, yet the evidence that paying participants encourages participation is equivocal (Head, 2009).

One limitation of this study was that recruitment into it was not based on individuals having multiple conditions, despite this twenty-one participants identified themselves as
having more than one condition in the initial interviews. Participants raised challenges about all conditions during the interviews which showed how the reality of management did not differentiate between conditions but rather identified the practices that were involved in management. This study had a longitudinal design, which enabled themes that arose to be explored further with the same participants. Cutting across respondents’ descriptions of multiple conditions was the prioritisation of management which changed over time, despite a range of participant ages, the type of co-morbid conditions present and the varying degree of impact on everyday life. By using research methods which enabled individual’s narratives to guide interviews, salient topics arose and a more complex and complete view of condition management, individual priorities and the strategies employed to embed it within the everyday was obtained.

9.6 Further research

Further research needs to identify ways to engage individuals with long term conditions, who value information and support from a variety of sources and responds to changes in support wanted (such as the onset of an additional condition). As this thesis has shown, people seek and value information from different sources and this influences the type of social network which they identify. Future programmes need to be able to identify and react to these changing support needs and where there are gaps or absence of support. As this study was exploratory in nature about the role of social networks for people with long term conditions, it was unable to identify whether referring patients with different types of social networks would result in use of different types of support services; for instance, would individuals with a healthcare professional based network be more likely to utilise information provided to them from clinician-led courses than lay led courses. A related study could examine the role of different types of facilitators or group formats as this thesis has demonstrated that individuals value and respond to information from different sources. Patients may benefit from being directed to different types of groups which could be identified from the type of social network they have to address the limitations of a one-size fits all approach to education support programs. Furthermore, some respondents described confusion about lifestyle factors such as dietary changes recommended or finding ways of normalising exercise into everyday routines. The implementation of these lifestyle modifications is reported by patients as difficult to sustain in their everyday lives. Furthermore, both patients and clinicians reported difficulties in discussing self-
management topics during consultations (Blakeman, Bower, Reeves & Chew-Graham, 2010). One mechanism that exists within communities which could support lifestyle changes are community and voluntary groups, yet it is unknown how acceptable and feasible these are for individuals with long term conditions. Some respondents in this study sought information and support from joining groups like WeightWatchers to embed the practices of weight management into their everyday life. The notion of ‘social prescribing’ has been proposed as one mechanism in bridging this gap in support for lifestyle modifications. Social prescribing links patients from primary care with non-medical community support (Brown, Friedli & Watson, 2004). It is acknowledged that for psychosocial concerns some G.P.s suggest social activities such as dance or arts classes, yet without a mechanism to support this it can be considered a tokenistic gesture (Brandling & House, 2009). In addition, little is known about the existing referral practices of G.P.s for patients with long term conditions. In a recent evaluation of a pilot social prescribing scheme, both patients and practitioners reported it as being a successful bridge between primary care and the voluntary sector (Woodall & South, 2005). Patients reported reduced isolation, increased confidence and access to non-stigmatised support, and health care professionals identified the potential to improve the patient-clinician consultation and reduce workload (Woodall & South, 2005). Although the majority of these projects have examined the mental health or general wellbeing of the elderly populations, there is considerable utility in these concepts within long term condition management and this could be examined as one mechanism for reducing social isolation and encouraging lifestyle changes. A future study could examine the acceptability of referral to these broader community resources from primary care.

Co-morbidity emerged as a salient issue in the utilisation of services, resources and expectations of support from both lay and professional networks. In the presence of multiple conditions the burden of chronic illness is increased as barriers to self-management can accumulate such as physical limitations and problems with medications (Bayliss, et al., 2003). The presence of multiple conditions could affect ongoing illness management as respondents described developing strategies to integrate and manage information, medications and the related management practices. All co-morbidities do not have the same impact (Piette & Kerr, 2006) and individuals prioritise conditions based on their manageability and predictability (Lindsay, 2009). In this study, the ability to adapt to and incorporate changes in management was influenced by additional conditions challenging existing explanatory models which could disrupt management practices;
whereas. If additional changes in management practices were framed within existing routines, they were more likely to be adopted. Respondents described how they managed to integrate new and old management routines with experience, yet clinicians may have a central role in being able to support patients to make these links earlier and so accommodate practices sooner and reduce disruption. A focus on each individual condition is reinforced through disease surveillance systems such as the general practice Quality and Outcomes Framework and this maintains a linear model of multiple condition management during consultations (Bower et al., 2011). A future study could explore how to reconcile different approaches taken by the clinician and the patient to more appropriately support shared-decision making that reflects the reality of patient prioritisation and everyday management.

In this study, participants did not describe routinely using the internet as they found the quality and content of information variable and were unable to determine the trustworthiness and accuracy of information. None of the participants had used online forums to discuss their illness management. For participants that did refer to using the internet to search for information, they sought confirmation about the trustworthiness and accuracy of this information from members of their social networks (such as going to the GP or friends) as trust in the latter had been established over time. Future studies, particularly with a focus on the experiences of younger people with chronic illnesses, may find accounts of increasing use of the internet as they may be more confident in searching and identifying credible resources online.

Another area of future research that has emerged from this study has been the direct role of pets, and in particular dogs, as an important part of daily social contact, encouraging regular exercise and connecting individuals to their local community. Respondents with pets in this study described the role of pets as shaping their daily lives. Conversely, some participants who did not have pets identified this as a barrier to exercise because they did not have the same impetus to walk every day. Dog owners are more physically active than non-dog owners (Cutt et al., 2007). In particular, women who have no company or pets to walk with were less likely to walk for exercise or recreation (Ball et al., 2001). Also, respondents in this study depicted pets as acting as bridging network members, connecting them to their local communities. Social isolation is often identified as a part of living with a long term condition, and has been linked to increased levels of stress depression and anxiety (Tweedy, Morrison & DeMichele, 2002). A consideration of how
pets can be supportive and influence management practices could be a useful study as a mechanism of connecting individuals with long term conditions to their communities and health management. Such a study might consider the role of dogs in the health and wellbeing of people with long term conditions. This would enable an understanding of the role of non-human elements in management, which has been underexplored despite its potential to influence directly lifestyle changes that are difficult to implement and maintain.

9.7 Conclusion

The degree to which management practices are adopted is influenced by the social context in which it occurs and is shaped by the value and meaning of key relationships. These relationships shape the normalisation of management through dynamic processes of negotiating and redefining the expectations of roles and responsibilities. Social network members provide access to a variety of support and resources. Although relationships were not always positive, the accounts in this study depicted processes of supplementation and substitution of support which reflected a degree of flexibility of support. Flexibility of support was limited across the social network because the functional size of the network was normally smaller than the actual size depicted. The functional size of the social network was particularly highlighted in times of crisis or changing circumstances when support would be more selectively sought. Multiple conditions added a further layer of complexity to condition management. Prioritisation of conditions changed over time at key transition points and was influenced by health care providers, family members and friends. Policies and disease education programs need to be tailored as different types of individuals need different types of support which will ultimately affect the utility and effectiveness of these programmes. This thesis has shown the value of investigating and assessing social networks for individuals with long term conditions and the types of work completed by members of the network in order to identify gaps and potential barriers to self-management, as well the existing support available.
References


Rapley, T. J. (2001). The art(fulness) of open-ended interviewing: some considerations on analysing interviews. *Qualitative Research, 1*, 303-323.

Richards, H. M. & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice, 19*, 135-139.


Saldana, J. (2003). *Longitudinal qualitative research: analyzing change through time*. California; AltaMira Press.


Appendix 1: Blank network diagram
### Appendix 2: Initial interview guide

#### Baseline WISE Qualitative Interview Questions

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Views of Illness and Current Health Status and identity</td>
<td>How would you describe your current state of health? What are the conditions you have? Which one if any has priority at the moment in terms of having to manage it? Which one causes you the most problems? Does this change or has this been the same for some time? How has having a long term condition changed the way you view yourself as a person and the things that you do (include at work and in the home and locally) and the way in which you relate to other people around you.</td>
<td>How long have you had your main condition? Has your view of your illness changed over time?</td>
</tr>
<tr>
<td>Contact with Services</td>
<td>When did you start to have contact with health services about this? Are you satisfied with help given to you by professionals? Do different parts of the system or health professionals provide different types of things? Have you noticed any differences or similarities between professionals? Do you discuss how you manage on a daily basis with people in the health service? What sorts of things, problems issues, things you do yourself would you not want to discuss related to your everyday life in living with a chronic condition and why</td>
<td>What prompted you to seek professional help? How did you cope with the symptoms of illness before you contacted services? Do you feel able to talk openly about treatment? Do you feel listened to/questions answered? Involved in decision making process? Can you give examples of good or poor treatment? E.g. GP/ consultants/ Nurses/ Physios. Do you have contact with social Services?</td>
</tr>
<tr>
<td>Impact on Daily Life</td>
<td>How does having your condition affect your life on a day to day basis?</td>
<td>How things were before you began to suffer with your condition? Any change to key areas of your life because of condition? Are there things that you can no longer do, that you could do before you became ill?</td>
</tr>
<tr>
<td>Ways of Managing Illness</td>
<td>How do you manage NOW on a day-to-day basis with your condition? Have you had to make any changes to your lifestyle and your diet? What do you currently do when your symptoms get worse? Tell me what happened yesterday and today? How has this impacted on your work routines and work relations if you work and if at home</td>
<td>Are there any things that you do to make living with your illness easier? e.g. give up work, modifications to the home, do more exercise, change to diet How this changed over the time you have been suffering with your condition? Have you ever used alternative therapies? Help from family and friends? Has this always been the case or has it changed over the course of your illness?</td>
</tr>
<tr>
<td><strong>Self-Management Resources</strong></td>
<td><strong>Expectations of CDM between patients and health services</strong></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Starting from when you first thought something was wrong can you tell me how you have responded to your illness and what sort of adjustments you have had to make to your life and what you do on a daily basis? Are there things that you think you should do in relation to your condition and can you say why you think you don’t do them and if you think there is anything that might help you do the things that you think would be a good idea? Are there things that other people tell you should be doing but you don’t do? What are these things and how do you feel about other people telling you these things? Have you used any information concerning your condition? Do you speak to the pharmacist at all about medication for long term conditions? Contact with voluntary organisations concerned with your condition? Who in your family or circle of friends locally do you talk to about your illness? When and what do you talk about? Are there occasions when you prefer not to talk to people and keep things to yourself and if so why? Do you or have you ever thought about claiming disability living allowance? (if no why not) If you have applied can you tell me about how you experienced that?</td>
<td>Have you ever looked up information about your condition on the internet? Have they been helpful? Has the self-help material provided you with a similar or different form of support than the support you get from professionals? Involved with any self-health support groups concerned with your condition? Has your involvement/use of voluntary organisations/self-help material changed the way you view and manage your condition? What are the things that the health service provides for managing your chronic condition? How satisfied are you with each of these aspects? What is it that the HS does the best in terms of supporting you Are there any areas where you think that services might help you more with managing your condition? What things do you think the health service does not provide which are important to you in managing a long term condition? Who should and who does provide this? What things in your neighbourhood make it easier to manage having a long term condition and what things make it difficult? What sorts of contact with people (your family and friends, neighbours, local people) make</td>
<td></td>
</tr>
<tr>
<td>Neighbourhood Attachment (cohesion, reciprocity and personal trust)</td>
<td>Over the time that you have been living here, do you think the neighbourhood has changed for the better or worse? Can you think of positive or negative examples?</td>
<td>Do you feel it is a safe area?</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>How long have you lived in the area?</td>
<td>Could you describe your neighbourhood to someone who wasn’t from the area?</td>
<td>Would you borrow/lend/do favours for each other?</td>
</tr>
<tr>
<td>Do you feel part of a community?</td>
<td>Do you get on with/look out for your neighbours and vice versa?</td>
<td></td>
</tr>
<tr>
<td>Would you say you know most of the people in your neighbourhood?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social networks and social support</th>
<th>Shopping, cooking, cleaning, dressing?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Does anyone help you?</td>
<td>How often? What did they do together?</td>
<td></td>
</tr>
<tr>
<td>How many times in the past two weeks have friends or family visited you or you visited them?</td>
<td>Who are you close to?</td>
<td></td>
</tr>
<tr>
<td>Who have you talked to about your health?</td>
<td>Who would help you in difficult times?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Civic engagement</th>
<th>What types? E.g. Church, lunch groups, activities? How active in the group are you? How many groups?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you a member of any groups?</td>
<td>Do you think that when people work together in the neighbourhood they can influence decisions that affect the area?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3: Patient demographic sheet

Background Information

1. Are you: (Please tick the appropriate box)
   Male ☐ Female ☐

2. Your date of birth: (Please write in the numbers below e.g. 1st May 1960 would be 01 05 60)
   Day: ☐ Month: ☐ Year: ☐

3. Who do you live with (if anybody) in your current home? (Please tick all the boxes that apply)
   ☐ Live alone
   ☐ Spouse / partner
   ☐ Parent(s)
   ☐ Children under 18
   ☐ Children over 18
   ☐ Other family
   ☐ Friends or other people

4. Is your accommodation: (Please tick one box only)
   ☐ Owner-occupied/mortgaged?
   ☐ Rented from local authority/housing association?
   ☐ Rented from a private landlord?
   ☐ Other arrangements?
   (Please describe) :
   ..........................................................................................................................

5. How many cars or vans are there normally available for use by you? (Please tick one box only)
   ☐ None ☐ One ☐ Two or more
6. Which of the following best describes you?  
(Please tick one box only)

☐ White ☐ Asian or Asian British

☐ Black or Black British ☐ Chinese

☐ Mixed ethnicity ☐ Other

7. Which of these qualifications do you have?  
(Please tick all the boxes that apply)

☐ 1 or more O levels/CSE/GCSEs (any grade)

☐ 1 or more A levels or AS levels

☐ Degree

☐ NVQ

☐ Other trade or professional qualification

☐ No qualifications

8. What is your current occupation?  (Please write in your own words below)


9. If you have a partner, what is their occupation?  (Please write in your own words below)


Appendix 4: Monthly telephone interview guide

1. How would you describe your current state of health?

2. Has there been any changes in your condition in the last month? Have you had any time off work?

3. Has your condition changed your life on a day to day basis in the past month? What has having your condition changed in your life?

4. Have you made any special changes to your diet or lifestyle in the past month?
   a. What prompted changes? Have you read anything/seen on tv/internet?
   b. Are you able to exercise regularly? What helps/hinders?

5. What health services have you used in the last few weeks?
   a. Who have you spoken to? Eg pharmacist, NHS direct, smoking cessation programme, condition specific clinic?
   b. Have you made any appointments?

6. Who have you asked for help from in your family or friends? If so who, how regularly and what have they been doing? Have you visited any friend or family in the past month or had them visit you? If so who, how often, where did you meet?

7. Who have you spoken to any friends or family about your condition?

8. Have you been in contact with any voluntary organisations concerned with your conditions? Have you received information or support from any other sources for your condition?

9. Is there anything important, that we haven’t discussed, that has happened in the last month that has affected your health which you would like to mention?
Appendix 5: Letter inviting participants back into the study

2nd October, 2009

Dear ,

About a year ago we met for an interview and you agreed that I could contact you for another interview. What you kindly shared with me was important and interesting. In the next interview I want to find out about your more recent experiences as well as to talk about some issues raised by other people I have interviewed.

I would hate to lose your opinion but I am also aware that it takes up your time and so I can pay you an extra £20 if you would be happy to complete a further interview. Also we have developed a self-care book which I can give you when we catch up. For the interview I can meet you wherever is best for you and at whatever time suits you. I will also bring along a written copy of the first interview that we did.

I have attached a form so you can let me know a good time to call you to arrange a time to meet. Also if your phone number has changed or there is a number that you would like me to ring you on please write this down and return the form to me in the stamped addressed envelope enclosed.

I will follow up with a phone call in a week’s time but if you would like to contact me please do either by telephone on 0161 2750748, by email at rebecca.morris@manchester.ac.uk or completing the enclosed form.

I value what you have already told me very highly and would like to thank you for taking part in this research,

Kindest regards,

Rebecca Morris
### Theme: Social networks

**Question:** In the inner circle place those who are most important to you in terms of your health, in the next circle place those who are important but not quite as important as those in the inner circle, in the outer circle places those who are important but not as important as those in the other circles.

**Prompt:**
- **Distance:**
  1a: co-habiting
  1b: short walk/drive away
  1c: live one hour away
  1d: over one hour away
- **Amount of contact:**
  2a: daily
  2b: at least once a week
  2c: at least once a month
  2d: every couple of months
  2e: less often than every couple of months
- **How and why did you decide to place them there?**
- **How do you know them?**
- **What made you place them in that circle (criteria)?**
- **Compare between different members of different circles. Do they give you help?**
- **How often do you talk to them/see them?**
- **Other colleagues/friends/services that weren’t included—why?**
- **Are they different?**
- **Out of these who would you talk to about health issues/ask for help?**
- **Is this different to the people you spend time with or talk to generally?**
- **Health professionals?**
  - Did they mention or not? How do you feel about your relationship? How do you prioritise their role in your health care?

**Distance live/work away**
- 1a: co-habiting
- 1b: short walk/drive away
- 1c: live one hour away
- 1d: over one hour away

**Amount of contact**
- 2a: daily
- 2b: at least once a week
- 2c: at least once a month
- 2d: every couple of months
- 2e: less often than every couple of months

**How and why did you decide to place them there?**
- **How do you know them?**
- **What made you place them in that circle (criteria)?**
- **Compare between different members of different circles. Do they give you help?**
- **How often do you talk to them/see them?**
- **Other colleagues/friends/services that weren’t included—why?**
- **Are they different?**
- **Out of these who would you talk to about health issues/ask for help?**
- **Is this different to the people you spend time with or talk to generally?**
- **Health professionals?**
  - Did they mention or not? How do you feel about your relationship? How do you prioritise their role in your health care?
<table>
<thead>
<tr>
<th>Change in illness management</th>
<th>different to the people that you are close to or spend a lot of time with generally (do you talk to them about your health? If no-why?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your main priority at the moment? How has your condition/s changed over the last year?</td>
<td>Is there a difference in how they affect you on a day to day level? If so in what ways? Are there things you do for one condition that makes your others worse? Are there things you do for one condition that makes the her better?</td>
</tr>
<tr>
<td>What conditions do you have? How would you prioritise them? Are there times when this changes? Have there been times in the past when you prioritise them differently? Do you feel you spend a lot of time thinking about you health (wellness)?</td>
<td>Have these circumstances changed at all?</td>
</tr>
<tr>
<td>What things have stayed the same, got better or changed for you over the last X months. What restrictions do you think your condition has had on your life?</td>
<td>Do you think you have been restricted from things that you don’t feel was associated with your condition? I.e. because of where you live, your finances, your psychological well-being?</td>
</tr>
<tr>
<td>Was there anything that you did or used to help you with your condition which you used to do which you have changed in the meantime?</td>
<td>Any books/internet? New resources and existing things you continue to use</td>
</tr>
<tr>
<td>Have you done anything differently about your condition over the last x</td>
<td>What is important that has stayed the same? Why?</td>
</tr>
<tr>
<td>Have you changed the way you think about your condition and in what way?</td>
<td></td>
</tr>
<tr>
<td>New things you have done: Have you talked to anyone or made contact with any service or local activity over the last year</td>
<td></td>
</tr>
<tr>
<td>Have you stopped seeing anyone or doing things you previously did at work home or locally if so what are the reasons?</td>
<td></td>
</tr>
<tr>
<td>More broadly how has the area changed? What’s the most important thing in the area that you use and things that you do daily activities-how have these changed? Has this been affected by your health?</td>
<td></td>
</tr>
<tr>
<td>Have you wanted to change things but not been able to if so why?</td>
<td></td>
</tr>
<tr>
<td>IS there anything you would have liked to have done but couldn’t do because of financial constraints or other barriers?</td>
<td>How accessible is primary care for you? How accessib...</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>If you have wanted things to stay the same why is this? Are there any reasons you can identify for any changes</td>
<td></td>
</tr>
<tr>
<td>Content of intervention</td>
<td>What was good/What was bad? Did you find there was an emphasis on any particular aspect that was previously not covered e.g. exercise, thinking differently? How did that fit in with what you were already doing? What are your views on exercise and lifestyle changes? What is your role in managing your condition? What are you doing now to manage your condition and is the doctor more aware of this than previously or the same? How do you find managing your medication? Do you keep a log for your tablets? What about the way you view yourself and the way you use services has this changed at all? Are you more inclined to look for resources and other things outside of the health service? Do you spend more on things such as foods, vitamins, OTCs, complementary therapies?</td>
</tr>
<tr>
<td>What did you think of consultations you have been having? What do you think of the menu of options relating to your condition? How did you find trying to articulate your needs? Aspects easy or more difficult</td>
<td>So overall what did you think about the content of primary care for managing your conditions?</td>
</tr>
</tbody>
</table>

**Content of intervention**

- What did you think of consultations you have been having?
- What do you think of the menu of options relating to your condition?
- How did you find trying to articulate your needs? Aspects easy or more difficult
- So overall what did you think about the content of primary care for managing your conditions?
<table>
<thead>
<tr>
<th>Issues around Co-Morbidity</th>
<th>Consultation Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>If have more than one condition – Did you focus on one condition over the other during your contact with services</td>
<td>How did you decide which condition to focus on? When you go to the Drs do you prioritise one over the other?</td>
</tr>
<tr>
<td>What conditions do you have? How would you prioritise them? Are there times when this changes? Have there been times in the past when you prioritise them differently? Do you feel you spend a lot of time thinking about your health (wellness)? Thinking about who you have spoken to about your health, would you talk to them about both of your conditions? Is there any difference in which/what you would talk about?</td>
<td>Is there a difference in how they affect you on a day to day level? If so, in what ways? Are there things you do for one condition which makes your other worse? Are there things you do for one condition which makes the other better?</td>
</tr>
<tr>
<td>How did you decide which condition to focus on? When you go to the Drs do you prioritise one over the other?</td>
<td>Was there room for you to express ideas/were these incorporated into your consultations?</td>
</tr>
<tr>
<td>When you go to the Drs do you prioritise one over the other?</td>
<td></td>
</tr>
<tr>
<td>Is there a difference in how they affect you on a day to day level? If so, in what ways? Are there things you do for one condition which makes your other worse? Are there things you do for one condition which makes the other better?</td>
<td></td>
</tr>
<tr>
<td>Have you noticed any differences in the priorities of the GP or nurse during the consultations? How often do you see the GP or nurse in the last 12 months?</td>
<td></td>
</tr>
<tr>
<td>Have you noticed any differences in the priorities of the GP or nurse during the consultations? How often do you see the GP or nurse in the last 12 months?</td>
<td></td>
</tr>
<tr>
<td>Care planning/wise: Have you talked to the GP/nurse about you health? What prompted this discussion? In the discussion did the doctor or nurse take notice of your views about how to deal with your condition? Did you and the doctor agree about how best to manage your health problems? Were you given a written document about the discussion you had? Did the doctor or nurse ever say that you had something called a care plan? Do you think that these sorts of</td>
<td>Why have/haven’t you had this discussion? Would you want it? Is there anything that would prompt you to do it? Have you talked with your GP or nurse about your condition and self care support options? What have you been offered?</td>
</tr>
<tr>
<td>Was there room for you to express ideas/were these incorporated into your consultations?</td>
<td>If so-how have you used it? What did you</td>
</tr>
<tr>
<td>discussions with your doctor or nurse might help you manage your condition?</td>
<td>do?</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Show PRISMS form</strong>-have you seen it/used it? Do you think it would be useful?</td>
<td></td>
</tr>
<tr>
<td>Broader social care/self care support from WISE</td>
<td></td>
</tr>
<tr>
<td>Would you think that you could talk to your GP about social support and other things? Have you? Would you feel comfortable bringing it up or do you think the GP or nurse should raise it? Do you think that the GP or nurse talks more about the support that is available now? Do you think that is something the health service should offer?</td>
<td></td>
</tr>
<tr>
<td>Service Utilisation</td>
<td>How well did the advice given to you by your drs fit in with what you were able to do at home?</td>
</tr>
<tr>
<td>---------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>What do you think about the NHS in general and in relation to what it is able to help you with?</td>
</tr>
<tr>
<td></td>
<td>If you had a wish list what would you like provided for you by the NHS?</td>
</tr>
<tr>
<td></td>
<td>How well does support and advice provided by health professionals fit in with what you think about your illness and how you have managed it in the past</td>
</tr>
<tr>
<td>NHS Vs Voluntary and wider social services local Sector</td>
<td>Are you involved with any voluntary organizations? Have you joined anything locally over the last year? Do you do anything differently in the way in which you talk to people about your illness or what you do on a daily basis including in the work place? What about claiming support or help in terms of financial assistance or help from other public services? Do you use any equipment or devices or information to help you self manage? Who do you talk to about your health problems in the family etc?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Care planning</td>
<td>Do you think that is something that you would want from the health service? Would you take any notice of it? To asses this they are going to use questions like these (show questions) which would be used to</td>
</tr>
<tr>
<td>incentivise the GP so that they would get paid extra based on how they score. What do you think about that?</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>What has been the most significant change for you over the last year?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 7: PRISMS Form

Using the PRISMS form

This form is something you can fill in before you come for a consultation with your doctor or nurse.

It is to help you think about how well you are able to manage your health and what you need most help with.

It will be used by your doctor or nurse to help them find the right sort of support for you.

The form can be used by anyone so some items may not be a problem for the health condition you have.

What to do

Here is a made-up example of how to fill in the form.

This is a woman who is worried about her breathing. She does not have a problem with pain at the moment.

<table>
<thead>
<tr>
<th>*</th>
<th>Shortness of breath</th>
<th>Not a problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pain</td>
<td>☹</td>
<td>☹</td>
</tr>
</tbody>
</table>

Put a cross in the box on the left to show up to 3 items you need most help with.

Mark the line to show how much of a problem each item is for you.

She feels that she is unable to get out and do the things that she would like to do. She would like some help with this.

<table>
<thead>
<tr>
<th>☒</th>
<th>Getting out and doing things that you enjoy</th>
<th>☹</th>
<th>☹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sexual problems</td>
<td>☹</td>
<td>☹</td>
</tr>
</tbody>
</table>

Please do not use or reproduce without the authors’ permission.

Please contact Anne Kennedy for further information (anne.p.kennedy@manchester.ac.uk)
March 2009
Copyright © 2008, University of Manchester, all rights reserved.
PRISMS – Patient Report Informing Self-Management Support

Please put a cross on the line to show how much of a problem each item is for you

<table>
<thead>
<tr>
<th></th>
<th>Not a problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being tired, no energy</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Stress and worry</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Managing to work</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Support from family and friends</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Support from the NHS</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Learning about your condition</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Being able to relax</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Doing exercise</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Getting out and doing things that you enjoy</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Sexual problems</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Healthy eating</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Stopping smoking</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Managing your medicines</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Measuring your symptoms at home</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Any other problems?

Now, please put a cross beside the 3 items you feel that you need most help with

Please do not use or reproduce without the authors’ permission.

Please contact Anne Kennedy for further information (anne.p.kennedy@manchester.ac.uk)
March 2008
Copyright © 2008, University of Manchester, all rights reserved.
### Appendix 8: Coded sheet of transcript (Tod’s final interview)

<table>
<thead>
<tr>
<th>Q</th>
<th>Can we talk a little bit more about where you've put people and what that means to you. I'll put that there. Thank you. Um, so yes, can we look at the diagram in a little bit more detail? Who is the most important to you in terms of your health?</th>
<th>Clarification of importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Wife, I think.</td>
<td>Most person important in network</td>
</tr>
<tr>
<td>Q</td>
<td>In what kind of, way?</td>
<td>Practical support</td>
</tr>
<tr>
<td>A</td>
<td>She looks after me, she looks after the kids, stress free. She just sort of, gets all the stress during the day when I'm not here with the kids. I mean, she copes, I don't, but I do everything else like, you know, clean the house and everything else so; all the jobs I do just keep the upkeep of the house, but, yes, she's just always there. Don't get married for no reason at all, yes.</td>
<td>Comparison about roles</td>
</tr>
<tr>
<td>Q</td>
<td>Excellent and then and so all of the people you've put in the sort of, most important circle. So you put G.P. there and you've moved him out to there?</td>
<td>Reasons for re-positioning network member</td>
</tr>
<tr>
<td>A</td>
<td>Yes. I mean, he's important because you need your doctor and he's been there when I've had problems before like, so and you know, he said like, 'Anytime on the phone just give me a bell, you know, and I will sort it out whatever you need', so but in the long term he's not as important like you know, you don't want to see him every day, don't want to see him every day but er...</td>
<td>Trust developed in relationship with GP based on previous experiences</td>
</tr>
<tr>
<td>Q</td>
<td>So does that make you feel reassured that he...?</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>Yes, he's a really good doctor, you know, he's er, there's a lot; I mean, I used to have a different doctor especially when we lived further away, because he weren't my family doctor, he was (wife)'s family doctor, so when I got married I ended up going to the same surgery like you know, but he is a really good doctor.</td>
<td>Comparing G.P with others experiences</td>
</tr>
<tr>
<td>Q</td>
<td>In what kind of, ways is he?</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>He's friendly, I mean, everybody who knows GP knows that he's a brilliant doctor and he's brilliant face-to-face as well.</td>
<td>More than expected role of GP</td>
</tr>
<tr>
<td>Q</td>
<td>Yes</td>
<td>Repetition of ‘good’</td>
</tr>
<tr>
<td>A</td>
<td>You know, I don't think there's a lot, more like a counsellor as well I think because sometimes like reassures people, 'you don't need to worry about anything, something can be sorted out' you know.</td>
<td></td>
</tr>
<tr>
<td>Q</td>
<td>So it gives you a kind of, confidence?</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>Yes, he is a good doctor</td>
<td>Placed in the diagram</td>
</tr>
<tr>
<td>Q</td>
<td>Excellent and then so looking at this sort of; who else is here? Sorry um...</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>It's just the immediate kids really.</td>
<td>Importance of family</td>
</tr>
</tbody>
</table>
Appendix 9: Ethical Approval Letter

National Research Ethics Service
Salford & Trafford Local Research Ethics Committee
Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP

Telephone: 0161 237 2336
Facsimile: 0161 237 2383

23 January 2009

Dr Anne Kennedy
Research Fellow
University of Manchester
5th Floor Williamson Building
University of Manchester, Oxford Rd
Manchester
M13 9PL

Dear Dr Kennedy

Full title of study: Evaluation of the WISE approach in Primary care: Improving outcomes in chronic conditions through effective self-management

REC reference number: 09/H1004/6

Thank you for your letter of 20 January 2009, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed of SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Consent Form: Trial of the Wise Approach in Primary Care (Patient trial)</td>
<td>1</td>
<td>11 December 2008</td>
</tr>
<tr>
<td>Participant Consent Form: Process evaluation of the Wise Approach in Primary Care (Patient Process)</td>
<td>1</td>
<td>19 December 2008</td>
</tr>
<tr>
<td>Participant Consent Form: Health Professionals and Managers Process evaluation of the Wise Approach in Primary Care</td>
<td>1</td>
<td>11 December 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: Health Professionals and Managers Process Evaluation of the Wise approach in primary care</td>
<td>1</td>
<td>19 December 2008</td>
</tr>
<tr>
<td>Questionnaire: IBS</td>
<td>1</td>
<td>15 December 2008</td>
</tr>
<tr>
<td>Questionnaire: Diabetes</td>
<td>1</td>
<td>15 December 2008</td>
</tr>
<tr>
<td>Questionnaire: COPD</td>
<td>1</td>
<td>15 December 2008</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>23 May 2008</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td>1</td>
<td>19 December 2008</td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>1</td>
<td>11 December 2008</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>11 December 2008</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>19 December 2008</td>
</tr>
<tr>
<td>Application</td>
<td>2.0</td>
<td>19 December 2008</td>
</tr>
<tr>
<td>Protocol</td>
<td></td>
<td>11 December 2008</td>
</tr>
<tr>
<td>Letter from NIHR</td>
<td></td>
<td>20 March 2008</td>
</tr>
<tr>
<td>NIHR Grant Assessment Template</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referee: Professor Harris Mark University of New South Wales</td>
<td>1</td>
<td>23 May 2008</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>23 May 2008</td>
</tr>
<tr>
<td>PRISMS - Patient Report Informing Self-Management Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referee from The University of British Columbia</td>
<td></td>
<td>05 November 2008</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>20 January 2009</td>
</tr>
<tr>
<td>Participant Information Sheet 2 Process Evaluation</td>
<td>2</td>
<td>20 January 2009</td>
</tr>
<tr>
<td>Participant Information Sheet 2 Trial</td>
<td></td>
<td>20 January 2009</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>2</td>
<td>20 January 2009</td>
</tr>
</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npea.nhs.uk.

09/H1004/8 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely,

Dr Mary P Tully
Chair

Email: carol.ebenezer@northwest.nhs.uk

Enclosures: * "After ethical review – guidance for researchers"

Copy to: Dr Karen Shaw
Linda Dack
Appendix 10: Participant Information Sheet

Patient Information Sheet

Exploratory study of the WISE approach in primary care

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?
Many people live with long-term conditions. We want to find out whether an approach we have developed will improve the way doctors, nurses and the NHS support people to manage their condition in their day-to-day lives. We have called this the WISE approach. WISE stands for: Whole Systems Informing Self-Management Engagement.

The WISE approach means that all the staff at your practice will be given training in ways the NHS can support people to self care. In this study, we will look at whether the WISE approach works for people who have diabetes, Chronic Obstructive Pulmonary Disease (COPD) or Irritable Bowel Syndrome (IBS).

Why have I been chosen?
Your GP’s practice has agreed to take part in the study. We are approaching you because you have diabetes, COPD or IBS. In order to help us find out if the WISE approach works, we would like you to answer some questions about the way your condition affects you and how you manage.

Do I have to take part?
No, participation is entirely voluntary.

It is up to you to decide whether or not to take part. If you do decide to take part you will need to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any
time, or a decision not to take part, will not affect the standard of care you receive. Should you decide to withdraw from the study, the contact details of the research team are provided below.

**What will happen to me if I take part?**

We will contact you by phone to ask you either to

1. Agree to two in-depth face-to-face interviews and having regular telephone contact with the research team over the course of a year. The in-depth interviews will take place at the start and the end of the year and will be audio-recorded. The interview will take place in your home and an interviewer will ask you questions about how you manage your condition and the type of support and help you get. The telephone contact will be a short 10 minute phone call every one or two months to ask you about your use of the health service and any self care support you have received in the previous month.

or

2. Agree to fill in a brief questionnaire with a researcher who will ask you to ‘think aloud’ while you fill in the questionnaire. This will help us to find out how you decide to answer the questions and if you have any problems understanding the questions. The interview will be face-to-face and audio recorded.

All the written information resulting from the questionnaires and interviews will be kept in a locked cabinet at the University of Manchester that only members of the research team will have access to.

Those of you who are asked and agree to take part in the in-depth interview study will be given £20 as a token of thanks. Those of you who are asked and agree to take part in the ‘think aloud’ interview will be given £10 as a token of thanks.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. Audio recordings will be destroyed at the end of the research project.

**What will happen to the results of the research study?**

A written report of the study is likely to be available by the end of 2010. If interested, you will be able to obtain an online copy of the report from The National Primary Care research and Development Centre’s website: [http://www.npcrdc.ac.uk](http://www.npcrdc.ac.uk). Alternatively, you may contact the researcher at the address given below.

**Who is organising and funding the research?**

The study is funded by The National Primary Care Research and Development Centre, The University of Manchester.

**Contact for further information**

For further information regarding the study, please contact:
Thank you for taking part in this study
Appendix 11: Participant Consent Form

Centre Number:

Patient Identification Number for this trial: □□□□

PATIENT Consent form

Exploratory study of the WISE approach in primary care

Name of Researcher: Rebecca Morris

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in interviews and to be contacted by telephone as described in the information sheet.

4. I agree to take part in the above study.

____________________  __________________  __________________
Name of Patient       Signature                        Date

____________________  __________________  __________________
Researcher           Signature                        Date
Appendix 12: Journal paper entitled "Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions"
Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions

Rebecca L Morris,1 Caroline Sanders,1 Anne P Kennedy1 and Anne Rogers2

Abstract
Objective: To examine what influences self-management priorities for individuals with multiple long-term conditions and how this changes over time.
Methods: A longitudinal qualitative study using semi-structured interviews completed with 21 participants with more than one chronic condition.
Results: The study demonstrates the impact of multiple conditions on many aspects of people's illness management. Narratives illuminated how individual's condition priorities changed at pivotal points and altered their engagement with self-management practices. This is influenced by contact with health professionals and how people framed illness and lifestyle changes. Medication management was a central point where individuals took control of their conditions. Additional conditions were more readily accommodated if people established a cognitive link between existing management practices. Thus, multiple conditions were not inevitably experienced as an increasing burden but subject to considerable flux and change.
Discussion: Prioritizing one condition over another at a particular time together with a transfer and amalgamation of practices appears to facilitate accommodation of multiple conditions and ease the burden of everyday management. These findings have implications for how we understand the variable nature of multimorbidity experience and management for patients. Clinicians might usefuly engage with patients' understanding to reduce complexity, and enhance engagement of condition management.

1National Primary Care Research and Development Centre, University of Manchester, 5th Floor Williamson Building, Manchester, UK
2NIHR School for Primary Care Research, University of Manchester, 5th Floor Williamson Building, Manchester, UK

Corresponding authors:
Rebecca L Morris, National Primary Care Research and Development Centre, University of Manchester, 5th Floor Williamson Building, Oxford Road, Manchester M13 9PL, UK. Email: rebecca.morris@manchester.ac.uk
Keywords
Co-morbidity, management priorities, multimorbidity, qualitative methods, self-management

Received 15 September 2010; accepted 16 November 2010

Introduction
Co-morbidity is associated with more complex clinical management, worse outcomes, and increased healthcare costs, thus posing major challenges for healthcare systems and professionals. Such challenges have been perceived as difficult to address because clinical practice has tended to be framed within a static, disease-specific model of management with contingent problems for co-ordinating service provision. However, there has been relatively little attention on the challenges of managing multiple conditions for patients themselves, and literature on the experiences of people living with chronic illness has tended to focus on single conditions.

Contemporary health policy has increasingly placed an emphasis on self-care and self-management for people with long-term conditions. Although multiple definitions have been used, these terms have often been used interchangeably. The Department of Health defines self-care as ‘the care taken by individual towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition [sic]; and to prevent further illness or accidents’ (our emphasis). Note that in this definition there is an implicit assumption that patients have one long-term condition, when in reality people are often living with multiple conditions. This assumption has also been reflected in existing systems of disease surveillance such as the general practice Quality and Outcomes Framework, where clinicians are financially rewarded for reaching targets for monitoring specific conditions such as diabetes, coronary heart disease and asthma. Additionally, the concept of self-management as used in policy discourse tends to be associated with education programmes focused on transferring information and skills to enable people to manage their own healthcare, maintain optimal health, and minimize the consequences of their condition. Some self-management education programmes are disease-specific, and whilst the Expert Patients Programme (developed in the USA and adapted for various international settings) was initiated as a generic educational programme for people with different conditions; the issues for people with multiple conditions are largely overlooked.

Bayliss et al. also outline multiple components of self-management including: engaging in activities that promote physical and psychological health; interacting with healthcare providers and adherence to treatment; monitoring health status and making associated care decisions; and managing the impact of illness on physical, psychological and social functioning (p. 16). All these components bring a heightened burden of work for people with co-morbidities and various activities or practices associated for example, with managing multiple drugs regimens, alongside requirements for diet and exercise that might be quite different (and sometimes inconsistent) for different conditions.

In the recent UK ‘Equity and Excellence’ White Paper, there is a shift in emphasis towards greater patient participation and shared decision making building on the previous White Paper which advocated greater control and empowerment for patients. In principle, this should enable patient priorities for self-management and self-care to influence the direction of care. However, as outlined above, existing disease surveillance and self-management education programmes tend to maintain a separation
between conditions which may not adequately reflect the reality of everyday management. \textsuperscript{13} As Kendall et al.\textsuperscript{8} state, there is a broader notion of 'self-management' (in contrast with policy representations of self-management) that involves 'navigating and responding to a myriad of information sources and experiences, many of which originate in their own lived bodily experiences and personal knowledge' (p. 1).

The way in which people with multiple conditions manage such navigation is important and has been hitherto underexplored.

The experiences of people living with multiple long-term conditions

There are a number of compounded challenges patients face in managing multiple conditions including: lack of care coordination that hampers effective use of services;\textsuperscript{14} a greater need for emotional support;\textsuperscript{10} and the need to develop multiple techniques to manage symptoms.\textsuperscript{15} Not all co-morbidities have the same impact\textsuperscript{16} and so may not require the same degree of management. With limited resources available for self-management, patients may prioritize conditions\textsuperscript{17} relative to perceived severity.\textsuperscript{15} Predictability and manageability by medication.\textsuperscript{13} The management of multiple conditions also raises practical and moral issues through attempts to maintain a 'normal life', that is often identified as a priority, but is sometimes only achieved by compromising symptom management in order to fulfill valued social roles.\textsuperscript{18} Sells et al.\textsuperscript{19} found that the experience of multiple conditions can create a cascade of crises whereby increasing physical, psychological and social challenges can place limitations on peoples' roles and relationships, inciting detrimental changes such as the loss of previously valued work roles. Additionally, people with co-morbidities identify challenges in distinguishing between, and responding to exacerbation of different co-morbidities and corresponding management of multiple medications that may interact.\textsuperscript{4} However, there is currently a lack of understanding of how and under what circumstances, patients prioritize conditions and adjust self-management practices.\textsuperscript{8} This also raises questions about how priorities might change over time and how these are negotiated with healthcare professionals. Thus, the aim of this article is to identify how individuals accommodate multiple conditions and how this is likely to influence patient engagement in managing multimorbidities.

Methods

This qualitative study was embedded within a randomized controlled trial aimed at improving self-management support for long-term conditions.\textsuperscript{5,20} Participants were purposefully sampled\textsuperscript{20} to have at least one of three conditions: irritable bowel syndrome, chronic obstructive pulmonary disease, and diabetes. We also sampled to include a range of ages and length of time since diagnosis. Out of 30 participants recruited, 21 (10 female and 11 male) had one or more co-morbid conditions (Table 1). Participants were recruited for interviews when attending two general practices in an economically depressed area in the North West of England. Consent was obtained from all participants before initial interviews. Here, we report findings on the experiences of individuals with multiple conditions which emerged early in the accounts.

Initial face-to-face interviews, telephone follow-ups and final face-to-face interviews a year later were conducted with participants. The semi-structured interview was developed to explore participants existing

\*Here and throughout the paper, we are referring to self-management practices associated with policy and clinical recommendations such as managing medications, taking care of diet and exercise requirements, as well as their own practices that emerge from 'bodily experience and personal knowledge'.
<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Gender</th>
<th>Age</th>
<th>Index condition</th>
<th>Co-morbid conditions (self-defined)</th>
<th>Education</th>
<th>Occupation</th>
<th>Housing tenure</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Female</td>
<td>36</td>
<td>IBS</td>
<td>Occipital neuralgia, re-occurring cystitis</td>
<td>GCSE/O-levels</td>
<td>Station clerk</td>
<td>Owner-occupied/ mortgage</td>
</tr>
<tr>
<td>300</td>
<td>Male</td>
<td>59</td>
<td>Diabetes</td>
<td>High blood pressure, cholesterol</td>
<td>NVQ</td>
<td>Fork truck driver</td>
<td>Rented from local authority/housing association</td>
</tr>
<tr>
<td>500</td>
<td>Female</td>
<td>53</td>
<td>COPD</td>
<td>IBS, depression</td>
<td>NVQ</td>
<td>Unemployed on incapacity benefit</td>
<td>Rented from local authority/housing association</td>
</tr>
<tr>
<td>700</td>
<td>Male</td>
<td>82</td>
<td>Diabetes</td>
<td>Rheumatoid arthritis, high blood pressure</td>
<td>No qualifications</td>
<td>Retired</td>
<td>Owner-occupied/ mortgage</td>
</tr>
<tr>
<td>800</td>
<td>Male</td>
<td>48</td>
<td>Diabetes</td>
<td>Cataracts and eye problems, tendonitis</td>
<td>Degree</td>
<td>Engineer</td>
<td>Owner-occupied/ mortgage</td>
</tr>
<tr>
<td>900</td>
<td>Male</td>
<td></td>
<td>Diabetes</td>
<td>Knee problems, kidney problems</td>
<td>No qualifications</td>
<td>Retired</td>
<td>Rented from local authority/housing association</td>
</tr>
<tr>
<td>100a</td>
<td>Female</td>
<td>66</td>
<td>Diabetes</td>
<td>MS, underactive thyroid, high cholesterol</td>
<td>No qualifications</td>
<td>House wife</td>
<td>Owner-occupied/ mortgage</td>
</tr>
<tr>
<td>110a</td>
<td>Female</td>
<td>57</td>
<td>IBS</td>
<td>Blood pressure, cholesterol, hypertension and COPD</td>
<td>No qualifications</td>
<td>Cleaner</td>
<td>Owner-occupied/ mortgage</td>
</tr>
<tr>
<td>120a</td>
<td>Female</td>
<td>57</td>
<td>COPD</td>
<td>IBS</td>
<td>Trade qualification</td>
<td>Unemployed on incapacity benefit</td>
<td>Rented from local authority/housing association</td>
</tr>
<tr>
<td>Age</td>
<td>Gender</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Occupation</td>
<td>Housing Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>--------</td>
<td>-----</td>
<td>-----------</td>
<td>------------</td>
<td>----------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>140a</td>
<td>Male</td>
<td>52</td>
<td>COPD, Hypertension</td>
<td>GCSE/O-levels</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>150a</td>
<td>Male</td>
<td>55</td>
<td>Diabetes, High cholesterol</td>
<td>GCSE/O-level and professional qualification</td>
<td>Industrial specialist</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>170a</td>
<td>Female</td>
<td>55</td>
<td>Diabetes, Epilepsy</td>
<td>GCSE/O-level and professional qualifications</td>
<td>Ward clerk</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>100s</td>
<td>Male</td>
<td>84</td>
<td>Diabetic, Ischemic heart disease, arthritis</td>
<td>Trade or professional qualifications</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>200s</td>
<td>Male</td>
<td>83</td>
<td>IBS, Hearing problems, high cholesterol, memory problems, back pain and signs of angina (particpant wording)</td>
<td>Trade/professional qualifications</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>300s</td>
<td>Female</td>
<td>50</td>
<td>Diabetic, Chronic depression</td>
<td>Trade qualification</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>400s</td>
<td>Female</td>
<td>84</td>
<td>COPD, High blood pressure, backouts Arthritis</td>
<td>No qualifications</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>500s</td>
<td>Female</td>
<td>76</td>
<td>COPD, Arthritis</td>
<td>A-levels/professional qualifications</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>600s</td>
<td>Male</td>
<td>65</td>
<td>Diabetes, High blood pressure, high cholesterol</td>
<td>GCSE/O-levels</td>
<td>Retired</td>
<td>Rented from local authority/housing association</td>
<td></td>
</tr>
<tr>
<td>800s</td>
<td>Male</td>
<td>65</td>
<td>Diabetes, Heart bypass, ulcers on bottom of feet</td>
<td>Unknown</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>110s</td>
<td>Male</td>
<td>69</td>
<td>COPD, Oesophageal problems (caused by a hiatus hernia), feet problems</td>
<td>GCSE/O-levels</td>
<td>Retired</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
<tr>
<td>120s</td>
<td>Female</td>
<td>54</td>
<td>Diabetes, High blood pressure and high cholesterol</td>
<td>A-levels and trade/professional qualifications</td>
<td>Catering supervisor</td>
<td>Own-occupied/ mortgage</td>
<td></td>
</tr>
</tbody>
</table>
management strategies, experiences with primary care, and the influence of social networks on management. A short questionnaire was completed at the beginning of the interview which included questions on age, gender, education, employment and ethnicity. All interviews were conducted by RM. Regular meetings with all authors continued throughout the data collection; so that areas which emerged of particular interest could be discussed and incorporated into further interviews. One participant withdrew 5 months into the study because of ill health and three were unreachable for final interviews. The longitudinal design allowed for emergent topics to be discussed in detail and the subjective experiences of illness to be placed within the temporal context of personal narrative accounts and changes in health. A semi-structured and narrative approach extended accounts allowing for topics like co-morbidity to emerge. Follow-up interviews allowed what had changed and remained the same in their health and illness management to be identified.

All interviews were transcribed, read and reviewed by all authors to identify key concepts and themes emerging. Discussion meetings were held regularly throughout the interviewing and analysis stages to discuss and reach agreement on emerging topics. Some themes were coded early in the process, such as the impact of having multiple conditions on the management of daily life, whereas others emerged after further analysis. In order to refine analysis, the transcripts were reanalysed to identify whether themes emerged across all interviews and to identify deviant cases. Through narrative analysis interviews were placed in context, allowing the complex, contingent and dynamic nature of illness management to emerge.

Ethical approval for this study was obtained by Oldham Local Research Ethics Committee reference 07/H1011/96.

**Results**

Multiple conditions impacted on many aspects of self-management. Central to interview accounts were descriptions of changing priorities for self-management over time reflecting a dynamic process of prioritizing conditions. Changes occurred at pivotal points where people expressed accommodation or rejection of new self-management practices associated with additional diagnoses. A key element to influencing engagement with multiple self-management practices was interaction with health professionals and this also related to perceived appropriateness of information received.

**The dynamic prioritization of conditions**

Most respondents described how they predicted the need to re-prioritize conditions, often in response to a negative effect of one condition (or its treatment) over another. Sometimes this was a response to external changes that threatened to exacerbate a particular condition. The need to focus on one condition more than another, also entailed assessment of available resources needed to manage a condition effectively:

*But it’s hard (to lose weight) I don’t know. So I put it down me personally to the tablet, whether that’s putting weight on I don’t know….just watching what I eat now you know with diabetes really more than anything like… But this breathing, this COPD that’s what will affect me in another few weeks when it starts getting cold, it’s the cold that affects me.*

ID 608 (Diabetes, COPD high blood pressure, high cholesterol, male, age: 65)

Additional conditions seemed to make management of daily life increasingly disruptive and burdensome rather than routine.
This can't be fixed, the damage has been done...I'm trying, I can't. And it's only these past months, to be quite honest with you, that I've had this, I've got to have this attitude, but I find it, I just don't. I get restricted with it, I can't walk, fifty yard sometimes. I can't get in the shower if it's too much steam, I have to get out of the shower and sit on the toilet and try and...I am stubborn, I suppose, but there are times when I feel like giving up because of it.

ID 0900 (COPD, IBS, depression, female, age 53)

The interpretation of information and capacity to carry out self-management activities were also a challenge:

I don't know whether it's I am carrying too much weight or I'm having too much sugar...but I'm trying to find out...and all I get from (G.P., it is your diabetics, they give it a different name all together. I forget, I can't get my bloody tongue round it and yeah, that's one main thing and the other is, I have had my eyes done cataract done and that, that were alright but um, it's just niggle.

ID 0900 (diabetes, knee problems & kidney problems, Male, Age, unknown)

I have, yeah just get on with it. It's a chronic condition, there's not a lot I can do about it other than, except I'd like to take more exercise, walking, but at the moment as I say because of my feet problems. I can't, so it's a double whammy as they say.

ID 110s (COPD, oesophageal problems, feet problems, male, age 69)

An interplay of factors was evident in the way in which people prioritized and reprioritized illnesses and their management over time. Such factors included timing between diagnoses, prior experiences, recommended self-management activities, bereavement, contact with health services and flare-up of conditions.

...there's been a lot of things going on, because I started with epilepsy in two thousand and it's like I was, I had like a cluster and then they settled down...and then out of the blue I started with another cluster, but I think it's hormonal because that started up. I started with diabetes and blood pressure you know, it seemed just, and I had gone through a period of depression because of [losing] my Dad.

ID 170a (Diabetes, epilepsy, female, age: 55)

Respondents described transition points where management activities were re-ordered. At these time points, participants sought support and reassurance more actively and outcomes from this process of help-seeking influenced whether individuals became overwhelmed and disengaged, or alternatively, felt able to take more control over their health (Figure 1). Reprioritization occurred when the perceived importance of different management practices changed due to negative or positive experiences. Tipping points arose in relation to medication management, lifestyle changes, or new understanding of a particular condition. Conversely, the smooth accommodation of further conditions could occur where there was congruence with existing management practices:

I have to sort of eat regularly for the epilepsy, eat regularly, not get over tired, not drink too much alcohol...don't skip meals, so that is what I do for the epilepsy anyway, so that's what helps with the diabetes as well.

ID 170a (Diabetes and epilepsy, female, age 55)

The above challenges a presumption in the literature that multimorbidity by definition requires ever more complex and burdensome self-management and that a new set of practices is required for each 'new' condition acquired.17

Whilst this is sometimes the case, just as salient is evidence of a process of continuation and congruence with existing
self-management where strategies that are deemed to work for one condition are applied to another.

A: Well she talked about diet and sun, yes really it was diet really you know, just be careful what I eat.
Q: And has that been a big change?
A: No not really ‘cos I was already on quite a healthy diet . . . You know, before that I’d um, I’d decided to lose a bit of weight if I could because with having MS it’s better not to carry a lot of weight with it.
ID 100a (Diabetes, Multiple Sclerosis, underactive thyroid & high cholesterol, female, age 66)

Respondents often described an accumulation of coping strategies over time that sometimes created tensions, as participants necessarily grappled with prioritizing in the face of limited resources available for management. The process was exacerbated with additional diagnoses prompting dynamic shifts in management priorities to meet multiple management needs.

Exercise
Exercise was considered an important part of self-management by participants although for many, this was not realistic

---

Figure 1. Diagram showing the factors which influence the impact of having multiple conditions on self-management and how these influences shift over time.
because of functional limitations. When conditions placed a physical limitation on
an individual this was often talked about as having the greatest impact on their
lives because it created a tension between self-management practices individuals
thought they should be prioritizing, and the embodied realities of restricted physical
functioning. Restrictions could accumulate and produce further problems which influ-
enced what could be attempted.

Breathing. Um, only that I can’t do the things I used to, but whether that’s breathing
or whether that’s old age I’m not sure. In
truth, I suppose I used to walk up to [town
centre], now I get a taxi... Or somebody
takes me, but seventy percent of that is
because of my feet, maybe thirty percent
[because of COPD]. If my feet were fine, I’d
still walk up to [town].

ID:10s (COPD, oesophageal problems &
feet problems, male, age: 69)
... and then I rejoined[gym] again last year,
and I’ve not been well and I left it again...
They just sent me a thing the other day about
rejoining again, they do all different uni,
there’s swimming, and a sauna and Jacuzzi
and everything like that, there’s a lot of
people, and you get it cheaper being over
sixty... yeah it’s cheaper like you know. And
I was in that, but then I was having this
trouble with me breathing and trouble with
this arthritis and... I just couldn’t draw
myself to going like you know.

ID: 60s (Diabetes, high blood pressure,
high cholesterol, male, age: 65)

**Interactions with health professionals**

The ‘sequential model’ of how health professionals’ clinically manage multiple condi-
tions during consultations suggests limited consideration is given to interactions
between conditions. By contrast, we found that most respondents described a
dynamic and variable process of self-
management with little demarcation made
between conditions. Respondents’ accounts of management practices were viewed across
conditions with links in practices and the
active weighing up of choices between
options. This apparent difference between health professional accounts and patient
approaches to multimorbidity was evident
when participants talked about seeking
information and management strategies
across conditions and were given little or
no information.

The degree of congruence or conflict
between views of health professionals and
patients regarding management priorities
impacted upon subsequent management
practices and therapeutic relationships. For
participants who described similar manage-
ment goals to their health professionals,
contact reinforced and maintained
priorities.

Q: What’s kind of your main priority at the
moment with [G.P.]?...
A: Probably blood pressure, probably and
cholesterol... so I’m more worried about
these because they are more serious things.
IBS didn’t kill anybody, you know, but blood
pressure is serious and cholesterol is serious
so IBS has gone into the background, you
know.

ID: 110s (Irritable bowel syndrome and
high blood pressure, female, age: 57)

However, for participants whose illness
management priorities conflicted with
health professionals, established relation-
ships were challenged. One woman with
diabetes and chronic depression described
being upset and ‘angry’ when her general
practitioner (GP) told her that she just had to
have willpower to control her diet for dia-
abetes. Her priority was depression and not
being able to control her eating, which she
recognized affected her diabetes control.
This was a complex problem which she
had actively tried to change over a number
of years. When she tried to obtain informa-
tion about managing both conditions she
found that the professionals couldn’t offer any help. The GP’s response conflicted with her priorities and had a negative impact on what she felt able to engage with in managing her health.

However, some respondents portrayed a sense of an ever increasing burden of tablets and perceived themselves to have little control over medication regimens.

I mean I’ve got to say when the doctor, when the GP said it to me, I actually came home and felt er, why should I stick to this diet, because I was depressed I felt, I’ve nothing to live for anyway, the diabetes will kill me anyway.
ID 300a (Diabetes, chronic depression, female, age: 50)

Where self-management instructions and information from the GP were incongruent with personal priorities as illustrated above, respondents remained disengaged from professional advice.

Medication management

The narratives of respondents were replete with references to medication management. Participants’ accounts of medications were framed in one of two ways: as an external event which was something ‘being done to them’ by health professionals that they had little control over; or conversely, as an internal process whereby they gained control of their illness management by establishing routines for taking tablets and personalizing medication regimens. For participants whose narratives were constructed around taking control, the presence of multiple long-term conditions played a minor role in everyday life.

I am quite vigilant about taking my medication um, and if I’ve missed it I do know that I do start feeling tired um, so I am quite compliant with me medication, but I have to take my epilepsy medication anyway so yeah, I take me medication morning and take my medication at night, like I say I am quite compliant about that.
ID 170a (Diabetes and epilepsy, female, age: 55)

Medications were also objects around which changes could be negotiated. Some respondents described seeking sources of information regarding the purpose and side effects of medication to supplement and verify information provided by clinicians. Participants did not always feel confident that the latter were aware of all the medicines they were taking or their interactions and effects. The main sources of verification came from the internet, pharmacists and other people with similar conditions. Participants sometimes depicted a change to becoming active self-managers and taking control by seeking out enough information to make legitimate decisions about continuing with or changing medications.

I asked the pharmacy yesterday, I rang them up, cos I’m taking so many different drugs, you’ve gotta be careful. And they were saying, I was saying could you take them at the same time, cos you’re supposed to take these with food but you can’t take ‘em all with food... there’s one or two more, but... you’ve gotta keep a track.
ID 0700 (Diabetes, rheumatoid arthritis, high blood pressure, male, age: 82)

I take a lot of tablets now, every time I go and see him, "Don’t give me another tablet...". He tries me on different things and what you know doesn’t agree with me, he doesn’t give me... he knows that you know...
what I mean. Same as pain killers, I won’t take pain killers, I only take paracetamol.
ID 120a (COPD and IBS, Female, age 57)

Understanding of conditions
The way participants understood and interpreted information relative to different conditions, influenced how they prioritized management activities. For many respondents, there was uncertainty over which condition was causing which symptoms, and individuals tried to deal with ambiguous feelings of ill health by relating back to their self-defined priority condition.

Information
Information was often received from multiple sources and was viewed as contradictory or too general with insufficient detail about interactions across conditions. This led respondents to either feel confused or to actively re-evaluate the suitability of information provided by practitioners in the light of their existing knowledge and direct personal experiences. Information and advice had to be re-interpreted and verified for it to be useable and for it to permeate the development of pragmatic routines.

Again, if you start to research it you come across dietary and nutrition, so that one kills all the sugars off and that kills all the fat off and the two of them just clash all the way down... You end up with you would be eating absolutely nothing except fruit and the odd slice of bread.
ID 150a (Diabetes, high cholesterol, male, age: 52)

Dietary advice
Dietary advice was often considered generic and insufficiently tailored for individuals. Healthcare professionals were sometimes reported to give conflictual information that did not always address the impact of other conditions. This meant that respondents were often left to navigate through conflicting information to find the most appropriate course of action or to seek further information.

Well she [practice nurse] gave me um, information on diet which you could read in any woman’s magazine, there was nothing specific. I did say to her that my problem was binge eating and she had nothing to offer at all. She could not comment you know she knew nothing about it, so she wasn’t able to help. So as I say it was a complete and utter waste of time.
ID 300s (Diabetes & chronic depression, female, age: 50)

Discussion
We know from previous research that individuals with multiple conditions often struggle to manage multiple and complex treatment regimes. The findings of this study illuminate further what causes these priorities to change and the impact this has on illness management practices. The shifting prioritization of conditions is an ongoing and dynamic process occurring around key points, such as contact with health services and medication management. Narrative accounts from individuals show how the prioritization of conditions for self-management are contingent upon a number of factors such as timing between diagnosis, the ability to make links across practices designed for one condition to another, the accommodation of new practices into existing routines, and understanding of conditions. Whilst the management of co-morbidities could be experienced as cumulative and burdensome our results also point to the transfer and use of practices learned to accommodate one condition applied to another. For this to happen, a flow of information and ability to negotiate and agree priorities and problems with professionals needed to be present.
Links made across conditions seem key to how respondents are able to integrate and accommodate further conditions into existing practices. On the whole, these links were made intuitively and experientially over time and mainly with little guidance from health professionals. This resonates with health professionals’ accounts of a sequential approach to multiple conditions. This has important implications as the current UK policy and disease surveillance indicators predominantly focus on clinical priorities for individual conditions in a way which reinforces condition separation. Patient education programmes also maintain this separation as they tend to focus on single conditions or conversely, programmes such as the Expert Patients Programme, are focused on general chronic condition management and are not intended to explore the experiential links that people can make across conditions. Medication management emerged as an anchor or point around which multiple condition management could be changed (or abandoned) and represented a point whereby a person could either take or abandon control. Similar to Townsend’s study, individuals described taking tablets with reluctance, as ‘something that had to be done’ with few connections to them as facilitators of roles except when describing management of conditions during exacerbation. Few individuals described ‘flexible regimens’. Medications from multiple sources with various recommendations led to confusion but also to the development of pragmatic routines which enabled respondents to take control.

Whilst our interviewees often identified what constituted a main condition for themselves, how and why this priority changed emerged as a salient aspect of self-management. The latter occurred through an accumulation of factors crossing a threshold and shifting an individual’s priorities. Conceptualizing this shift in priorities in a cyclical way (Figure 1) is novel in showing a complex interplay of influences from lay and professional sources which may influence the engagement with and content of multiple condition self-management. This shifting prioritization might be explained by the fact that although the interview focused on one condition, it was important for respondents to portray their illness management in its totality. When practices conflicted, prioritization became explicit as choices were made according to limited resources. This latter observation has the potential to help health professionals understand people’s abilities to coordinate management of their conditions and has implications for shared decision making.

Individual’s decisions were based on personal experiences and influenced by recursive relationships with their healthcare providers and other priorities in life. Individuals reflected back before deciding to complete or abandon a practice.

Finally, multimorbidity did not necessarily mean an addition to illness work as further conditions fitted within existing notions of illness management. The ability to adapt to changes in management at points of transition related to how acceptable and predictable these were, reflecting either biographical ‘anticipation’ or ‘disruption’. If a practice challenged existing notions of prioritization, it became disruptive when it threatened existing explanatory models, leading to confusion and disengagement. Whereas if changes in practices were framed within existing management they required fewer resources and were more likely to be integrated, any further changes which pushed these norms of practice were more acceptable. Recognizing and highlighting to patients where links can be made from existing management practices is a central role for clinicians. Rather than treating each condition separately, acknowledging similarities with existing practices can reinforce or promote these behaviours and
may be a key way to support patients. Also, it is important to identify points where there are opposing management strategies and support individuals to make the most appropriate decision for their situation and review this as it changes over time. This has important implications for informing shared decision-making in consultations within primary care if there is to be congruence between clinical practice and the way in which individuals prioritize and cope with multiple conditions in the reality of everyday management.

Strengths and limitations

One limitation of this study was that recruitment was not based on having multiple conditions, although the longitudinal design enabled themes that arose to be explored and furthered with the same participants. However, 21 participants identified themselves as having more than one condition and raised issues about them all during the interviews showing how in reality management of health was not defined by condition alone but also through the practices involved. Using a self-definition of co-morbid conditions meant some conditions were included which might not be medically defined as long term, however the conditions had on-going influence and challenges for participants’ health management. Despite the range in number and type of co-morbid conditions and degree of impact as well as most participants being over 50 years old; the way in which management was prioritized and changed over time cut across descriptions. Although socioeconomic status has been linked inversely with multimorbidity, there were clear differences in localities between participants and such nuances were not reflected in the socioeconomic variables collected (Table 1), but should be addressed in future research. By using research methods which enabled individual’s narratives to guide interviews, salient issues arose. This allowed a more complex and complete view of: condition management; individual priorities; and strategies employed to embed practices within everyday routines to be obtained.

Conclusions

The processes through which additional conditions are adopted into existing management practices requires understanding so that they become ‘minimally disruptive’. This study shows that individuals prioritize conditions and management practices and this changed over time and was reflected in the relative engagement of self-care activities for the various conditions. This has implications for clinical practice and self-management interventions as they need to reflect a dynamic model of illness management which acknowledges that management of multiple conditions is enhanced when links between existing practices and new condition priorities are explicitly highlighted and reviewed over time. These findings suggest that training for clinicians should encourage them to make explicit links across conditions during consultations in order to reduce the impact of multiple conditions by highlighting the transferability of existing management practices so as to engage patients in the accommodation of new routines. Patient education programmes also need to address the complexity and reality of managing multiple conditions. Future policy initiatives need to recognize the impact of managing multiple chronic conditions in both the commissioning of care and through policies to engage individuals with multiple conditions such as promoting disease surveillance which combines testing and education to reduce the amount of time and resources that patients must allocate in the monitoring of their conditions which often is
additional to the existing consultations that patients require.

Funding
This qualitative study was funded as an NCCRC research training fellowship granted to RM by the Primary Care Research Group, University of Manchester. The WISE study, from which respondents for this qualitative study were drawn, is funded by the NPCRDC, Department of Health. The views represent those of the authors and not the funders. The Department of Health had no involvement in the research process or writing of this article.

Acknowledgements
The authors thank the patients who gave their time sharing their experiences and thoughts, the practices that took part in the study and all members of WISE research group.

References


