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Living with a long-term condition and low health literacy skills: how a tactical use of health literacy skills and a personal social network can contribute to self-management

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by

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Abstract

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Doctor of Philosophy

Living with a long-term condition and low health literacy skills: how a tactical use of health literacy skills and a personal social network can contribute to self-management

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This thesis posits that investigating and understanding the everyday process by which people living with a long-term condition self-manage can contribute to the debate about how people with long-term conditions can become empowered. A pragmatic, design-based study was undertaken to address the research question;

> How do health literacy skills and a personal social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills?

Twenty-two people living with at least one long-term condition were interviewed on two occasions. The first interview followed a structured approach to understand the person's health literacy skill level and the composition of their personal social network. The second semi-structured interview aimed to reveal further detail about the contribution of health literacy skills and a personal social network to the management of their condition. Framework analysis was applied to elicit themes and findings from the data.

Participants were recruited from community clubs, which provided them with opportunities to meet others, including others with the same conditions. A novel finding was that, to assist them with de-coding health information, participants living with a low level of health literacy skills required translators; people or technology that could de-code the information and relay the information in such a way that the participant could understand the information.

The constructs of affinity, utility and reliability were useful for understanding how participants perceived the social ties that were available to them and three tactics for negotiating social ties were identified.

The process of being part of a social group facilitated empowerment, where empowerment is viewed as a process of personal transformation enabling control over one's management of health. The community clubs provided participants with the opportunity to view their own situation through the eyes of others, which brought a new perspective to their difficulties *and* potential solutions.

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Research Thesis: Declaration of Authorship

Print name: Lyn Margaret Wilson

Title of thesis: Living with and managing a long-term condition: how a tactical use of health literacy skills and a personal social network can contribute to empowerment

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: .... Date:...........................

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The community clubs that enabled recruitment

And finally - *many* thanks to the participants who so willingly offered me their time, thoughts and experiences.

Abbreviations & Definitions

AAHLS	All Aspects of Health Literacy Scale
CSE	Certificate of Secondary Education
DH	Department of Health
ERGO	(University of Southampton) Ethics and Research Governance System
FCCHL	Functional, communicative and critical health literacy tool
GENIE	Generating Involvement in Network Engagement
GP	general practitioner (primary care doctor)
HCP	health care professional
HLS-EU	European Union Health Literacy Scale
HLS-14	14-item Health Literacy Scale
IMD	Index of Multiple Deprivation
LTC	long term condition
LTCs	long term conditions
NHS	National Health Service
O level	General Certificate of Education, ordinary level
REALM	Rapid Estimate of Adult Literacy in Medicine
TOFHLA	Test of Functional Health Literacy in Adults
UK	United Kingdom
US	United States
WHO	World Health Organisation

Empowerment	a process of personal transformation enabling control over one's management of health
Health information	information which is useful for managing health, can include written or verbal information such as facts, treatments and management actions
Health literacy	a process whereby society works to enable populations to become health literate
Health literacy skills	skills of finding and reading health information, understanding (or de-coding) information, applying information to one's situation, judging the quality of information, and explaining information to another person
HL skill ability	the degree to which an individual can obtain, understand and apply information required for health-related decisions and actions
Long-term condition	a condition that impacts on a person's health and lasts at least a year (National Institute for Health and Care Excellence 2016)
Motivation	a person's judgement of the importance for making a change and their confidence to make a change
Personal social network	a theoretical construct which explains, and accounts for, the social relationships that an individual experiences
Self-management	a dynamic lived process (Kendall et al 2011) through which a person undertakes actions to promote their health, manage illness and manage life with a long-term condition (Audulv et al 2012)
Social capital	the benefit accrued from working with others within a community
Social support	the provision of resources, by alters, which is perceived by an ego as to improve the ego's health and well-being
Tactics	the art and skill of employing available means to accomplish an end (Merriam-Webster 2018)

Chapter 1 Introduction and Background

1.1 Introduction

This thesis discusses the rationale, design, methods and findings for empirical research which aimed to answer the following research question:

> How do health literacy skills and a personal social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills?

This chapter presents the aim and rationale for the selected topic, the research paradigm and the study design. The first two sections present concise definitions and explanations for the key concepts explored in the thesis. The personal rationale explains why the research is important and why the work is significant for me as a public health practitioner. A reflexive section on my stance toward the research is followed by the chapter summary.

1.2 Thesis aim and rationale

1.2.1 Thesis aim

In this thesis I take a health promoting stance toward self-management of long-term conditions where *health* is seen as a resource for life (World Health Organisation (WHO) 1986), *self-management* requires people to be ‘active agents’ in managing their health (WHO 2020) and *health promotion* is the process whereby people are enabled to become *empowered*, that is, to have control over and to be active in the management of their health (WHO 1986). People’s involvement and participation in taking control of their health is a key principle of health promotion, as is tackling the determinants of health and encouraging health professionals to educate and advocate for health (Wilkinson & Marmot 2003, Green et al 2015). The determinants of health include political, social, economic, environmental, behavioural and biological factors (Dahlgren & Whitehead 2007), that is, factors which are within an individual’s ability to change *and* structural factors determined by societal choices. Health promoters may therefore instigate a range of actions or interventions to promote the health of individuals, groups, communities or populations, including lobbying for and building healthy public policy, reorientating health services, creating supportive communities and developing people’s knowledge and skills (WHO 1984).

This thesis has a pragmatic focus on understanding the process of self-management of a long-term condition from the perspective of individuals, an objective being to draw on these understandings to inform health professional and public health practice as to how best to support and encourage self-management. Taking a health promoting standpoint I situate self-management of a long-term condition (LTC) within *everyday* life, where the person living with a condition is informed and supported to manage their condition but ultimately has control over their own decisions and actions (Dean 1989, Foss et al 2016). Dean (1989) suggests that, as self-management requires behaviours, social interactions *and* positive attitudes, the process can be normalised as a 'lifestyle'; in other words, self-management is a personal behaviour which impacts health. LTC self-management therefore has equivalence with definitions of health behaviours, which comprise activities undertaken to prevent or detect disease or to improve health and wellbeing (Conner & Norman 2015). The actions undertaken include lifestyle behaviours, use of health services and management of medical conditions. Health behaviours and self-management of LTCs can therefore be viewed as one and the same, with perhaps the context for the behaviours being clearer in the term 'self-management of LTCs'. However, it is important to acknowledge that self-management and its success or otherwise is not completely dependent upon individual behaviours alone. A study by Rowland et al (2017) found that, when asked about managing their health, people acknowledged that their decisions were important but they also recognised that the broader social determinants of health, such as money or work, impacted the way they lived their life and, ultimately, their health and well-being status.

It is pertinent here to explore the positioning of the thesis key concepts within an adapted version of the Dahlgren & Whitehead (2007) determinants of health model. See Figure 1 which presents the determinants of health for a person living with a long-term condition. Health literacy skills are positioned within the individual factors layer, and social and community factors contribute to the personal social network that an individual experiences.

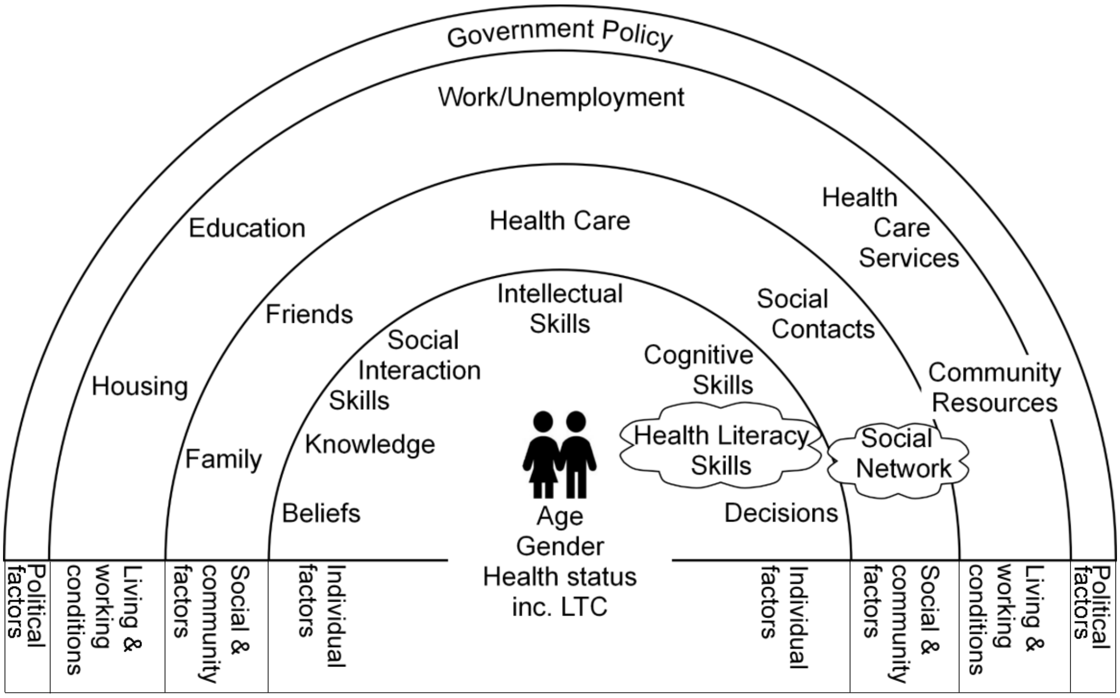

Figure 1 **The Determinants of Health** (adapted from Dahlgren & Whitehead 2007)

In the original model the first layer of factors is labelled as individual lifestyle factors, this has been expanded in Figure 1 to illustrate the factors which underpin health behaviours, including knowledge, skills and cognitions. Health literacy skills are positioned as an individual level factor and integral to decisions about health behaviours. A personal social network is positioned within the second layer of social and community factors, comprising factors which can support, prevent and influence an individual's health behaviours. Social interaction skills, however, are an individual level factor. Figure 1 additionally indicates the social determinants of health that impact LTC self-management, for example the provision of health care services, the type and level of education an individual experiences, and government policies. The Dahlgren & Whitehead (2007) model is therefore helpful for illuminating the range of factors which impact health and the level at which determinants act however it can be critiqued as lacking explanatory power in terms of pathways to explain how the factors, separately and in combination, impact health status. When considering LTC self-management the potential pathways of action for health literacy skills and personal social networks are explored and debated throughout this thesis but the following section introduces some underpinning theoretical assumptions.

People living with an LTC experience inequalities in health across geographical areas, gender, socioeconomic group and ethnicity (Department of Health (DH) 2012) and a range of health determinants, social and individual, mediate LTCs. The incidence of LTC and co-morbidity increases with age meaning that people aged over 85 are most likely to be living with a LTC (NHS

England 2014). Lifestyle factors directly impact some LTCs, for example smoking is a causal factor in heart disease, stroke and lung cancer, and being obese or overweight increases the chance of developing type 2 diabetes (Diabetes UK 2016). There have been reductions in the prevalence of some lifestyle risk factors such as smoking, but health inequalities are still widening (Institute of Health Equity (IHE) 2020); people living in poverty are more likely to smoke, be inactive, drink excess alcohol or be obese. In terms of health inequalities the impact of social and economic determinants, for people living with LTCs, is even more compelling than lifestyle factors, experiencing a chronic condition can itself create hardship and deepen poverty (Furler et al 2011). People living in severe deprivation such as homelessness are significantly less able to self-manage their health and more likely to use emergency services (Aspinall, 2014). The recent Marmot Review update (IHE 2020 p94) found that particularly deprived areas, known as 'left-behind' communities, experience high rates of chronic conditions such as coronary heart disease and diabetes. The Review concludes that poverty, fuel poverty, air pollution and unhealthy high streets (for example, lacking green space and access to healthy options) all determine and exacerbate health inequalities, including higher risks of developing LTCs (IHE 2020).

In Figure 1 health behaviours are an individual level factor, additionally health behaviours are indirectly impacted by wider social determinants, for example, a lack of education will impact the level of health literacy skills an individual possesses (Finbråten et al 2020). In turn, health literacy skills will determine the level of knowledge and whether information is understood, thereby impacting the ability to apply information to oneself and the understanding of the need and method for enacting the information (Nutbeam 2000, Kickbusch 2001). For example, if a person cannot read the instructions on a medication they may not understand how to take the medication and may not take it as required, and their lack of reading ability is not a personal choice but determined by social factors.

The personal social network is positioned in Figure 1 as a social and community level factor yet an individual will make decisions as to whether to accept or reject social support. A personal social network can comprise other people providing support with doing things (instrumental support) and/or emotional support and/or informational support (Bury 1991, Berkman et al 2000, Thoits 2011). Informational support can 'overlap' with health literacy skills in that others may 'perform' health literacy skills that an individual is unable to undertake (Edwards et al 2015). To engage with the network individuals will require social interaction skills, and debate continues as to whether some of these skills, for example communicating, are also health literacy skills (Nutbeam 2000, Tones 2002). Other social and community factors that can contribute to LTC self-management include community resources such as clubs, the Internet and health care professionals, and individuals may lack capacity to engage with these resources or decide not to engage. The thesis focus on people being informed and knowledgeable about how to manage their LTC, and supported to gain control over the day-to-day management, identifies the context for self-management behaviours. However, this supposition raises a question of how, and whether, people can gain control over and become informed about self-management, particularly when they live with low levels of HL skills.

In terms of long-term condition self-management a range of evidence (Paasche-Orlow & Wolf 2007, Johnson et al 2010, Ellis et al 2012, Aaby et al 2020) demonstrates that possessing health literacy skills and having social support is positively associated with a person’s capacity to manage a long term condition, and that poor health is associated with low health literacy skills and living alone (Easton et al 2010, Aaby et al 2020). Correspondingly, people living with low levels of health literacy and low support experience health inequalities in terms of access to care, increased risk of morbidity and premature death (Roberts 2015). Finbråten et al (2020) found that high levels of health literacy were associated with more education, good general health and empowerment; the authors suggest that strengthening health literacy could improve people’s health but are vague as to how this could be achieved. Social support is integral to self-management with supporters providing emotional, practical and informational support (Schiotz et al 2012, Foot et al 2014, Vassilev et al 2016) and Waverijn et al (2016) found that people living with an LTC and a good level of health literacy skills were able to leverage health information via supportive networks. Waverijn et al (2016) reflect on whether access to support and information can be enabled for people living with low health literacy ability and suggest there is more to discover about the transfer of health information within communities and the ways in which people draw on information and support from others.

This thesis posits that people living with a LTC and experiencing low health literacy skills may lack control over their health, particularly if they find it difficult to understand their health condition and the actions required (Easton et al 2010). It is also acknowledged that LTC self-management is perceived by people as a part of or a product of their life and all that entails (Foss et al 2016), fitting within the health promotion aim to act within settings in which people live, work and play (WHO 1986).

In summary, a health promotion aim to support people living with LTCs and a low level of health literacy skills is important and has the potential to reduce health inequalities (Roberts 2015, Gibney et al 2020). Health literacy skills are required for gaining knowledge from information however it is unclear whether health literacy skills play a part in accessing support for self-management (Edwards et al 2015, Waverijn et al 2016). Consequently, when focusing on people living with LTCs and a low level of health literacy skills, there are gaps in the evidence for understanding how they self-manage, the role their personal social network plays in the self-management process, and how they can be supported and empowered to manage their health. This synthesis leads to the formulation of the thesis aim:

> To identify how health literacy skills and a personal social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills

1.2.2 Thesis rationale

In social care a long-term condition is defined as a condition that impacts on a person's health and lasts at least a year (National Institute for Health and Care Excellence 2016). The Department of Health (DH 2012) takes a medical-focused approach stating that LTCs are incurable but can be controlled by medication or other therapies; both sources agree that LTCs include conditions such as diabetes, asthma, arthritis and chronic obstructive pulmonary disease. The key points are that LTCs are long-lasting health conditions which - if people living with such conditions wish to minimise symptoms, health problems and deterioration in their health - require management. Managing a long-term condition (LTC) can be known as self-management (Matarese et al 2018), potentially a slightly confusing term as the 'self' refers to the individual person, not 'managing alone'. Self-management of an LTC requires undertaking a range of actions and behaviours to manage one's health and, ideally, this is undertaken with the support of others - including family, friends and health care professionals (National Voices 2014).

Long-term condition self-management requires knowledge and to acquire knowledge people use information (Wilson 2000). Wilson (2000) argues that knowledge is a characteristic of an individual, that is, only that individual knows what they know. Knowledge can be shared with and transmitted to others as information. Because information is transmitted verbally or in a written form knowledge as information is provided in a coded form (Egan & Gajdamaschko 2003). For example, information about LTC self-management can be provided in a written or digital form or verbally by health care professionals (HCPs). Reading (or hearing), de-coding and understanding information requires skills and *health literacy skills* therefore incorporate the skills *required* to read, understand and apply health information to one's situation (Egan & Gajdamaschko 2003). Hence health literacy skills include the ability to: find and read health information, understand information, apply information to one's situation, judge the quality of information, and explain information to another person (Nutbeam 2008, Ishikawa et al 2008). In this thesis the breadth of health literacy skills will *not* include numeracy skills because literacy is viewed as a language skill and numeracy skills are viewed as mathematical skills, hence skills surveys in the UK and globally assess literacy and numeracy separately (Organisation for Economic Co-operation and Development, OECD, 2020). Health literacy skills in this thesis do not include oracy; although oracy is a language skill Nation (2006) surmises that the oracy skills of speaking and listening are evolved behaviours and do not need to be taught. In contrast, reading, interpreting, and understanding information requires the use of skills that need to be learnt and therefore skills of reading and interpreting - literacy skills - need to be taught (Nation 2006, Duncan & Schwab 2015). To acquire knowledge for self-management an individual will require health literacy skills.

The term *personal social network* is understood in this thesis as a theoretical construct used to study relationships, where the network encompasses the social relationships that an individual experiences when managing one or more LTCs. The focus is on personal or ego-centric networks (Brissette et al 2000), where the ego - in this work the person living with the LTC - is seen as central within the network. The structure is the extent, shape and nature of the network, the functions of the network are the psychosocial mechanisms provided to the individual, for example provision of informational, instrumental or emotional support (Berkman et al 2000). The network functions are referred to in this thesis by the term social support. The definition of social support is taken from Shumaker & Brownell's (1984 p13) definition: 'the exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient'. Only the view of the recipient of support is taken in this thesis, that is, all the participants were managing at least one LTC and they were asked about the support (or resources) they drew on to help them manage their condition. Therefore the definition of social support in this thesis is: the provision of resources which are perceived by the recipient to enhance their health and well-being.

Self-management is endorsed within health policy as a way to improve quality of life and health outcomes for people living with LTC (Sanderson & White 2018), interventions are available to support self-management (Foot et al 2014) and health care professionals are encouraged to promote self-management (National Voices 2014, Morgan et al 2016). However Van De Bovenkamp & Dwarswaard (2017) critique policy guidance for implying that participation within health care and enacting self-management is straight-forward; they suggest that shifting health management to individuals gives people choice and autonomy with their treatment and care but is also positioned as a way for health care services to save money. Francis et al (2019) posit that the evidence for health care cost-saving as an outcome of self-management is weak and will remain so while the structural factors that create barriers to people's agency, for example poverty, a lack of education and inaccessible healthcare services, fail to be addressed. While recognising that removal of structural barriers to health is an important aim for health promotion practice (WHO 1986) the investigation of structural factors is beyond the remit of this thesis.

For an individual the 'self-management as a choice' policy agenda creates three problems (Van De Bovenkamp & Dwarswaard 2017, Francis et al 2019): patients[1] can feel blamed by health care professionals (HCPs) if they do not actively manage their condition; power relations are such that patient expertise is not always acknowledged; and the relative importance of patient goals versus health care service goals is contested. Riegel et al (2018) posit that 99% of everyday self-management is undertaken by an individual or their family, that is, the majority of 'health care' for LTCs occurs in the home. However within policy and research healthcare service goals for self-management, for example levels of disease-specific knowledge and adherence to specific health behaviours, continue to dominate. Boger et al (2015) found that outcomes - such as independence; having positive relationships; 'being me' and learning or having skills to manage - were as important to those living with an LTC as markers of biopsychosocial health but were not reflected in the empirical literature. To avoid the application of self-management as something which is imposed upon people by health care services this thesis takes the positioning of self-management described by Kendall et al (2011 p95), as: 'a dynamic lived practice (…) which people choose to engage [in]'. The perspective has been taken that participants are living with their condition(s) and that what they relay as pertaining to management of their conditions is their lived experience and no judgement will be made regarding their management choices.

The title of this thesis implicates the importance of people being *tactical* when they self-manage an LTC. A dictionary defines tactics as, 'the art and skill of employing available means to accomplish an end' (Merriam-Webster 2018) which encapsulates my sense of how someone might self-manage an LTC. That is, a person can draw on resources to enable self-management but how they do this will be informed by their context (what's available), their skill and their art of being. The position that participants have choice or agency is encapsulated through using the term empowerment, where empowerment is viewed as a process whereby people gain control over their health (Laverack 2016). Enabling empowerment of individuals to, in a small way, reduce injustice and inequalities in health is a core philosophical stance for me as a public health practitioner and, therefore, within the thesis.

For clarity, within most sections of this thesis the constructs of health literacy skills and a personal social network are considered separately; however health literacy skills are an individual level factor that are enacted by individuals within social contexts so the use of skills is inextricably linked to social context (Sentell et al 2017). The reality of long-term condition self-management is that it occurs in social contexts - constructs overlap and are drawn on concurrently.

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[1] The term 'patient' is used in this thesis where the context is that people are receiving health care.

1.3 Long-term condition self-management

In the United Kingdom (UK) the term ‘long term condition’ (LTC) has superseded the term ‘chronic illness’ and encompasses a wide range of health conditions including hypertension, asthma, diabetes, chronic obstructive pulmonary disease, cancer, heart disease, kidney disease, mental illness and musculoskeletal conditions (DH 2012). Over 26 million people in the UK live with at least one LTC and an estimated 10 million have two or more LTCs (Sanderson & White 2018). Pressure has come from patient groups not to disassociate the person from the condition so NHS England, which has responsibility for policy pertaining to LTCs, defines LTC self-management in terms of the aim to support people to live as well as possible with their condition (NHS England 2014). Within UK policy the term self-care, with its connotation that one cares for oneself, has been superseded by the term self-management and in their review Richard & Shea (2011) define self-management as the process of managing health conditions with the support of others.

Encouraging self-management of an LTC is a normative approach to participation in health care (Van De Bovenkamp & Dwarswaard 2017) and caution should be used when applying the term to people living in difficult circumstances. An influential paper on self-management, Lorig & Holman (2003), posits that a person cannot ‘not manage’ as even a decision to undertake an unhealthy behaviour or to ignore a physical symptom is a management choice. It could be argued that sometimes people do not have a choice, experience powerlessness and/or are unable to act (Laverack 2016). However, as this thesis is aiming to understand self-management from an empowerment stance a premise is made here that, by definition, the research participants are not completely powerless and have at least some autonomy over their health and their actions. Self-management of health can then be conceived as a continual, iterative process which people undertake and, for those living with an LTC, self-management has been identified ‘…as a way to bring order into their lives.’ (Audulv et al 2012 p332). Hinder & Greenhalgh (2012) view the juggling of self-management requirements as a natural part of managing the social demands of maintaining a ‘normal’ life and self-identity. Ong et al (2011) debate the ‘hard work’ which self-management comprises; it takes up time, resources and energy; individuals need to balance these potentially competing agendas in terms of what appears best for them at a particular time. Self-management therefore requires individuals to make moral decisions regarding what is important and meaningful in their life (Bury 1991, Townsend et al 2006). A qualitative study by Thorne et al (2003 p1349) concluded that self-management of an LTC is, ‘a complex developmental process that takes place within ….. a uniquely meaningful life.’ This reiterates self-management as a subjective learning process, over time, during which a person makes decisions that are pertinent and important to them. The perspective of ‘the person’, rather than the LTC, and *how* a person self-manages, rather than *what* they do, is the standpoint taken in this thesis.

Researching self-management from an everyday perspective and understanding the role of health literacy skills and social networks in the process of self-management can support a health promoting, empowerment approach to self-management of LTCs. The following section will explore why a pragmatic and empowering stance, within this research, is important to me.

1.4 A personal rationale

Ever since I can remember I have been obsessed with reading – if I see words written down I must read them. To me words reveal information, which can improve my knowledge, make me think and maybe even inspire me. If I want to know about something I will read about it, in a book, a journal or on the internet, nowadays information is so easy to get hold of. Life experience though has shown me that many others do not feel the same way about reading; my need for words to be taken in by my brain and imagination is not what others aspire to. To me, identifying solutions can be simple: find it out, read about what others have done and learn. Education as a means for ‘getting on’ is an important belief for me, alongside the idea that if we want to achieve specific life goals then good health and a good education are important. But some people do not have these opportunities; some live with chronic health conditions, for others education is not important, they experience a good life through hard physical graft. Thoughts about difference triggered an interest in exploring how people manage an LTC when they have difficulties with reading; I wanted to understand the strategies and resources that people with low literacy draw on to manage their health.

Social contact and participation are important for providing opportunities for knowledge and skills to be shared, not just with professionals but also between peers. Through contact with others individuals can be encouraged to access services or information and, in doing so, their behaviour and attitudes are influenced. Attitudes impacting health improvement include acceptance, for example acceptance of a situation; and empowerment, that is, doing something rather than doing nothing. I am interested in how individuals can be encouraged to be powerful and to make changes, but I also recognise that social structures can impede self-efficacy and participation. Ultimately the state can have a huge impact on populations through the level of education available, through other opportunities available to individuals and through the provision (or not) of a healthy environment.

In a previous role as a health promotion specialist and now as a lecturer in health promotion I spend a lot of time training professionals and students to engage with their service users to encourage health behaviour change. A pivotal point for me was when I had the opportunity, in

1999, to join a group of health promotion specialists developing a behaviour change training course. The course was based around a book, Rollnick et al (1999), which presented a method for health care professionals working with patients to encourage behaviour change. The authors' consideration of motivation as comprising importance to change and confidence to change was a revelation to me, particularly when I could see that the theory 'made sense' to practitioners and clients. When delivering the training I saw that the approach worked, in that it helped people to understand, and sometimes resolve, their ambivalence to change. The stance taken with this approach is that people are 'experts' in their own situation; they know that they should change a behaviour, particularly if it is having a detrimental impact on their health, so the professional's role is assisting the person to elicit how they can change the behaviour. It is very important that the professional does not tell the person what to do as the person will feel obliged to justify, rather than change, their current behaviour.

My intent with this thesis was to build on my knowledge of motivation and behaviour change and take a person-centred approach to understanding how people manage a long term condition and the role of health literacy skills and a personal social network in the self-management process. I was interested in the tactics people used to self-manage, how their actions were informed by their context (what was available), their skill and their art of being. As a pragmatist, gaining a deeper understanding of how people undertake self-management of an LTC had the potential to enable me to assist healthcare professionals to work more effectively with service users, the applied nature of this work is very important. The following section will explore how a pragmatic and empowering stance was reflected in the research process.

1.5 The research paradigm – a critical reflexive account

Establishing the research paradigm for an empirical study is an iterative process involving, amongst many aspects, consideration of the research topic, the research design and methods in terms of appropriateness for the topic, the researcher's preferences and the potential audience for the research findings. This section presents a discussion of three texts which have informed the philosophical stance assumed in this thesis: Greene's (2007) book on mixed methods, Goertz & Mahoney's (2012) book discussing the application of qualitative and quantitative paradigms in social science research and Hall's (2013) chapter on pragmatism. Because, in doctoral study, 'the personal' informs the development of the research aim, the following discussion is heavily influenced by my beliefs about reality and my philosophical assumptions. It is necessary to show some of the evolution of my thinking in order to thoroughly explore the ontological, epistemological, axiological, rhetorical and methodological assumptions for this thesis. Therefore this section takes a personal but critical stance.

Greene's work on mixed methods (Greene 2007) has resonated with me, she has a background in education (as do I) and she espouses the use of evaluation methods (a key tool in health promotion practice). Her chapter discussing the mixing of paradigms, mental models and methods is particularly insightful. On first reading the dialectic stance appeared appropriate as Greene (2007) suggests this stance can enable work for the public good. Greene (2007) goes on to discuss the idea that dialogue between different assumptions and perspectives can lead to 'a meaningful engagement with difference' (p 80) which in turn can promote values which are important for health promotion and include tolerance, acceptance and equity. Using an example of participatory action research to illustrate the dialectic stance Greene (2007) demonstrates that this stance aims to influence, rather than observe, how people behave. My study aimed to understand self-management of an LTC from the perspective of participant's, it would not have been appropriate to aim to change participant's behaviours. Greene's (2007) substantive theory stance fits best with the aim of the research and is congruent with my background and strengths. This stance emerged from the field of evaluation, a field and process with which I am comfortable. The substantive stance privileges understanding what we want to get out of the research over the methods used to conduct the research. Paradigms are not viewed as of paramount importance, but conceptual and substantive theories are; concepts drive the choice of methods and data analysis. It was important that concepts inherent to this study were carefully defined.

Goertz & Mahoney (2012) acknowledge that in causal qualitative research data is collected and semantically transformed, that is, the data is put into 'sets' depending on its meaning and interpretation. Their book explores in depth the different perspectives and the mathematics underpinning qualitative and quantitative approaches to research. They discuss that an outcome explanation from a qualitative study prompts a reflection on whether the explanation is true in the population and, accordingly, published quantitative results can prompt consideration of whether the results hold true for individuals. In health promotion practice there is an almost constant tension between considering the population whilst recognising the population comprises individuals, meaning that both qualitative and quantitative findings are useful for informing practice. Goertz & Mahoney's (2012) discussion also makes the point that qualitative findings can inform health promotion work to reduce health inequalities, as inequalities are experienced, not by the average person, but by 'exceptional' cases within the population. Understanding difference is important in health promotion.

Goertz & Mahoney (2012) affirm that in qualitative work concepts have to be explained in terms of their meaning and the cases researched must exhibit ‘necessary conditions’, that is, be examples which are relevant to the concept. For example, for this study ‘low health literacy skills’ must be defined and cases selected which meet this condition. Causal factors are investigated in context and the tools used to collect data must make sense in terms of the meaning and definition of the concepts. Greene’s (2007) and Goertz & Mahoney’s (2012) discussions have underpinned the decision for mechanisms and theories for self-management of LTCs to be privileged in this study, rather than the method of data collection: the method is directed by the mechanism. For example, to understand a participant’s level of health literacy skills a tool which measures levels of health literacy skills is required. To understand people’s experience of using health literacy skills to self-manage interviews are required. Having jumped ahead to discuss the methodological approach for this study it is necessary to review the underpinning paradigm. Greene (2007) asserts that the substantive approach is not underpinned by a paradigm, Hall (2013) disagrees, suggesting that the appropriate paradigm is pragmatism.

Hall (2013) draws on the work of John Dewey to explore the ontological assumption of transactional realism, the philosophy that underpins Deweyan pragmatism. Reading about Dewey’s work and philosophy (Dewey 1916, 1933 and in Dalton 2002) it becomes clear why Dewey’s pragmatic approach resonates with the aims of this thesis and with my personal philosophy. Dalton (2002) posits that Dewey believed that when people experience new or problematic situations perceptions and memory are drawn upon to make the situation resolvable and comprehensible. Dewey proposed that the changes from the normal behaviour were measurable as a person becomes aware of (and can therefore articulate) the emotion and actions required to deal with the new or difficult situation. My understanding was that interviewing a person can enable them to explore and explain a difficult situation, such as managing an LTC.

Dewey also emphasised the social nature of emotion and behaviour, understood the capacity to communicate as vital to shared experience and rejected the dualism of qualitative inquiry and quantitative inquiry (Hall 2013). Dewey takes the ontological stance that transactions are real, people’s actions, behaviours and social constructions are significant and when we notice change then we can gain a logical understanding of it. Logical understanding, or knowledge, enables us to make connections and enables us to act (reasonably) intelligently to achieve our purposes. The premise of learning occurring only through experience is a weakness in Dewey’s stance as arguably it is not possible, nor safe, to learn everything about LTC self-management, for example, through experience. I therefore draw on Vygotsky’s work (Karpov 2014) to recognise that scientific concepts, such as safe medication use, need to be taught, not just experienced.

Hall (2013) discusses Dewey's approach as 'embedded pragmatism', that is, inquiry requires links between theory and practice. The 'social' is emphasised, the researcher's prior knowledge is drawn upon and intellect is applied to not only drawing upon appropriate methods but being collaborative and showing empathy. Dewey's ideas resonate with my health promoting and educational experience as his aim was to understand how to address social problems by acting and working in an intelligent way. Dewey's pragmatic focus on social justice, reflection and ethics (Hall 2013) is appropriate for the thesis aim and important for me as a health promoter undertaking a doctoral thesis which explores self-management of long term conditions. His understanding of democracy, as a shared responsibility to work together well and as a social good, requires researchers to consider power relationships. Empirical research is an opportunity to uncover the ways in which we might empower people who may be disempowered due to culture, politics or economics.

To conclude, a substantive and pragmatic approach has been applied to the study design. My hope is that this empirical work has a logical approach, albeit with pluralistic methods, leading to conceptual, practical and applied knowledge of the role of health literacy skills and a personal social network within the process of self-management. Consequently the findings enable an understanding of how people can be supported, by healthcare professionals and others, to gain control over their health and ultimately become empowered to manage their condition.

1.6 Chapter summary

This chapter has set out the rationale for the thesis and the ontological approach taken within this thesis. The self-management of a long term condition and involvement in one's health care is postulated as a political agenda for reducing health care costs and which often fails to recognise the complexity entailed for individuals, health care professionals, health care services and society. This thesis posits that investigating and understanding the everyday process by which people living with a long-term health condition and low health literacy skills self-manage contributes to the debate about how people living with LTCs can become empowered. Researching self-management from an everyday perspective and understanding the role of health literacy skills and social networks in the process of self-management can support a health promoting, empowerment approach to self-management of LTCs. This chapter has discussed how a pragmatic and empowering stance came to be reflected in the study design and the research process.

The over-arching research question for this thesis is:

> How do health literacy skills and a social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills?

The following chapter incorporates an in-depth discussion, critique and synthesis of relevant literature to explore the key concepts in this work, including empowerment, health literacy skills and a personal social network.

Chapter 2 Literature Overview

2.1 Introduction

This chapter presents literature syntheses for the significant concepts in the thesis; these include self-management of a long term condition (LTC); motivation and empowerment; health literacy skills; and personal social networks. Each section critically reviews relevant literature, defines a concept in terms of the thesis aims, explores the implication of the concept for LTC self-management and evaluates the possible links between the concepts. Chapter 1 section 1.5 has emphasised the need, in pragmatic and substantive approaches to research, to define key concepts as concepts drive the choice of methods.

This thesis encompasses a range of concepts which have origins in different disciplines. *Self-management of one's health* arose as a concept within the Health sector (Lorig & Holman 2003) and *empowerment*, depending on its definition, can be viewed as arising from health promotion practice (Laverack 2016) or community psychology (Agner & Braun 2018). *Health literacy* evolved from work in public health and education (Nutbeam 2000, Kickbusch 2001), and *personal social networks* are viewed as a sociological concept (Bury 1991). It has therefore been necessary to review a very wide range of literature while selecting literature relevant to the aims of the thesis. Holloway & Wheeler (2010 p38) suggest, 'qualitative researchers have an ongoing dialogue with the literature', such that literature searches proceed throughout the research process, with differing aims for the searches at different stages of the research. Certainly the process of reviewing literature for this thesis was not one of aiming to answer a focussed review question through the application of specific key terms but rather an iterative, flexible process guided by ongoing needs, developing themes and emerging findings.

The following sections therefore discuss, critique and synthesise a broad range of literature comprising; literature which informs me as a public health practitioner and lecturer; literature recommended by experts in the field; literature retrieved through focused searches updated over seven years of doctoral study; relevant evidence referenced by the retrieved literature; and recently published evidence. When database searches were undertaken key terms were used to focus the search, limiters such as specific years or populations were applied and the resulting titles, and if necessary abstracts, were scanned to identify literature relevant to the aim of the study. Inclusion and exclusion criteria were applied, for example, evidence for interventions to improve self-management or health literacy skills were not relevant, whereas evidence which explored people's experience of self-managing an LTC or of applying health literacy skills was relevant. Full text copies of relevant literature were sourced and saved. Literature was read and summaries made of the key points, quality and potential relevance for the thesis.

In the early stages of the research authoritative or foundational literature regarding self-management of LTCs, personal social networks and health literacy was selected. Reviewing this literature enabled the development of definitions for the key concepts and facilitated the identification of gaps in knowledge and therefore the wording and positioning of the study research questions. When designing the study research methods literature was drawn upon, plus I reviewed how other researchers had researched similar concepts. While undertaking the research, and as findings emerged, I searched for and identified literature which aided the development or refutation of themes and theoretical explanations. At this stage I ensured I kept up to date with newly published literature relevant to the study concepts and, through reviewing the reference lists of articles particularly pertinent to the thesis ensured that literature cited by others was gathered or had already been selected and reviewed. While analysing and writing-up, as Holloway & Wheeler (2010 p37) posit, the literature became ‘a source of data’ for the study. Having accumulated a large volume of literature, through reviewing the summaries it was possible to identify literature which facilitated analysis and brought new perspectives to the study data. Finally, I reviewed my definitions, research questions and findings in terms of recent (2020) literature to ensure that my work was up to date and in line with current thinking.

The syntheses below, for each concept, present an evaluation of literature identified through the approaches outlined above.

2.2 Literature synthesis: self-management

This section synthesises key and recent literature selected as contributing differing perspectives for understanding long-term condition self-management. Lorig & Holman (2003) present self-management through a medical lens, Ould Brahim (2019), Riegel et al (2018) and Matarese et al (2018) take a nursing viewpoint, Kendall et al (2011) a socio-political view, Bury’s (1991) work is sociological and Auduluv et (2012) took a qualitative empirical perspective. Through critique and synthesis of these texts a definition of LTC self-management, pertinent to this thesis, is presented.

Lorig & Holman’s (2003) influential work suggests that, for people living with long term conditions, there are three tasks of self-management: medical management, role management and emotional management. The use of the word ‘medical’ implies that health will be improved if these tasks are undertaken to a standard required or expected by the healthcare profession.

Taking a ‘lay’ understanding of LTC self-management the division of tasks could perhaps be better explained as actions for physical, social and emotional health. To achieve these tasks Lorig & Holman (2003) propose that six skills are required: problem-solving, decision-making, finding and utilising resources, forming partnerships (which they restrict to HCP/patient partnerships), taking action, and self-tailoring, that is, judging how actions should be applied to one’s situation. Although it is helpful to explore the skills required - and self-management programmes and interventions have often been based upon attendees gaining these skills (Ould Brahim 2019) - the supposition that skills alone will be sufficient for self-management is dated. Writing from a nursing point of view Ould Brahim (2019) posits that ‘relational autonomy’ - that is, self-identity forged within relationships - could be an addition to Lorig & Holman’s (2003) model of self-management. Ould Brahim (2019) suggests that relational autonomy encourages HCPs to consider the social embeddedness of patients, thereby enabling consideration of the social support the person experiences and of the environmental and structural factors that impact health behaviours and health outcomes. While this approach has utility for encouraging HCPs to discuss the broader determinants of health with their patients it is perhaps vague about the potential for HCPs to effectively intervene and improve circumstances for their patients. The positioning of self-management within health care settings by Lorig & Holman (2003) and Ould Brahim (2019) limits applicability of their models for this thesis, which is aiming to understand self-management in everyday life.

Riegel et al’s (2018) work attempts to develop a measure of self-management (they use the term self-care) comprising three aspects and illustrating the difficulty with demarcating self-management behaviours. The first aspect is self-management *maintenance*, defined as doing things that enable the person to maintain their health. Maintenance comprises two parts, health promoting actions such as managing one’s diet, and condition-specific actions such as taking medications. The second aspect is *monitoring*, that is, noticing how one feels, noticing changes or symptoms. The third aspect is *management*, doing something to mitigate the change or symptom. This aspect includes autonomous behaviour (what the person does) and consulting behaviour (what happens when a person has decided to consult an HCP). Recognising that monitoring is an important component of self-management, the difficulty with this model is that maintenance and management aspects overlap. For example, it is unclear how we might distinguish action to promote health from action to manage a symptom as an action, for example a diet change, could address both goals. This conceptualisation of self-management also lacks utility for this thesis as the aspect of social support is unclear within the model.

Kendall et al’s (2011) work critiques the competing agendas of delivering LTC self-management as a framework to ensure effective delivery and use of health services while also claiming it as a panacea for building patient autonomy. The authors evaluate self-management policy, warning that a policy-led self-management agenda could ultimately contribute to health inequalities rather than reduce them. While critiquing the positioning of self-management as a cost-cutting opportunity to encourage people to be ‘responsible’, and self-management knowledge and expertise being viewed as the domain of HCPs, Kendall et al (2011) posit the conceptualisation of self-management as potentially emancipatory for people living with LTCs. The authors caution that, to avoid emancipation becoming another opportunity to ‘blame’ people for the ‘wrong’ behaviours, self-management must be conceived as a ‘dynamic lived practice’ (Kendall et al 2011 p95), recognising an individual’s choice to ultimately accept or reject information, support and treatment. Two aspects of this critique, which can be combined, are relevant to this thesis; the acceptance that people can choose which self-management actions they undertake and that what they choose is not ‘wrong’, as it is what they want. This suggested that, when interviewing, I should take an enquiring but non-judgemental attitude toward hearing what people did or did not do when self-managing. I also had to be aware of, and listen out for, situations where people felt they did not have a choice and perhaps felt helpless.

In Bury’s (1991) ground-breaking work on the sociology of LTCs (chronic illness in his work) he acknowledges how people living with LTCs make decisions about treatments or behaviours they are expected to follow and their impact on daily life. Bury (1991) posits that people undertake positive actions to adapt to their LTC and these actions can be categorised in to three aspects. The coping aspect is how a person learns to tolerate or put up with their LTC, this includes their attitude toward their LTC. Coping attitudes are outside the scope of the research question and aims so are not investigated in this study. Similarly, style, which Bury (1991) relates to why people respond to features of their LTC and the treatment and management required, is not considered in this study. Style relates to a person’s long term need to self-manage and this study interviewed participants at one point in their LTC trajectory. The third aspect, strategies, pertains to what people do (Bury 1991); in a discussion of Bury’s work Williams (2000) suggests that this aspect is to do with ‘the strategic mobilisation of resources’ (Williams 2000 p45). This aspect of Bury’s conceptual framework is highly relevant to this thesis, which is aiming to understand how health literacy skills and a personal social network are ‘mobilised’ for self-management. However the term ‘tactics’ is preferred in this thesis as this describes actions and decisions that occur in the here and now, possibly without much conscious thought. Strategy, as Bury (1991) himself points out, implies rational forward-planning with clear goals, which perhaps does not fit well with the thesis understanding of self-management as a dynamic process (Kendall et al 2011). What has been drawn from Bury (1991) is the call for research to focus on understanding people’s experiences of self-management and to be open to a multidimensional view of LTCs and their management.

Audulv et al (2012) undertook a longitudinal qualitative study of twenty-one individuals during the first three years after being diagnosed with an LTC. They suggest that, what they call self-management integration, that is fitting self-management in to everyday life, has four phases. The phases included, ‘searching for self-management strategies, considering costs and benefits, creating routines and plans of action and negotiating self-management to fit one’s life’ (Audulv et al 2012 p332). These phases were not chronological but were applied by participants according to their context, for example their illness situation, personal beliefs and level of social support. They defined self-management as ‘the strategies individuals undertake to promote health (...) manage an illness (...) and manage life with an illness’ (Audulv et al 2012 p332). This definition neatly summarises three aspects of self-management to reflect the importance of managing health and illness and incorporating these strategies in to everyday life. Again, for reasons explained above the term tactics rather than strategies is preferred.

Finally, Matarese et al (2018) undertook a concept analysis of self-care terms including self-management. The authors take a health care services approach to their definitions rather than a person-centred approach however the definition has some utility for this thesis, albeit with caveats. They identify information and knowledge as prerequisites for self-management. In this thesis information is knowledge in a coded form, for example information that is written, digital, visual or communicated by another person (Egan & Gajdamaschko 2003). Knowledge is understood as what the person (participant) knows (Wilson 2000). Matarese et al (2018) identify a second prerequisite, of motivation. They do not explore their understanding of motivation in depth so it is presumed to be motivation to self-manage. Motivation as a concept in this thesis is critiqued in the following section. Their third prerequisite is social support; the social support provided through a personal social network is a key concept in this thesis. The authors suggest the outcomes of self-management for the individual include quality of life and empowerment. There is a focus in this thesis on the outcomes of self-management that the individual deems important, i.e. outcomes that contribute to their life quality. Another aim is to understand whether and how people might become empowered to self-manage.

Following the critique of these papers, within this thesis I posit the overarching ‘ontology’ for self-management as being a dynamic lived process (Kendall et al 2011). The ‘epistemology’ for self-management is posited as actions to promote health, manage illness and manage life with an LTC (Audulv et al 2012) and the ‘methods’ as requiring the tactical use of skills, drawing on social support and being motivated (Bury 1991, Matarese et al 2018). Importantly, this conceptualisation of self-management has underpinned the methodological approach and the study design and data collection. Having explicated self-management as comprising motivation to act, alongside the use of skills and social support, it is helpful now to distinguish between the concepts of motivation and empowerment, as key terms in this thesis their meanings are critically evaluated in the following section.

2.3 Literature synthesis: motivation and empowerment

In this section the concepts of motivation and empowerment are critically discussed. The exemplification of these two concepts illustrates the utility of pragmatism for the study design. The following sections explore how *motivation* to self-manage an LTC can be elicited through asking participants specific, theory-based, questions, while *empowerment* will be inductively elicited from my viewpoint as researcher.

2.3.1 Motivation for behaviour change

To manage one's health, and maintain wellness (Lorig & Holman 2003), requires a willingness to undertake actions to maintain or improve one's health and to change one's behaviours if necessary. Such health behaviours include using medical services, undertaking medical regimens (e.g. taking insulin) and self-directed behaviours such as not smoking or taking exercise (Conner & Norman 2015). A considerable body of evidence aims to understand how to intervene to encourage the undertaking of health behaviours (Conner & Norman 2015), one aspect of which is how health care professionals can encourage and support patients to actively, and positively, undertake such behaviours (Rollnick et al 1999). Rollnick et al (1999) posit that the logic of behaviour change can appear to be that a person generally knows whether a behaviour is healthful or not, therefore when an HCP tells someone what to do, they will do it. They also point out that telling a person what to do often results in resistance, meaning that the person does not change, instead becoming entrenched in the unhealthy behaviour. The authors suggest that, in healthy behaviour conversations, HCPs should move away from simple advice-giving and modify their communication approach to understand, as a starting point, a person's readiness to change.

Rollnick et al (1999) posit that readiness to change, as described in their interpretation of Prochaska and DiClemente's stages of change model (Rollnick et al 1999 p19), was revelatory within the field of health promotion and behaviour change as it explained that people could be at different stages of change for different behaviours and recognised that relapse was a normal part of change. Readiness to change or motivation to change are terms sometimes used interchangeably but, as Rollnick et al (1999) discuss, neither term fully explains a person's willingness (or not) to make a change. They posit that there are two aspects to motivation to undertake a specific change: how someone judges their feelings of importance for making the change; and their judgement of feelings of confidence to undertake the change (Rollnick et al 1999). For example, a person who experiences a health problem as a result of a behaviour may feel that it is now important to change the behaviour, but they may lack confidence in changing the behaviour. The HCP role in such a situation would be to work with the person to provide information about ways in which to change and elicit actions for change. Drawing on substantive knowledge the terms importance and confidence have been mapped, as examples, to theoretical concepts in four well-known and well-used behaviour change models, see Table 1.

Table 1 Mapping importance & confidence to models of health behaviour change

Model	Concept	Relation to importance or confidence
Stages of change **Rollnick et al (1999)**	Precontemplation	Not important to change (not aware of need to change)
	Contemplation	Importance has risen (e.g. because of health problem caused by behaviour) need to build confidence to make change
	Action	Important to make change and confident to undertake change
Health belief model **Champion & Skinner (2008)**	Cues to action	Reminder that it is important to change Having an explanation of how to change can build confidence to change
	Susceptibility	If feel susceptible will be important to change (but may not be confident)
	Perceived barriers	Barriers can impact confidence – e.g. "I've not got the money/skills/knowledge" to undertake the change so asking about confidence helps a person to identify the barriers to change.
Theory of planned behaviour **(Conner & Sparks 2015)**	Feelings about behaviour	e.g. "I can't do it"- not confident, "I won't do it" – not important
	Normative beliefs	"Others won't support me" – will impact on confidence. "My wife wants me to do this" – may impact on importance (but may lack confidence to do this)
Social Cognitive Theory **McAlister et al (2008)**	Self-efficacy	Belief about personal ability to perform behaviour – confidence to undertake a behaviour
	Outcome expectations	Belief about likelihood of making change – confidence Value of outcome of change – importance

My experience over twenty years of using the terms *importance* and *confidence* in training and learning situations is that the language and its meaning in terms of behaviour change readiness is understood by HCPs, students and the people they work with. The questions: “how important is it for you to make this (specified) change?” and “how confident are you about making this (specified) change?” are easily asked by HCPs, are patient-centred and are understood by patients (Wigley & Wilson 2009). Discussing feelings of importance and confidence is powerful as it can reveal, as explored in Table 1, a wide range of factors underpinning motivation and assist the patient and HCP to understand the barriers, solutions and supports for change for the patient. In this thesis the use of the term *motivation to change* encompasses the two components of a person’s judgement of the importance for making a change and their confidence to make a change - this theoretical position has informed the wording for interview questions pertaining to motivation for self-management.

The following section presents a critical synthesis for the interpretation and definition of *empowerment*. The discussion emphasises the important health promotion aim of striving for empowerment and the potential for it to be a lever for building social networks, while positing that empowerment as a construct is of importance to me as researcher, may not be explicitly mentioned by the study participants, and will be interpreted from my viewpoint as a health promoter.

2.3.2 Definitions of empowerment

Empowerment as a process of enabling people to gain control over their health is a key value for health promotion (WHO 1998) whereby practitioners aim to create conditions in which people’s efforts to improve their health lead to improved health outcomes. Green et al (2015 p 35) posit that, ‘Empowerment, by definition, has to do with people acquiring power and control’, correspondingly a key issue for health promotion is enabling people who lack power to gain more control over their lives. Discussions of power relations require a recognition that social structures are such that some people within a society may be given more power than others. For Green et al (2015) this emphasises the importance of healthy public policy within health promotion efforts; they posit that, rather than taking power from some, policy should aim to equalise power and control across a society. In the realm of LTC self-management power changes are problematic. Francis et al (2019) suggest that a paradigm shift is required to move biomedical services - developed to counter acute illness - to the patient-centred, holistic services required for management of chronic disease.

Empowerment can be used to describe individuals gaining control over their lives; in this thesis the emphasis is on empowerment to control and manage one's *health* rather than all aspects of one's life. Empowerment for health at the individual level is the situation whereby an individual feels they can manage their health, as Laverack (2016 p11) posits, a feeling of personal power or 'power-from-within'. Laverack (2016) cautions that a focus on encouraging feelings of personal power can ignore the impact of circumstances where people do not or cannot have personal control, hence the importance of generating empowerment at the community or population level too. The definition of community empowerment as a situation where people act with others to gain control over and influence community health outcomes (WHO 1998) provides a theoretical connection to the concepts of *social capital* and *social networks*. Members of a community co-operating to improve health could be deemed to be enacting social capital, where social capital is defined as the benefit (capital) gained from being social (Hawe & Shiell 2000). Enacting social capital, i.e. working together as a community, inevitably builds relationships and links between individuals, forming social networks. Social capital and social networks enable access to and mobilisation of social support for health (WHO 1998, Moore & Carpiano 2020). A community which is co-operating and co-ordinating for health could be said to be an empowered community, and one in which social capital - at the organisational level, and social networks - at the individual level, exist (Moore & Carpiano 2020).

The methods through which empowerment of individuals or a community can be generated can be complex to operationalise and evaluate and Woodall et al (2012) argue that the multiplicity of meanings for the term empowerment causes problems for research and practice, despite its importance for health promotion practice. The next three sections critique conceptualisations of empowerment through the lens of empowerment as: an outcome, a belief or a process, enabling a justification for the positioning, within this thesis, of empowerment as a process.

2.3.2.1 Empowerment as an outcome

This conceptualisation of empowerment is premised on it being a determinant for health outcomes (Anderson & Funnell 2010). Empowerment could be deemed to have been achieved when, as a result of interventions or policy changes, certain outcomes are achieved. Empowerment outcomes can include the redistribution of resources (e.g. those most needing resources gain them), a decrease in powerlessness (e.g. fewer people reporting powerlessness), or increased control (e.g. more people reporting control over their behaviours and circumstances) (Woodall et al 2010). Laverack (2016) and Woodall et al (2012) suggest mechanisms for empowerment include enhancing individual self-esteem and encouraging participation in groups within the community; this builds links with others, enables resource mobilisation and can potentially redress power inequalities and bring about structural changes. However these types of mechanisms and outcomes are difficult to evaluate and the evidence for links between empowerment and improvements in health status is reportedly weak (Woodall et al 2010, Green et al 2015).

Woodall et al (2012) critique the neo-liberal ideology of individual empowerment, which includes the current policy approach of promoting ‘supported self-management’ (NHS England 2020), arguing that it has a focus on developing individual attributes, such as motivation to act, and fails to consider the impact of social determinants on health status. Empowerment, for Woodall et al (2012) and others (Green et al 2015, Laverack 2016), is the opportunity to enable people to go beyond ‘just managing’ their health, it is an opportunity to enable people to become socially, politically and critically aware and to work with others to influence and improve their lives and their health. Addressing the more radical aims of empowerment to combat oppression and injustice (Woodall et al 2012) is maybe beyond the reach of this thesis however the aim to encourage participation within communities, and to work with others to become more informed, is within the scope of this thesis. Achieving participation and social learning are worthy outcomes but are potentially difficult to measure, more helpful perhaps is to consider the processes that need to go in to generating these outcomes. Hence the understanding of empowerment as a process, rather than an outcome, is more applicable to this thesis. Before discussing empowerment as a process the premise for empowerment as a belief is explored as personal beliefs about agency are an important component of decisions about action - in this thesis - actions for self-management.

2.3.2.2 Empowerment as a belief

Some writers, including Laverack (2016) discuss empowerment as personal power or power-from-within or an inner strength. Zimmerman (1995) used the term intrapersonal empowerment to describe how people think about themselves, particularly in terms of their perceptions of control over aspects of their life that are important to them. This theoretical approach of empowerment as personal control therefore draws parallels with the concept of ‘self-efficacy’ - a belief that an individual holds (Bandura 1982). Perceived self-efficacy is concerned with judgements of how well one can ‘execute courses of action required to deal with prospective situations’ (Bandura 1982 p 122-3). A simpler way to define this is as ‘confidence in one’s ability to take action’ (Champion & Skinner 2008 p 48). This thesis argues, following Miller & Rollnick (2013 and Rollnick et al 1999), that confidence to undertake a behaviour is just one component of motivation, which also comprises an evaluation of the feeling of importance to undertake the behaviour. Consequently an individual may feel confident to undertake a behaviour but the behaviour, and its outcome, may not be important to the individual. Alternatively an individual may perceive a behaviour as important but their situation may be such that they are unable to carry out the behaviour. Empowerment as a belief that one has the confidence to undertake an action could therefore be deemed to have equivalence with the motivation to undertake an action.

Zimmerman (1995) posits that psychological empowerment, or the opportunity to make a free choice and enact empowerment, is dependent on favourable social, environmental, physical and cultural circumstances. Zimmerman (1995) suggests that intrapersonal empowerment (or motivation) is not equivalent to empowerment of an individual as psychological empowerment can only be brought about through an empowerment process. That is, *believing* one can do something is not necessarily sufficient for undertaking a behaviour therefore empowerment as a belief, alone, is inadequate. Finally, Woodall et al (2010) argue that engendering empowerment is more than encouraging an individual to feel motivated or gain a sense of control, they argue it is a social and political process; the conclusion that can be drawn is that empowerment must therefore occur, as a process, at the community or population level.

2.3.2.3 Empowerment as a process

Laverack (2016) explains empowerment as attaining power, a process whereby people gain or seize power of decisions and resources. As being empowered to self-manage a long-term condition requires working with others the idea that power and resources need to be seized is arguably beyond the aims of this thesis, however the notion that people should manage in a passive way is also inadequate. Zimmerman's (1995) theory of psychological empowerment is useful here, suggesting that psychological empowerment is an individual level concept which incorporates perceptions of control, awareness of social context and a critical understanding of one's socio-political environment, and arguing this can only be attained by being an active participant in the social world. Mok (2001) too recognises the importance of being social, defining empowerment as a process by which people develop a sense of inner strength, which requires connection with others. Mok's (2001) conceptualisation is particularly helpful for self-management of an LTC as 'working with' others rather than 'gaining power over' is emphasised. Mok (2001) reiterates the importance of 'the social', positing that someone cannot just become empowered, it is a process which occurs in a social context. Mok et al (2004) develop Mok's (2001) view of empowerment as a process of transformation, that is, through working with others one sees a new perspective as others can help one to see situations in a re-framed and newly interpreted way. The process of seeing things through others' eyes can aid a person with acquiring knowledge and developing skills and assist the person to find meaning in situations (Mok et al 2004). In a situation of self-managing one's health knowledge, skills and changes in beliefs can contribute to motivation and learning for behaviour change, ultimately contributing to capacity for action.

As LTC self-management requires knowledge, skills and a belief that it is worthwhile managing one's condition (Matarese et al 2018) the conceptualisation of empowerment as transformation in a social situation is potentially a powerful contribution to this thesis. There are resonances with Dewey's philosophy of transactional realism which, put simply, posits that interacting with others and searching for knowledge provides knowledge *and* enables people to act *and* through acting people gain knowledge (Garrison 1994). Empowerment as a process of transformation has utility for people living with an LTC, hence one aim of the study was to enable me, as the researcher, to elucidate whether and if so, how, health literacy skills and a personal social network contributed to opportunities for the participants to experience a process of transformational learning.

In summary, motivation has been defined as an individual's perception of how one feels about undertaking an action such as managing one's health. Motivation comprises the feelings of importance and confidence (Rollnick et al 1999) such that someone who is motivated to undertake an action or behaviour would know why the action is important to undertake and feel confident to undertake the action. Empowerment is discussed as being more than feeling motivated; empowerment as a process that involves participation and working with others is most helpful in this thesis, where the study aims to understand individual's self-management actions *and* the involvement and support of others.

2.4 Literature synthesis: health literacy skills

The incidence of long term conditions is associated with multiple risk factors and one of the risk factors is low health literacy skills (WHO 2013). People with low HL skills are more likely to live with LTCs than people with high levels of HL skills *and* more likely to experience other determinants of LTCs (WHO 2013). These determinants range from unhealthy behaviour choices, such as smoking, lack of exercise or alcohol use, to socio-economic factors such as low income and to non-modifiable factors such as older age. As discussed in Chapter 1 health literacy skills mediate socio-economic status and health (for example someone with low HL skills may be in low-paid and risky work) and HL skills are mediated by socio-economic status and health status (for example a young person with poor health may miss out on educational opportunities). Evidence that social determinants of health determine health literacy skill level has been provided by the European Health Literacy Survey (Sørenson et al 2015) which found that the gradient in health literacy skills matched financial difficulty, education and social status gradients. These findings are supported by a survey undertaken in an English city (Protheroe et al 2016) which identified that limited HL skills were associated with the individual factors of older age and perceived poor health, and social determinants of health such as lack of access to the Internet, low formal educational levels and low income.

When considering the impact on individuals living with a long-term condition Berkman et al (2011) identified low health literacy skills as associated with more hospitalisations, greater use of emergency care, less access to screening and vaccination opportunities and poorer ability to take medications appropriately. The WHO (2013) also suggest that people living with LTCs and low health literacy skills will experience difficulties with day-to-day self-management activities. However, there are indications that, despite difficulties, people wish to manage their health, recognise their difficulties and understand the impact of the broader determinants of health. In a qualitative study of adult learners Rowland et al (2017) found that their participants understood that knowledge and understanding underpinned their health decisions and discussed the impact of their previous experiences, including ethnicity and culture, on their ability and willingness to draw on a range of health information sources and to read and understand the information. Importantly the participants also discussed the impact of social determinants of health on the way they lived their lives; that is, they recognised that factors such as having money or work (or not) determined the resources available to them and therefore the actions that they could undertake. In a population survey Gibney et al (2020) found that, in self-reported low social status groups, higher health literacy scores were associated with a lower probability of living with a limiting illness, fewer hospital admissions and less likelihood of smoking. The authors suggest that working to improve health literacy skills in communities with low social status can potentially lead to health behaviour changes and improvement in health outcomes.

In summary, low health literacy skills are associated with poorer health outcomes and a higher incidence of LTCs, and one explanation for this is that people with low health literacy skills may find it difficult to manage their health (WHO 2013). Additionally, low health literacy skills are associated with demographic factors such as older age, low educational achievement and low income. People are aware of the impact of social determinants on their health status (Rowlands et al 2017), health literacy skills can fail to develop because of difficult and impoverished experiences *and* health literacy skills alone can be insufficient in such circumstances. However there is evidence that interventions to improve or mitigate low health literacy skills can result in an improved ability to self-manage health (Gibney et al 2020). This study aims to illuminate the role of health literacy skills in the self-management process and identify findings which can be applied to health care or health promotion efforts.

The following sections define the term health literacy skills, explore the utility of describing three levels of health literacy skills and debate the contribution of health literacy skills, alongside social support, to self-management of a long-term condition.

2.4.1 'Health literacy' versus 'health literacy skills'

Debate about the meaning and measurement of health literacy has continued over the past decade (Berkman et al 2010, Shaw et al 2012, McCormack et al 2013, Salter et al 2014 and Mackert et al 2015, Parker & Ratzan 2019); the breadth of health literacy is a contentious issue. Liu et al (2020 p1) go so far as to suggest that flexibility in the concept of health literacy is such that, 'anyone [can] identify nearly whatever one wants as health literacy.' Researchers are unanimous however in recognising that raising levels of health literacy in the population has the potential to improve access to care, improve health outcomes and reduce health inequalities (McCormack et al 2013) and is therefore a legitimate and important concept within research and health service development. Following the publication of the World Health Organisation (WHO 1998) definition of health literacy, in the United States (US) Federal funding for health literacy research (Parker & Ratzan 2019) led to a boom in interest and exploration of health literacy as a lever to reduce health care costs and improve compliance with preventative and treatment services (Tones 2002, Osborne 2014, Samerski 2019). The global interest in health literacy as a topic for health research, policy and services is promulgated then by the expectation that 'raising health literacy' could encourage populations to make better choices about their health and health care. However there is little accord on how 'health literacy' should be defined, elevated within populations or measured (Mackert et al 2015).

Definitions drawn from US government health briefs and cited in papers discussing health literacy definitions, illustrate the range and historical development of the term 'health literacy'. The first is:

> '…the currency patients need to negotiate a complex healthcare system' (Selden et al 2001 cited in Tones 2002 p287)

and the more recent is:

> 'health literacy occurs when a society provides accurate health information and services that people can easily find, understand and use to inform their decisions and actions' (Fielding et al 2019 cited in Parker & Ratzan 2019 p924).

As Samerski (2019) points out, older definitions of health literacy (Selden et al 2001 above) can be critiqued for requiring people to fit in to healthcare systems rather than the system facilitating access. Salter et al (2014), drawn from Nutbeam (2008), discuss the idea of health literacy as an asset or, in the case of low health literacy, as a risk, that is, health literacy can be a personal positive resource or a health hazard. Conceptualised as a predisposing factor ('the currency' above) health literacy acts to render individuals' vulnerable (or not) to poor health (Nutbeam 2008). The risk perspective is illuminated as an assumption that, if people are provided with the conditions to make informed choices, then 'not doing the right thing' is seen as synonymous with undesirable health choices and low health literacy. So, although a risk perspective could be seen to encourage health care professionals to be sensitive to low health literacy, if the expectation for professionals is that 'there is a problem' or, 'this person does not do as they are told' then interactions will not be productive. Low health literacy ability is then viewed as a risk factor which impedes health and self-management (Nutbeam 2008, Salter et al 2014).

Nutbeam (2008) critiques the 'health literacy as a risk factor' approach, encouraging researchers and policy-makers to consider health literacy as an asset however this has not restricted the development of health literacy measurement tools which draw on the risk approach. Nutbeam (2008) critiques the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) for measuring reading ability only and yet these measures are still used in research (for example Schrauben et al 2020). Samerski (2019) critiques the EU Health Literacy Scale (EU-HLS) for leading questions, for example, 'do you understand why you need vaccinations?' And for questions which, if someone is health literate become contentious and difficult to answer, for example, 'can you decide whether you should go for health screening?' (Sørensen et al 2013 annex). These types of question are also illustrative of questions that probe whether people are doing what the health care service expects them to do rather than their free choice of behaviours (Samerski 2019).

Recent definitions of health literacy (see Fielding et al above) do attempt to address the calls to consider health literacy as an asset rather than a risk. As Nutbeam (2008) suggests, health systems are now encouraged to create an environment which enables people's access to information and health care services. The criticism here, however, is that the process of *enabling* is health promotion rather than health literacy. Tones' (2002) main critique of Nutbeam's (2000) conceptualisation of health literacy is that the breadth of definition and the inclusion of 'semantically unrelated constructs' (Tones 2002 p288) has led to the term 'health literacy' being used for processes which could (or should) be labelled 'health promotion'. I would argue that conflating health literacy with health promotion has exacerbated the difficulties in defining and measuring health literacy. The WHO (1998) definition of health promotion states that it is the, 'process of enabling people to increase control over and to improve their health' and the Fielding et al definition above attempts to replicate this process. Green et al (2015) posit health promotion as a discipline with an ideology and core values including social justice and empowerment; it is not always evident that health literacy, and research and actions to improve health literacy, are underpinned by such an ideology.

In summary, the difficulty is the breadth of definition of health literacy and its application, which can range from an understanding of health literacy as a personal skill to health literacy as a 'cure all' for improving the health of populations. Samerski (2019) critiques many health literacy approaches as being dependent on understanding people as autonomous, rational agents and recognises that, in addition, inadequate and differing conceptualisations lead to measurement problems. The measurement tool debates include; the breadth of concepts to include (Lee et al 2017); whether measures should be specific to particular LTCs (Lin et al 2020); whether to include numeracy or not (Parker & Ratzan 2019) and; whether there are different types of health literacy, such as media or e-health literacy (Levin-Zamir & Bertschi 2018). As an indicator of the range of health literacy measures, Huan et al (2014) provided a review of fifty-one instruments published between 1990 and 2013. A review of health literacy measures and the method developed to elicit participant's health literacy skill level is discussed in Chapter 3.

In this thesis I use the term 'health literacy skills' to affirm that I am discussing the health literacy skills of individuals, while appreciating that the use of health literacy skills occurs in a context, which could provide barriers or facilitators to the use of skills. Measurements of skills, for example literacy and numeracy, often occur at the level of the individual (OECD 2020) and, keeping Samerski's (2019) critique in mind, I would argue that individual skill level measures do not implicate context as unimportant. On the contrary, through understanding who experiences low levels of health literacy skills we can start to understand how to improve skill levels and, beyond the individual, understand how to provide an environment where low health literacy skills are recognised and everyone is facilitated to access the health information and services they require.

In the sections below the literature will be critiqued and synthesised, in the context of the philosophy of this thesis, to; define health literacy skill ability, define health literacy skill levels and discuss how health literacy skills contribute to long term condition self-management.

2.4.2 Health literacy skills and levels

This section discusses the rationale for the thesis focus on health literacy skills, how health literacy (HL) skill ability is defined and the three levels of HL skill ability.

Some definitions of health literacy (Nutbeam 1998, 2000, Sørensen 2013, Osborne 2014) include the component of motivation implying that having information, and having the skills to use the information, impact positively on whether someone acts on the information. This premise is flawed if health literacy is defined as a skill because, unlike a skill which must be taught and learnt (as reading and writing require), motivation can change from moment to moment and be directly influenced by interpersonal context (Miller & Rollnick 2013). For example, a person could be motivated to read information but not motivated to act on it; a person could be motivated to follow instructions but not motivated to understand why a specific procedure is proposed. As motivation can vary across the ability to obtain, understand and use information in this thesis motivation is considered as a separate component of the self-management process, not as a component of health literacy skills.

In a pivotal discussion Kickbusch (2001) defined the tasks of health literacy as being; obtaining information, understanding and acting on the information. Kickbusch's (2001) definition of the tasks has informed the compilation of a working understanding of health literacy skills; in this thesis health literacy skill ability is defined as:

> The degree to which an individual can obtain, understand and apply information required for health-related decisions and actions.

Through synthesising learning theories the conceptualisation of *health literacy skills* for this thesis has been evaluated. The starting point is that literacy skills enable the ability to de-code information and to use information to further one's learning (Egan & Gajdamaschko 2003) and *health* literacy skills can be understood as the ability to de-code information for health purposes and in health care contexts (Barton et al 2007). Literacy skills (and health literacy skills) give us the ability to access and understand information; information being knowledge in a coded form, and which can be written but can also be spoken. Information can be a tool for personal development and behaviour (Egan & Gajdamaschko 2003), including behaviours which enable self-management of health and well-being. However information must be understood by the recipient, i.e. become part of the person's knowledge, before it can be applied to their situation and acted upon. To learn from health information health literacy skills of reading, understanding and applying information are required.

Dewey's approach to learning was that people learned from investigating and discovering information (Hall 2013, Karpov 2014) however this learning approach is not entirely suitable for the situation of learning about self-management of an LTC due to the potential harm that could be caused; Vygotsky's learning theories are of assistance here. Vygotsky (Karpov 2014) posited that spontaneous concepts can be learnt and understood through experience, that is, some aspects of knowledge *are* developed, learnt and applied in an everyday context. Scientific concepts however, which Vygotsky posited as taxonomic and abstract, are required to be taught (Karpov 2014). Teaching a scientific concept requires someone who understands the concept (a 'teacher') to externalise their thinking and actions and explain these to the 'learner' and support the learner to understand and use the concept (Karpov 2014). Langewitz (2020) discusses the necessity, and difficulty, for health care professionals of providing information to patients in a way which enables patients to understand and act on information, that is, HCPs are required to take a role as teachers of scientific and medical concepts, including aspects of LTC management. LTC management often comprises scientific concepts, such as treatment regimes, and such concepts need to be learnt by patients, which means that, either patients need to have the skills to learn scientific concepts, or teaching is required. Ideally HCPs would be competent teachers and understand the importance of discussing knowledge, skills and beliefs in conversations about LTC self-management. In conclusion, health literacy skills enable the de-coding of health information and, depending on the level of skills that a person experiences, may enable understanding and application of health information and inform health-related actions and behaviours.

To understand the degree to which an individual can apply skills it is usual to define ability levels which summarise what people experiencing skills at a specific skill level can do (OECD 2020). Nutbeam (2008) proposed three levels for health literacy ability, functional (lowest level), interactive (intermediate) and critical (highest level). A functional level of health literacy skills is suggested to be the level of skills required to function in everyday health situations (Nutbeam 2000). Interactive skills (Nutbeam 2000, 2008) or communicative skills (Ishikawa et al 2008) are skills which enable the application of new information to a range of situations or changing circumstances and require the use of social or communication skills. A critical HL ability is the use of skills to critically evaluate information (Nutbeam 2000). However, the integration of social skills complicates definitions of the levels, particularly for the intermediate level of skills. In this study the data collection process has been organised such that gaining support from others, including the provision of informational support by others, is viewed as a function of a personal social network. This thesis proposes that the intermediate level is redefined and re-labelled as an applied level of skills. This argument is built on through this thesis however the basis for this supposition is set out here.

Londoño & Schulz's (2015) work describes a difficulty with distinguishing between communicative and critical levels of skills implying there is scope for re-definition of the intermediate ability level. On reading Ishikawa et al (2008) and Nutbeam (2008) definitions of skill levels there are some parallels with learning theory, in this instance Bloom's taxonomy of cognitive skills (Heick 2020). Blooms' taxonomy sets out levels of learning from the most basic skill of remembering to the highest cognitive skill of critiquing, see Table 2, page 29. The taxonomy is useful as it enables educators to understand which skills are easiest to apply when learning and which require a higher cognitive level. Table 2 maps Bloom's levels of cognition to the corresponding learning skill (as Heick 2020). I have then mapped Ishikawa et al's (2008) and Nutbeam's (2008) health literacy skills to the cognition levels and demonstrated that the skills of interactive or communicative health literacy map to the cognitions of application and analysis. Bringing the three levels of health literacy proficiency into alignment with Bloom's taxonomy illustrates that the key HL skills of the intermediate level can be defined as an applied level of skills, the key learning skills at this level being those of analysing information and applying it to one's situation. In Chapter 1 it was posited that oracy skills of speaking and listening are evolved behaviours and do not need to be taught Nation (2006). As the terms communicative and interactive imply the use of oracy and social skills, rather than literacy skills, these terms are avoided. Finally, considering Bloom's taxonomy, the important skill for a HL skill level above functional is enabling the application of new knowledge to a range of situations or changing circumstances. This second level will be referred to in this thesis as 'applied health literacy skills' as this term, or label, more clearly describes the level expectation.

Table 2 Mapping of cognition levels to learning skills and health literacy skills

Bloom's levels of cognition (as Heick 2020)	**Corresponding learning skill** (as Heick 2020)	**Corresponding health literacy skills for this thesis** (Nutbeam 2008, Ishikawa et al 2008 definitions in smaller font)	**Health literacy skill level**
Knowledge (lowest level)	Remember	Finding, reading, & remembering information Skills needed to function effectively in everyday situations (Nutbeam 2008) Read health information (Ishikawa 2008)	Functional
Comprehension	Understand	Understanding information	Functional
Application	Apply	Interpreting & applying information to own situation Apply new information to changing circumstances (Nutbeam 2008) Extract, understand, apply and communicate information (Ishikawa et al 2008)	Applied (interactive or communicative Nutbeam 2008, Ishikawa et al 2008)
Analysis	Analyse	Recognising how & why information applies to self	Applied
Synthesis	Evaluate	Evaluating information from a range of sources	Critical
Criticality (highest level)	Critique	Judging reliability and quality, assisting others to understand information Critically analyse information & use information to exert greater control over life events and situations (Nutbeam 2008) Critically analyse information & use it to make decisions, check credibility & reliability of information (Ishikawa et al 2008)	Critical

Nutbeam (2008, 2009) suggests that critical health literacy skills entail using information to exert control over one's circumstances and gain autonomy, in this way critical health literacy skills act as a link to the process of empowerment. Zimmerman (1995) and Laverack (2016) both suggest that developing people's health literacy skills can promote empowerment through enabling criticality. This thesis posits that critical health literacy skills can enable empowerment but also recognises that empowerment is a social process and therefore connections with others are an essential component of empowerment (see section 2.3.2.3). Hence it could be that people can become empowered through processes other than applying critical health literacy skills.

In support of Nutbeam's (2008) and Ishikawa et al's (2008) inclusion of 'the social' in their health literacy skill definitions the extent to which drawing on others to understand information is a health literacy skill or a social interaction skill *is* difficult to ascertain. In this thesis health literacy skills are defined as skills applied to find, understand and apply health information, which does not include drawing on others to provide support to access or understand information. Gaining support from others, including the provision of informational support, is viewed as a function of a personal social network. There are, inevitably, overlaps in definition, for example one aspect of a critical level of health literacy skills is that people can help others to understand information. However this too is about the individual's skills, that is, through teaching others the individual demonstrates that they understand information. Distinctions between skills and 'the social' have been made to facilitate the research process and data collection but skills and social networks are not simple to disentangle because the use of health literacy skills always occurs in a social context (Chin 2011, Samerski 2019).

2.4.3 Health literacy skills, social networks and LTC self-management

Studies examining self-management behaviours identify that functional levels of health literacy are required for self-management (Ishikawa & Yano 2008) and a higher level of HL is advantageous (Heijmans et al 2015). There is utility in understanding the level of HL functioning as there is evidence from Heijmans et al (2015) study that HL level impacts the ability to self-manage. Surveying adults living with chronic conditions Heijmans et al (2015) found lower levels of HL amongst groups experiencing advanced age, lower levels of education or income, multi-morbidity and physical limitations. They conclude that, for successful self-management, basic literacy skills are less important than higher cognitive skills, however the context for self-management is important. For example, the daily consequences of an LTC might be coped with using functional skills; successful navigation of treatment regimens might require the use of higher order skills.

The association of HL skills with LTC self-management is still not fully understood, possibly because of the range of definitions and measures for health literacy (Huan et al 2014). As an example, Schrauben et al (2020) attempted to examine the relationship between knowledge and health literacy on self-care when people were living with chronic kidney disease, finding that health literacy ability was not associated with self-care behaviours. The researchers used the REALM tool to measure HL, which has been previously critiqued to simply measure reading ability (section 2.4.1), and only 18% of their sample were deemed to experience what they term as inadequate HL and which could be described as reading difficulties. The REALM tool does not incorporate measures of comprehension, nor application of information to actions, potentially key aspects for eliciting the role of HL skills in LTC self-management. In conclusion the authors postulate that self-efficacy was a more important factor for self-care than knowledge and HL level, possibly implying that, if people believed taking action was worthwhile then they would act. Fortunately they do also discuss the role of HCPs in providing information in such a way that patient's confidence to act is encouraged (Schrauben et al 2020).

Ultimately, as noted by Schrauben et al (2020), even if people have health literacy skills it does not follow that they will act on health advice or information. This reality led Nutbeam (2008) to expand his definitions of health literacy to encompass health literacy as an asset, which can be built and is not static. Health literacy skills can develop as a result of an individual's experiences - which includes education opportunities and the support and input of others, enabling the individual to exert control over a range of factors which impact their health, an empowerment approach (Nutbeam 2008). A pertinent point here is that when people are diagnosed with an LTC the importance of using health literacy skills increases as the individual comes to understand that information could support them to self-manage (Gaglio et al 2012). However, people experiencing low levels of health literacy skills may avoid information or only draw on information from health care professionals (Shaw et al 2009, Gaglio et al 2012). To avoid exacerbating health inequalities some people will require support, from HCPs, to build their confidence to use health information.

The term 'a personal social network' has been explained in Chapter 1 as the structure and functions of the social relationships that an individual experiences when managing one or more LTCs. Personal social networks are discussed in the following sections but it is useful at this point to briefly explore the interplay of social networks and health literacy skills in the process of self-management. Health literacy skills are defined (section 2.4.1) as the skills of obtaining information, understanding the information and applying the information to one's decision-making, therefore it is an individual ability (*that* individual, reads the information or does not, *that* individual understands, or not the information, c.f. Nutbeam 2008). Individuals may draw on their social networks to help them understand information and to help them make decisions about actions but this is a use of the social network, not a health literacy skill (Ellis et al 2012 and Wyke et al 2013). Studies that examine relationships between network size and self-management behaviours find it difficult to judge the direction of causation as people with low health literacy skills experience difficulties with access to services (WHO 2013), tend to have smaller social networks (Johnson et al 2010) or networks that obstruct self-management (Mayberry et al 2014) and are more likely to ignore or find it difficult to follow self-management advice (WHO 2013). This thesis takes the stance that people will usually attempt to manage their LTC positively so difficulties with access to services, for example, would be deemed to be the problem of the services, not the people attempting access. Likewise, finding information difficult to follow can be a function of the complexity of the information provided.

Health literacy skills are inextricably linked with social networks. For example, Barton et al (2007) in work with adult literacy teachers found that teachers recognised that their learner's greatest need was not for 'literacy skills' (although having those was helpful) but for social factors such as making relationships; their experience was that a lack of opportunities for social relationships impeded learning and progression. Hall (2013) discusses Dewey's proposition that learning is the opportunity to participate in a democratic community and that interacting and co-operating with others can build social capital and assist with adjustment to new challenges; outcomes that are beneficial when people live with an LTC. Sentell et al (2017) reviewed evidence that explicitly measured health literacy and a social context variable, finding the relationship between health literacy and social support statistically significant in all but one study. They posit this as confirmation that people draw on others to support their HL skills; social context can be a facilitator when people experience a low level of HL skills.

When considering self-management of an LTC, health literacy skills are required for gaining knowledge, understanding how knowledge relates to one's self and the LTC experienced and understanding how to act, so HL skills are useful tools for self-management (Gaglio et al 2012). A study by Macabasco-O'Connell et al (2011) found that low HL was associated with lower heart-failure related knowledge, self-efficacy and self-management. Importantly they also found that low HL mediated self-management, implying that a lack of HL skills also impacts how people feel about making changes or acting on information. However there is evidence that the factors preventing self-management are more complex than a lack of HL skills or motivation. Schinckus et al (2018), for example, found that emotional burdens such as diabetes-related distress or depression interfered with the cognitive resources, including HL skills, required for self-management. In conclusion, there is scope to understand more about the contribution of HL skills to the process of LTC self-management.

The depth, breadth and complexity of the health literacy literature has been presented and I have posited utility in focusing on the specific contribution of health literacy *skills* to the process of LTC self-management. While recognising that self-management occurs in a social context, there is an opportunity to examine how people use their health literacy skills and, when they lack such skills, how they compensate for or manage this situation. Consequently the first aim of this thesis is:

> **Aim 1:** To identify how health literacy skills contribute to the process of long-term condition self-management for the participants.

2.5 Literature synthesis: personal social networks

Utilising the determinants of health model, Figure 1, has emphasised that self-management of a long-term condition is situated within people's everyday opportunities to live, love, work and play (WHO 1986) and not just comprised of a person's lifestyle choices. Self-management as a dynamic, lived and therefore contextual process encompasses the role of social and community factors, including friends, family and health care professionals, in the process (Kendall et al 2011, Foss et al 2016). There is evidence that the absence of a social network, that is, experiencing loneliness - a subjective feeling, or isolation - having few social contacts, i.e. a small personal social network, can have a direct detrimental impact on health. Valtorta et al's (2016) systematic review found a link between loneliness and social isolation and an increased risk of developing coronary heart disease and stroke. Risk factors for loneliness and social isolation include socioeconomic status, bereavement and health status (Valtorta et al 2016), risk factors which exacerbate the incidence of, and ability to cope with, LTCs too (DH 2012, IHE 2020).

The impact of social and community factors can be health-enhancing, for example, supporters may provide appropriate instrumental and emotional support that assists health self-management (Thoits 2011). Alternatively the support can be absent or unhealthful. As explained above a lack of support may lead to a deterioration in health and support that encourages unhealthy behaviours will damage rather than improve health (Berkman et al 2000, Sani 2012). As with low health literacy skills a restricted or unhealthful social network is a risk factor for people living with LTCs and this study aims to understand whether, and how, people negotiate unhelpful supporters. If a person has a low level of health literacy skills supporters within a personal social network could potentially fill the gap by providing informational support (Sentell et al 2017). Understanding whether, and how, people draw on informational support for LTC self-management is an objective for this study.

While social connectedness is a good predictor of health and wellbeing Cruwys et al (2019) found that older people experiencing financial insecurity were more likely to be lonely and/or isolated. Aaby et al (2020) found that people living alone, particularly men over 60 with a low level of education, were more likely to lack social support. Living with an LTC can impact people's capacity and desire to interact with others, for example, certain conditions can affect people's ability to drive or use public transport (Boniface et al 2015, Christie et al 2017). Coyle & Atkinson (2018) posit that concerns about the needs and symptoms of LTCs and worries about being a burden to others led to people limiting the number of supporters with whom they interacted. The Internet can provide links to others and be supportive of self-management (Allen et al 2020) but older people are less likely to have access to the Internet (Protheroe et al 2016). An objective of this study is to understand how people mobilise their social network when they live with an LTC, particularly when they experience some of the difficulties described above.

The following sections critique the term *personal social network*, explore the contribution of a personal social network to self-management of health and examine the role of social networks, alongside health literacy skills, when a person is living with a long-term condition.

2.5.1 What are 'social networks' for health?

The term 'social network' is used in two main ways, to describe a network of social (i.e. personal) relationships and to describe the use of digital technology to communicate with others. This thesis will concentrate on relationship networks. The network as relationships concept is applied to a multitude of settings including business, sociology, marketing and health and, to add to the confusion, relationships can be promoted through digital networks. Social networks are therefore studied within a broad range of disciplines interested in understanding human behaviour, including anthropology, history, psychology, political science and human geography, as well as the field of health care. Prell (2012) explains that, at its simplest, social networks comprise actors (people) and the relationships which occur between the actors. In this thesis the focus is on the actors and the relationships that impact on health actions and outcomes, in the context of personal or egocentric networks (Brissette et al 2000).

In ground-breaking work presenting a conceptual model of how social networks impact health Berkman et al (2000 p847) define social networks as, 'the web of social relationships that surround an individual and the characteristics of those ties'. They explain that anthropologists working in the mid-1950s found that categorising people into 'groups' did not fully explain their behaviours as the ties and relationships extended across and between groups. Social network analysis was developed to enable understanding of networks with individuals at their centre (egocentric networks) or large networks such as those existing within communities or workplaces. The assumption within social network analysis is that the network structure and form dictate the resources available to individuals, thereby determining individual behaviour, emotional responses and attitudes (Berkman et al 2000). This thesis recognises that a network may enable or restrict choices but also acknowledges the power of the individual to make their own decisions, reiterating the health promotion aim of empowerment.

Tsai et al (2015) clarify that social networks are the *structure* within which the *content* of relationships, including social support, operate. They explain that at the mezzo level social networks are what the network of supporters' looks like; at the micro (individual) level the content is, for example, the support provided, peer pressure applied or resources provided. The structure of networks themselves are affected by macro or social-structural conditions (Berkman et al 2000, Tsai et al 2015). In-depth consideration of macro factors is beyond the remit of this thesis, the focus is on mezzo and micro factors within the network. The research design has enabled an in-depth focus on the micro network factors, going beyond a consideration of the support and resources provided to understand the grounds for tie development. This work aims to illuminate how people make decisions and choices regarding the social network resources that are available to them.

A personal social network is therefore a conceptualisation of an ego, with the ego being the 'abstract initial actor' (Berkowitz 1982 p51), and the relationships and alters (others, Berkowitz 1982) that surround them. Conceptualisation of a network as comprising a person surrounded by supporters can be applied when investigating how individuals draw on resources to assist them with managing a long term condition. As Bellotti (2016) explains, recording and representing relationships in the formal structure of a social network diagram enables participants to visualise and understand their network and enables researchers to compare participant networks. This has informed the study design decision to include network diagramming as a method for mapping participant's social networks.

2.5.2 Exploring the contribution of a personal social network to LTC self-management

This section critiques, synthesises and evaluates the contribution to this thesis of; suppositions for the impact of social networks on health; the types of support provided by network alters; and the 'work' of the ego in building, maintaining and managing connections with alters (Ong et al 2011).

Berkman et al (2000) posit four psychosocial mechanisms for the impact of social networks on health status; the provision of social support (by one person to another); social influence; social engagement and attachment and access to resources and material goods. There are overlaps between these mechanisms, for example social support can provide people with access to resources and access to social support is likely to be reduced if an ego has no social engagement opportunities (Berkman et al 2000). The focus in this thesis is on the provision of social support by the network, which is commonly categorised into types of support including emotional, instrumental, appraisal and informational (Berkman et al 2000). Emotional support for LTC self-management can include empathy, caring and love (Heaney & Israel 2008). Several authors (Browne-Yung et al 2013, Vassilev et al 2013 and Morris et al 2015) acknowledge emotional work, or emotional *sustenance* as Thoits (2011) labels it, as key to the support provided by others to those living with LTCs. Instrumental support includes tangible aid or the provision of resources or services and informational support is the provision of advice, suggestions or information to address a problem (Thoits 2011, Barańczuk 2019). In this thesis informational support goes beyond just providing the ego with information to include support for the ego with *understanding* health information for LTC self-management, thereby potentially enabling knowledge and action. Thoits (2011) considers that appraisal, that is, providing constructive feedback to the ego, is a component of informational support. Berkman et al (2000) suggest that appraisal support includes giving feedback *and* assistance with decision-making and help with deciding upon a course of action. As the term 'appraisal support' may be confusing, 'support for making decisions' was the term used during data collection.

Social networks are postulated to have a direct impact on health through three pathways: health behavioural, psychological and physiological (Berkman et al 2000). The ego's network has a direct positive or negative effect on physical health through; encouraging (or discouraging) health-related behaviours, for example smoking, taking medicines, exercising; exposure to infectious diseases and lowering (or heightening) the stress response which in turn reduces (or elevates) blood pressure and enhances (or depletes) the endocrine and immune system. The ego's social network has a direct positive impact on psychological health through boosting self-efficacy, self-esteem and emotional well-being (Berkman et al 2000). Thoits (2011) discusses the buffering effect of social support in detail suggesting that there are at least seven psychological mechanisms. Thoits (2011) includes social influence, social control and behavioural guidance, which Berkman et al (2000) posit as health behavioural rather than psychological effects. In tandem with Berkman et al (2000) Thoits (2011) lists promotion of self-esteem and self-efficacy. In addition, Thoits (2011) discusses mattering - the sense of purpose that a social interaction can bring - belonging and companionship and perceived social support. Barańczuk (2019) iterates that people can report received *and* perceived support. Received support generally refers to support that has been given to the ego by others and perceived support is that which is understood by the ego to be available to them. Sani (2012) found evidence for the impact of depression being reduced due to just a perceived ability to deal with demands. In this thesis perceptions of support, by the ego, are understood to be important for the building of social ties, where a social tie is a connection between an ego and an alter (Thoits 2011). If the ego perceives that the support offered is beneficial then a social tie is likely to be built (Thoits 2011, Sani 2012).

When considering the size and structure of a network it could be assumed that the larger the network the greater the likelihood of more different and supportive ties (Sani 2012). Cattell's (2001) work, exploring networks in communities within areas of deprivation, suggests the reality is more complicated than this. She found that some people had large networks, but the ego could be drained by having to support a lot of others. Other large networks provided some types of support, for example instrumental, but lacked other types of support such as emotional. Homogeneous networks limit access to different types of resources and support, heterogeneous networks provide a greater range of resources (Cattell 2001, Vassilev et al 2016). It is useful here to consider the terms ‘needs’ and ‘wants’. The term need is generally used within public health to indicate goals for avoiding harm or promoting health (Green et al 2015). Wants are subjective and therefore vary from person to person and although a want may promote health it may not necessarily avoid harm. In this thesis the term ‘wants’ is used when discussing the preferences of participants and the term ‘needs’ is used to indicate normative need. So, for example, during a stressful health-related event an ego will consider the support they want and make judgements about who within their network they perceive as being able to provide this support. Thoits (2011) argues that supporters may provide several different types of support, for example instrumental, emotional and informational and that egos select alters who provide the type of support they want, rather than what the situation requires them to need. Variety within a social network therefore enables the ego to draw on the type of support they want at a particular time (Thoits 2011), and if the support is what they want then a social tie may be made. Perry & Pescosolido (2015) conclude that people living with an LTC are strategic, or for this thesis, tactical, in their choice of supporter and the choice of supporter can impact outcomes. The grounds for potential ‘matching’ of support wants with support offered, or social tie building, are a focus for this thesis.

Being tactical in one’s choices of support and supporters can be viewed as requiring empowerment. Empowerment has been appraised (section 2.3.2) as a process whereby people gain control over their health and well-being (Laverack 2016) and creating conditions for health is a collective responsibility as empowerment is built through relationships and participation in society (Green et al 2015). Social networks are collective and relational so it appears logical that drawing effectively on a social network when support is wanted requires and produces empowerment (Garrison 1994). Assumptions cannot be made, however, regarding the degree of choice and level of empowerment that people experience or perceive. Browne-Yung et al (2013 p10) discuss the concept of habitus, that through experiencing everyday social life individuals come to accept, ‘taken for granted ways of thinking and behaving’. Through habitus people living with an LTC may find that their experience of the condition and what works and what does not work may not be valued by HCPs (Francis et al 2019); not all health-related social situations will facilitate choices and empowerment. Hall (2013) explains Dewey’s theory of learning as positing that in new or changed circumstances people may be prompted to act in a novel way, just as actions may be prompted when an LTC requires management. While recognising that deprivation, poverty and very difficult circumstances can severely limit people’s choices, if a person has access to a healthful social network there is utility in encouraging people to make decisions about how to draw on their social network and gain the support they need and want. An empowerment perspective therefore would be one in which people are enabled to make decisions about their social support through a deliberate process rather than just through habit.

Small & Sukhu (2016) posit that when people want support mobilisation of social ties occurs as the person thinks about the help they want, decides on the type of help and activates the support by asking for help. Thinking and deciding are cognitive actions for the ego, the activation part is the 'social' part (Small & Sukhu 2016). As activation of a tie requires a tie to be available Small & Sukhu (2016) suggest that mobilisation of ties is not necessarily deliberate or rational as the process is dependent on the accessibility of ties. A reflective or deliberate decision to approach a specific person or resource is only likely to occur if the ego is aware of an alter within their network that can support them. That is, an ego is more likely to reflect on their ties and make a choice of tie if they have a good quality or large network to draw upon. Where an ego has a small network they may have to make use of incidental or spontaneous support, but this depends upon them having the opportunity to access others. Activation of ties for support is reiterated as a social process in which an ego can only activate the ties that are available (Small & Sukhu 2016). An important part of the study design has therefore been to map the structure and size of participant's personal social networks for LTC self-management *and* understand how they draw on their support network. The decision to recruit participants from community club venues has ensured that participants do have opportunities for drawing on incidental or spontaneous support.

Understanding of social tie formation is drawn from Azarian (2010) who posits that a social tie exists when a relationship has some degree of durability, that is, there is more than a momentary interaction between the ego and the alter. In this discussion, and throughout the thesis, the term matching refers to a match for the ego only. The alter's role and what they gain (or lose) during tie-building is beyond the scope of this thesis which has a focus on the ego's perceptions and experience of their social network for LTC self-management. As ties take time to develop, and over time circumstances for the ego may change, Azarian (2010) suggests that a tie is never settled, it remains contingent and requires 'work' to manage as an ego can never fully control what is provided by an alter. However, Azarian (2010) posits that matches are made and a tie is formed when the ego perceives that they have affinity with an alter, that they may gain utility from the tie and that the alter exhibits reliability, that is, there is a reasonable expectation that their support will be provided. There is value in applying Azarian's (2010) conceptualisation of matching for building social ties and this basis has guided the analysis of the social network aspect findings.

2.5.3 Social networks, health literacy skills and self-management of LTCs

A large volume of research demonstrates the importance of social support for LTC self-management (Bury 1991, Lorig & Holman 2003, Thoits 2011, Kennedy et al 2014, Vassilev et al 2014); the provision of informational support, emotional support, encouragement and instrumental support by others are suggested to be prerequisites for successful self-management (Matarese et al 2018). Investigating the link between health literacy level and social support Johnson et al (2010) found that people with low health literacy and supporters they trusted coped better with medication adherence than people with low health literacy and no or little support. Edwards et al (2015) found evidence that people managing an LTC and with low health literacy drew on the health literacy skills of others to find and explain health information. Rather than this being explained as 'distributed health literacy' (Edwards et al 2015) I would suggest that this is an example of an ego drawing on alters for informational support. Waverijn et al (2016), in a paper exploring the links between health outcomes, health literacy and social capital, suggest that there is more to know about how knowledge is transferred within communities and how people draw on the knowledge, support and guidance of others. Finally, Sentell et al (2017) suggest that social context is an important limiting or facilitating factor for health literacy skills and people are required to leverage their social network to achieve health-related goals. This raises an interesting point as to whether people living with low levels of HL skills are able to leverage their social network and, if so, how they accomplish this.

The evidence critiqued above points to social networks being used to compensate when health literacy levels are low and health literacy skills possibly being important for enabling access to social support resources. Schiøtz et al (2012) call for more research to understand the relationship between social networks and health-promoting behaviours as interventions based on these understandings can better support people with LTCs to self-manage. Reeves et al (2014) go further to suggest that promoting social support, within communities, could be more effective than patient education interventions for self-management. Follow-up work by Vassilev et al (2019) has found that a social network intervention did encourage the building of new community-based relationships, enabling people living with LTCs to meet their health-related personal goals. In this study the focus on the role of a personal social network for self-management when people are living with an LTC *and* low health literacy skills could enable an illumination of how people negotiate the contribution of supporters to fulfil their LTC support needs, and whether this is contingent on their level of HL skills. The second aim of this thesis is:

> **Aim 2:** To identify how a personal social network contributes to the process of long term condition self-management for the participants.

2.6 Chapter summary

This chapter has critically synthesised a wide range of literature to posit the process of self-management as fundamental to people living with a long term condition, with health literacy skills and a personal social network making important contributions to the self-management process. An intention of this study is to better understand the self-management process undertaken by people living with LTCs, particularly people experiencing low health literacy skills, as it is known that individuals with low health literacy experience health inequalities (Roberts 2015).

Self-management of an LTC has been defined as a dynamic lived process (Kendall et al 2011) through which a person undertakes actions to promote their health, manage illness and manage life with an LTC (Audulv et al 2012). The actions require the person to be motivated and entail drawing on social support and the use of skills (Matarese et al 2018). One aim of the study is to understand participant’s ability to use health literacy skills, which are defined in this thesis as the degree to which an individual can obtain, understand and apply information required for health-related decisions and actions. The concept of a personal social network is enacted to understand the social support the participant (ego) draws on for self-management and a second aim of the study is to collect data to understand how and why a participant builds ties with supporters or other resources. Throughout it is recognised that participant’s motivation to undertake a particular action will depend on their judgement of the importance of undertaking the action and their confidence to undertake the action. Finally, empowerment as a process that derives from participation and working with others is conceptualised as a potential method for facilitating an individual’s health-related goals.

The next chapter will present the methodology for the research study, the study design and the methods followed.

Chapter 3 Methodology, study design and methods

3.1 Introduction

In Chapter 1 I set out my stance toward this research, which is informed by the aims of the thesis and my experiences as an educator and as a health promotion specialist. Section 1.5 discussed the ontological stance for this thesis as deriving from pragmatism and in this chapter I draw on a pragmatic approach and philosophy, which enables a flexible use of research methods appropriate to the study aims (Kaushik & Walsh 2019). This chapter sets out the research aims and questions, the study design, the methods and the data analysis process.

3.2 Study aims and research questions

Critique and synthesis in Chapters 1 and 2 has presented self-management as fundamental to people living with an LTC, with health literacy skills and a personal social network playing an important role in the self-management process (Matarese et al 2018). There is utility in understanding how people self-manage when experiencing a low level of HL skills and the overarching research question is:

> How do health literacy skills and a social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills?

The main concepts being investigated, health literacy skills and personal social networks, are from differing paradigms. Health literacy skills are an individual level factor (Liu et al 2020, Champlin et al 2017) and social networks exist at a social and cultural level (Berkman et al 2000). This led to the decision to undertake design-based research such that health literacy skills and social networks were theorised separately and data collection methods were selected to examine the two factors separately, while recognising both factors as being contiguous within self-management of an LTC. Accordingly the aims and specific research questions (HL 1, SN 2 etc.) for this study comprise;

Overall study aim: To identify how health literacy skills and a social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills.

Aim 1: To identify how health literacy skills contribute to the process of long-term condition self-management for the participants.

Specific research questions for aim 1:

HL 1. What is the level of health literacy skill (e.g. functional, applied or critical) for each participant, as quantified by health literacy skill questions?

HL 2. What are the barriers and facilitators to using health information for self-management when an individual's health literacy skills are limited?

HL 3. If an individual's health literacy skills are limited, what other tactics do people use to acquire information?

HL 4. How do health literacy skills contribute to empowerment for an individual?

Aim 2: To identify how a personal social network contributes to the process of long-term condition self-management for the participants.

Specific research questions for aim 2:

SN 1. What is the structure and size of the social network for each participant, as measured by the concentric circle mapping?

SN 2. How are social ties for long-term condition self-management built?

SN 3. How are social ties for long-term condition self-management negotiated?

SN 4. How does a personal social network contribute to empowerment for an individual?

3.3 Study design

The study comprised a cross-sectional pragmatic design. An overview of the study design is provided in Table 3.

Table 3 Study design overview

Aspect	**Design decision**
Overall design	Design-based; cross-sectional pragmatic design with purposive selection of cases (participants) Two interviews with each participant Two phases to data collection
Sampling method	Purposive, convenience sample
Setting	Community clubs
Population sampled	People aged 49 - 70 attending/working at community clubs Self-report as living with arthritis or diabetes Self-report as left school with no qualifications &/or self-report experience difficulties with reading or live with dyslexia
Key ethical considerations	Enabling participation – accessible language Maintenance of confidentiality and anonymity Shopping voucher offer Managing risk of harm
Phase one (September – November 2017)	Trial of recruitment method and data collection methods Five participants
Phase two (June 2018 – July 2019)	Repeat of phase one methods following minor changes to data collection tools only, seventeen participants
Data collection	Interview one – structured interview, 20 minutes Interview two – semi-structured in-depth interview, 30 - 45 minutes
Data analysis Interview one	- scoring of health literacy skill questions - scoring of social network diagram - scoring of social network questions
Data analysis of interview transcriptions Interviews one and two	- Framework approach to data management - thematic analysis - abstraction

3.3.1 Study design justification

In Chapter 1 I elucidated a personal reflection and critique of three texts which influenced my thinking in terms of methodology. I posited that the ontological assumption of pragmatism rejects the duality of objectivity and subjectivity, instead drawing on transactional realism (Hall 2013) which recognises the constant interactions and re-adjustments of individuals with their world. Kaushik & Walsh (2019) go further to suggest that pragmatism helps bring together scientific and humanistic understanding. This stance frees the researcher from decisions about whether the selected methods fit within positivism or interpretivism, instead permitting a pragmatic approach where methods are selected based upon the research questions. The research question for this thesis requires participants to be living with an LTC and, ideally, a low level of HL skills and requires the elucidation of the HL skill level and personal social network structure for participants.

A pragmatic approach allows the application of methods as appropriate to answer the research question, rather than being dictated by the paradigm (Kaushik & Walsh 2019) and this stance has underpinned the study design. Pragmatism has a focus on action, which is apposite for research investigating the actions people undertake to self-manage. The study aims to understand the relationship between actions and outcomes and hence solve the problem of how HL skills and a social network contribute to LTC self-management and empowerment. Pragmatism respects the solving of problems in people's worlds, the problem within this study being understanding how people living with low HL skills self-manage and what supports them to manage. Pragmatism prioritises meaningful research and an aim for this study is that findings should be meaningful to people who live with low HL skills and an LTC *and* meaningful to HCPs. An important decision was made to recruit participants outside of health settings, to enable elicitation of what people do to self-manage that may not be expected or understood by HCPs and that people may not reveal in a health setting. Finally, pragmatism allows a scientific approach, as required for ascertaining HL skill level and mapping of social networks, and a humanistic approach, required for understanding how people self-manage LTC every day. This informed the decision to undertake two interviews, one structured interview with a focus on HL skills level and social network mapping, and a second semi-structured, in-depth interview.

Within pragmatism Hall (2013) positions the primacy of theory for inquiry and the research question requires that the mechanisms and theories of self-management, including the contribution of HL skills and a personal social network, must be understood and underpin the data collection methods. Hence I have critiqued a wide range of literature in Chapter 2 and presented my theoretical stance for the researchable aspects. In the findings chapters I reiterate the theoretical frameworks underpinning the analysis.

Pragmatism enables me to undertake some data collection not as a neutral observer but from the point of view of a person with many years' experience in education and health promotion. The grounds for the intent to comprehend the level of HL skills that each participant lives with has been scrutinised in section 2.4 and guided the decision to develop and use a tool to quantify the level of skill for each participant. Similarly, the decision to enable participants to develop a visual diagram of their social network for self-management was premised as a pragmatic visual prompt for the participant, ensures a record of their network and provides a starting point for further discussion (Bellotti 2016). Additionally, structured questions enquiring about the types of support that participants received fulfilled the aim of the first interview to understand the context of self-management for each participant. Importantly, in the second semi-structured, in-depth interview I did take a neutral observer role, albeit guided by theory-driven questions (Flick 2002).

The pragmatist's aim for social justice is key; Kaushik & Walsh (2019) reiterate the ideal for research to enable tolerance, respect and the removal of barriers to access, which I have interpreted in a broad sense as being not just access to services but 'access' to resources, HCP language and ways of working. Empowerment is viewed as enabling people to gain control over their health and managing on their (informed) terms. Of significance was the stance that I listened out for self-management actions that worked for participants, and I listened for barriers and how they got around barriers, as their tactics could be helpful for others in a similar position. My interpretation is of viewing pragmatism, that is, of design-based research, as a method for exploring real-life situations in a theoretical way and using this to develop practical solutions, the applied nature of this study is central.

3.4 The study population

The study design required that the study population should initially be identified and sampled purposively based on LTC experience and age. In addition the wish to recruit people who lived with low health literacy skills was an important factor to consider, this was complex to operationalise and is discussed in section 3.4.1. Purposive sampling was appropriate in the initial stages as the study aims required the contribution of people with specific characteristics (Bowling 2002). Once in the field convenience sampling was used to ensure adequacy of the sample and this is discussed in section 3.5.

The first purposive recruitment aim was to identify people who self-reported as having lived with either arthritis (oesteo or rheumatoid) or diabetes (type 1 or 2) for at least one year. These conditions are reasonably prevalent within the general population, 3.7 million people in the UK have been diagnosed with diabetes (Diabetes UK 2016) and 8.75 million people in the UK have sought treatment for osteoarthritis (Arthritis Research UK 2016). These conditions were selected because much is known about how these conditions can be managed, particularly in terms of medication regimes and health behaviours (Arthritis Research UK 2016, Diabetes UK 2016). The two conditions differ however in the aspects of self-management skills required. Living with diabetes requires daily management of diet and monitoring of blood to ensure sugar levels are maintained safely (Thorne et al 2003 and Diabetes UK 2016). Living with arthritis requires people to manage pain, a key recommendation being to exercise even if experiencing pain (Arthritis Research UK 2016). Pain management is known to be an important but difficult aspect of self-management of LTCs (DH 2012). Finally, the aim to recruit participants who had lived with a condition for more than one year was levied because, within the first year of diagnosis, self-management routines may not be established while coming to terms with the condition may be the dominant priority (Bury 1991, Thorne et al 2003).

The age range of 30 – 70 year olds was selected to enable elicitation of the factors that facilitate adults to self-manage during middle adulthood. Understanding the barriers and facilitators of self-management for this age group has the potential to inform HCPs and public health practitioners as to how to best support LTC self-management in adults, and early adoption of healthy behaviours could promote a healthier late adulthood (National Voices 2014, Harbour & Grealish 2018). The frequency of LTCs increases with age; the Department of Health (DH) LTC Compendium (DH 2012) suggests that at age 30 17% of the population have one LTC which rises to 30% at age 60. In the field the experience was that people aged 49 – 70 volunteered. Interviewing people aged 49+, rather than 30+ has reduced the differences that might have been expected across participants in terms of worldview, literacy and information technology skills (Office for National Statistics 2017) and ensured a focus on middle adulthood. Furthermore, Harbour & Grealish (2018) suggest that people born between 1946 and 1966 - the so-called 'Baby Boomer' generation - experience a high burden of chronic disease and, despite having access to health information, may require HCP support with the application of knowledge to self-management. Consequently, as they age, this generation are predicted to be high users of health care services and there is benefit to be gained from understanding how such services can best support their self-management.

3.4.1 Identifying people with low health literacy skills

As an intention of this study was to understand how people experiencing low health literacy skills self-manage an LTC it was necessary to attempt to recruit people with low HL skills. However, as people were unlikely to be aware of their health literacy level (Mackert et al 2019) I had to use a proxy measure for low HL skills. Van Der Heide et al (2013) posit that a range of evidence demonstrates that people with low education experience low HL skills. More recent empirical work by Finbråten et al (2020) identified a significant association between HL skill level and education level and Cudjoe et al (2020) also found that low education was linked to low health literacy. In England leaving school without qualifications is often used as a proxy measure for a low level of education (Department for Business, Innovations and Skills 2012). I therefore aimed to recruit people who had left school without any qualifications, that is, with no Ordinary level General Certificates of Education (O levels) or Certificates of Secondary Education (CSEs) as it was deemed an acceptable requirement to ask about and could be indicative of low HL skills. Evidence that up to 44% of people with no qualifications live in poverty (Joseph Rowntree Foundation 2020) led to the decision to focus recruitment to locations experiencing social disadvantage.

People having English as a second language can experience barriers of accessibility and availability to health services and information, however these difficulties occur independently of their level of health literacy skills and/or level of qualifications in their first language (Santos et al 2014). As the focus for this study is on cognitive levels of health literacy skills, rather than health literacy as a social practice (Barton et al 2007), the decision was made not to include people having English as a second language.

People who self-reported challenges with reading, including living with dyslexia or experiencing other difficulties with reading, possibly as an outcome of their LTCs, were recruited. Dyslexia is a specific learning difficulty such that, regardless of intelligence, people experience difficulties with reading (Ritter & Ilakkuvan 2019). For people living with dyslexia reading can be challenging and time-consuming because of the cognitive effort required to understand information. There is some evidence (Kim et al 2019) that poor cognitive functioning in people living with LTCs can be associated with advancing age (O'Connor et al 2019), and progression of the condition or other comorbidities. In addition, Schinckus et al (2018) suggest that depression, distress and the burden of an LTC can impact people's cognitive ability to deal with information required for self-management. It was appropriate to include people who lived with an LTC and self-reported reading difficulties.

3.5 Gaining access to potential participants

Riese (2019) acknowledges that access, as a requirement for research, can become an instrumental process when there are demands on the researcher to gain ethical approval and to meet deadlines. For me, time, being a novice researcher and practical restrictions meant that I had to plan ways to gain access, and submit the plan for ethical approval, before I entered the field. Ethical approval to commence data collection was sought from the University Ethics and Research Governance system (ERGO) and approval was awarded in April 2017 with ERGO reference number 23842. On entering the field to recruit participants I made practical changes to ensure that I gained access to appropriate potential participants, this process of convenience sampling is explored and explained below (Holloway & Wheeler 2010).

Having set out parameters regarding the people I was hoping to recruit and acknowledging that recruitment through NHS services was inappropriate for a health-promoting approach and a researcher with no clinical experience, I needed to reach out and find people living with LTCs in the community. The recruitment of participants from the community was granted ERGO approval. Initially I attempted to identify possible participants via community services including health trainers, literacy classes and (non-NHS) healthy living centres. However my experience was that such services acted as gate-keepers and ignored or turned down my requests to speak to their clients about my research. An initial positive contact within a local authority changed when personnel moved roles. Although a new contact could not facilitate interviews with her clients she did encourage my idea of recruiting via local community clubs, agreeing that a club would also provide me with a convenient and safe venue for interviewing. She suggested that I could locate such groups through library notice boards. I therefore changed my approach to prioritise community clubs, particularly clubs sited in areas of deprivation, to aid identification of people living with low HL skills (Joseph Rowntree Foundation 2020). I visited libraries to identify possible clubs that women may attend and I was aware of the existence of Men’s Sheds so I pursued that avenue, initially via a website, to find male participants. Men’s Sheds are community clubs which provide opportunities for men to take part in practical activities, such as woodwork, while also enabling social interaction and support (Kelly et al 2019).

An early plan to distribute postcards or posters with information about the study and asking people to contact me to arrange an interview became untenable. This approach did not give me any control over who would be recruited, nor whether anyone would come forward. Once in the field I perceived potential problems, including the realisation that people experiencing difficulties with reading were unlikely to read postcards or posters, and practical problems of how people could contact me, where we might meet and whether people would wish to contact me, a complete stranger. Alongside being encouraged to pursue community clubs as venues for potential participants I came to appreciate that, by visiting clubs in person, I could productively explain the aim of my research and speak directly to possible participants. Volunteers would see me and hear about what I aimed to achieve. As Flick (2002 p57) suggests, gaining access, building a relationship and encouraging willingness to participate in research are key to facilitating a situation where ‘research becomes possible’, and I was only able to achieve this by visiting community clubs in person.

3.5.1 Enabling recruitment from community clubs

I identified clubs in a variety of ways including driving to and then walking around a known area of deprivation, searching for Men's Shed locations and opening times on the Internet, visiting libraries and making a note of local clubs displayed on notice boards and asking people, such as community venue receptionists or club members, for their local knowledge of suitable clubs. Some clubs I visited were closed, unwilling to enable access to their members or, once I had gained access, found to comprise members who were all either over 70 or had exited school education with qualifications. Finding the clubs and identifying the opening times was sometimes difficult, website information was out of date, incomplete or non-existent. This reflected difficulties some clubs had with finding and maintaining appropriate premises. One Men's Shed had originally been run in a church and I was informed by a participant that the club members improved the room and then the church asked them to leave. A website and the participant told me the club was run at a new venue, I visited the area three times but could not find the group.

Entering a club was difficult for me, I am a naturally shy person and felt like, and often was, an outsider. I was also never quite sure whether, once I had successfully parked my car and found the club entrance, there would be some sort of unwritten 'rule' about access which I would need to navigate. For example, one Men's Shed doorway was through a (locked) gate as the entrance was within the grounds of a children's nursery. I had to speak to the community venue receptionist and reassure the nursery staff about who I was and why I was visiting.

The Men's Sheds were a little intimidating for me as they were all-male environments with lots of woodwork tools and equipment, but, where I gained access, the men were interested to hear about my research. Men's Sheds are formally organised, for example the men are Disclosure and Barring Service checked, wear identification badges when attending the club and the club is run through a committee format. Not all the Men's Sheds I approached enabled me access. One Shed had hosted a researcher a few months previously and the leader I spoke to explained that the interviews had taken too long and exhausted the members. I was not invited in to speak with any of the members and I did not recruit any participants from that club.

The local authority contacts agreed with my plan to offer a shopping voucher as a thank-you to participants, particularly as people I aimed to recruit could be experiencing marginalisation or deprivation. My original plan was to offer a £30 shopping voucher but this was changed when I came upon the first club from which I recruited participants, the Crochet Club. Sitting down with group members, talking to them and hearing them talk I soon realised that offering a £20 shopping voucher to participants and £10 per participant to the club would be more suitable. £30 came to seem out of proportion, particularly as participants would not have to make a special journey to meet with me, and it seemed appropriate to divide the donation and offer a small contribution to the group to thank the group for enabling the recruitment. This change was submitted to and approved within the ERGO system in September 2017. Participants reported that donating to the group was a good idea and were humble about the voucher for themselves. Offering the shopping voucher at the end of interview two potentially encouraged participants to undertake both interviews and all participants completed both interviews.

3.6 Being ethical and managing risk

Having discussed how potential participants were identified this section will evaluate the recruitment of participants and the interview process, particularly in terms of gaining consent, managing confidentiality, anonymity and potential risks for myself or participants. I had to adhere to the University Ethics Policy (University of Southampton 2012) which requires that research should have integrity, quality and be transparent. Following the ERGO approval obtained in April 2017 I subsequently sought permission for two changes. The first was a change to the voucher offered (as above). The second change was made, and agreed, in April 2018, prior to undertaking phase two, when I presented the adapted data collection tools.

3.6.1 Recruiting participants and gaining consent

An ethical approach to research requires that participants are informed of the aims, process and ultimate outputs of the research, this ensures that participants understand what they are consenting to, thereby enabling informed consent (Webster et al 2014). The (written) participant information sheet (PIS) had to be read and understood by potential participants, taking in to consideration that they may experience difficulties with reading and understanding written information. It was important to design the PIS ensuring it was respectful, informative, accurate and easy to read. Straight-forward language and short sentences were used and readability tests (available via the Internet) were applied to the content. The font and layout were adjusted and expert advisors (supervisors and ethics committee members) provided a final check that the content was easy to read and appropriate. See participant information sheet in Appendix A.

For the clubs from which I did recruit participants I entered and spoke to the community group about my research or spoke to a club leader about the particular people I was hoping to interview. On commencing recruitment I quickly realised that I had to make the recruitment criteria clear so that the participant group did meet the study requirements. I therefore stated as soon as possible after gaining entry that I was seeking people aged 70 or under, who had lived with diabetes or arthritis for more than one year and had left school with no qualifications or found reading health information difficult. When people volunteered to be interviewed I gave them the PIS and organised a date and time for interview one. For the final four participants, the group leader gave them the PIS and I organised specific dates, with the leader, to undertake the interviews and the leader informed the volunteers of the organised dates. In every case a potential participant received the PIS in advance of interview one, ensuring that they had time to take the PIS home and read it.

At the start of interview one I asked each person whether they had had the opportunity to read the PIS and I received ‘yes’ responses. I then went through a copy of the PIS summarising why I was doing the research, how the findings would be used and how anonymity would be maintained. As Yeo et al (2014) suggest this, as well as ensuring the PIS was reviewed, introduced the research and the process I would follow. I checked that the person was still willing to be interviewed and then asked the person to read and sign the consent sheet (Appendix B). I read out each aspect of the consent sheet as they initialled each section on the first page as I noticed that some people just signed, possibly without reading each statement, and I wanted them to hear what it was they were signing up to. Once the form was initialled, signed and dated I added the participant number. I reassured participants that their full name was only required on the consent form and would not be used alongside interview data. At the start of interview two I checked that the person was willing to be interviewed again and added the date for interview two to the consent form. On return from interviewing signed consent forms were stored in a locked cabinet to which only I have access.

3.6.2 Recording data

Once signed consent was gained a digital dictation machine, Sony ICD-PX333D, was used to record all interviews. While travelling the device was kept in a bag and on my person. On return from interviews the interviews were downloaded on to a password protected personal computer, which only I can access. Audio data was stored on the computer in Sound Organiser software. When not in use the dictation machine was retained in a locked cabinet. Transcription is discussed in section 3.9.1.

3.6.3 Managing participant distress

Holloway & Wheeler (2010) caution that interviews can provoke awareness of difficult issues or unveil issues which have not previously been considered. I worked and asked questions in a way that ensured distress was minimised, while recognising that it may not always be possible to avoid distress. The topic of how someone manages a long term condition on a day to day basis was understood to be an acceptable topic to discuss with minimal psychological distress. However, I had to keep in mind that the interview might provoke difficult and distressing feelings, for example around the fact that the LTC is going to get worse over time (DH 2012) or because of concerns generated if the person's social support is particularly lacking, recently changed or unhelpful (Walker et al 2015).

I had to be mindful that participants may experience depression alongside diabetes or arthritis (Bower et al 2012). One participant became tearful when discussing his daughter and four of the participants became upset when discussing recent bereavements. I gave each participant time to recover their composure and checked that they were okay to continue with the interview before re-commencing. For each club I provided a list of potential supports which listed helpful local organisations and websites, see example Appendix C. As the data collection, and consideration of findings, proceeded I added useful tips for self-management. I found, as Bashir (2020) notes, that speaking with and asking people about their difficult circumstances elicited feelings of powerlessness for me; I had to remind myself that all participants were in contact with a club, and therefore with a group of people who could, and did, provide them with support.

3.6.4 Managing risk

While undertaking the ethical approval process ensured that I considered potential risks to myself and participants maintaining an ethical approach is an ongoing component of research (Webster et al 2014). In the field awareness of ethical considerations and reflection were important. For example I did as much as I could to maintain anonymity for participants, while one participant insisted I could use his name if I wished – which I did not. I had to look out for participants being coerced into taking part (Webster et al 2014). For example one female participant who ran the Crochet Club tried to encourage her friend to be interviewed, possibly because of the voucher and money I offered to the club. I could see that her friend looked very reluctant so I did not approach her.

As I interviewed people at their club I had to find a place where we could speak without being overheard. Most venues had a separate room where I could speak with participants but the amount of privacy this afforded could vary. I had to be alert to the possibility of interruptions and I took care to stop interviewing quickly if we were interrupted. One Shed did not have a separate space so we sat and talked in my car. This option was suggested by one of the participants and did provide privacy. I judged that this was a safe option for me as it was during the day, the car was in a public car park and right next to the venue, with people coming in and out of the venue for the duration. I checked with the male participants that this was acceptable for them before proceeding with the interview.

Bashir (2020) notes that researchers must consider their safety, well-being and potential vulnerability. I experienced two situations which were difficult for me. One was interviewing in an enclosed office in a concrete multi storey car park which brought on feelings of claustrophobia, the second was getting an unexpected reaction when I offered a participant the shop voucher. I had decided, for that club, to purchase Waitrose vouchers, as there was a Waitrose in the area. The participant had been talking to me about how he lived in poverty so really I should have realised that he would reject a Waitrose voucher as of poor value and not helpful to him. He went rushing up to another club member and asked him if he wished to purchase the voucher for cash; as the other man agreed, he started to relax. As Bashir (2020) posits it is not the case that the researcher is always in a powerful position, the researcher too can become or feel vulnerable as an outcome of 'the built environment…and participant unpredictability' (p670).

Having fully explained the recruitment process the following section presents the development and application of the interview one data collection tools.

3.7 Interview one data collection tools

This section presents the development of the data collection tools applied in interview one, which comprised the health literacy skill level tool, the personal social network diagram and the social network questions. For each tool the theoretical basis for choice is critiqued and the form of the tool applied in phase one and two, the rationale for any changes and the scoring systems are presented. Interview one was recorded and the interview was transcribed. Interview one transcriptions were analysed alongside transcriptions for interview two.

3.7.1 Health literacy skill level measurement tool

An aim of this study was to understand how people experiencing low health literacy skills self-manage an LTC so it was necessary to apply a tool which measured HL skill level for each participant. The tool used was developed in 2016, whilst preparing the study protocol and prior to applying for ethical approval.

Four literature reviews of health literacy instruments were critiqued: Mancuso (2009), Jordan et al (2011), Altin et al (2014), and Haun et al (2014). These reviews were identified through a database search for health literacy instrument reviews in 2016. Considered together the reviews provided a comprehensive view of health literacy instruments published since 1990 and up to

2013. The predominant finding in all four reviews is the diversity in definitions of health literacy and, correspondingly, the aims, content and style of health literacy measures. Mancuso (2009) critiques the older instruments for reflecting medical settings rather than everyday self-management and for only measuring sight-reading ability and not comprehension or application. She also discusses the difficulty of decisions about generalising or specificity in application to LTCs or other health conditions. Jordan et al (2011) debate the desire to measure health literacy at the individual and population level; these authors subsequently developed the Health Literacy Questionnaire (HLQ, Osborne et al 2013) which incorporates aspects of social support and navigation of health care services. Altin et al (2011) note the weaknesses of many HL instruments, and the lack of consensus as to what the tools should measure and suggest that development of further tools is required. Haun et al (2014) comment on the disparity of tools, finding that different dimensions of health literacy are measured and that different tools are developed for differing contexts and populations. As Haun et al (2014) suggest the diversity of tools complicates the task of interpreting findings across studies and - I would suggest - the task for researchers when making decisions about which tool to use.

The study aim to understand the HL skills each participant possessed, and whether the skills were at a functional, applied or critical level (see section 2.4.2), guided the decision to use a tool which focused on HL skills. Through focusing on the measurement aims and requirements for this study (see Appendix D, Table A) many HL tools were eliminated as: not defining HL in a way which was relevant to this study, too focused on one LTC, not suitable for a UK audience, or not of practical use.

Following the application of the study requirements to a range of HL tools, two tools were identified as relevant (Table 4). The All Aspects of Health Literacy Scale (AAHLS, Chinn & McCarthy 2013) was suitable as it measures functional, communicative and critical health literacy. The authors themselves conclude that the scale did not adequately measure critical health literacy, however. The Ishikawa et al (2008) Functional, Communicative and Critical Health Literacy tool (FCCHL) also measures three levels of health literacy ability and was the basis for the 14-item health literacy scale (HLS-14, Suka et al 2014), the only difference being that FCCHL was designed to measure HL ability in people living with diabetes and the HLS-14 is a generic measure. Lin et al (2020) suggest that specific LTC types should not be mentioned in questionnaire items as people view self-management as something they undertake to manage their health generally rather than managing an LTC. My aim was to understand how a person self-managed on an everyday basis so it was not appropriate to refer to specific medical tasks, expectations or LTC type in the health literacy skill questions. The FCCHL and AAHLS were critiqued by applying the study tool requirements, see Table 4.

Table 4 Study requirements applied to FCCHL and AAHLS

Study health literacy measure requirements	**FCCHL** (Ishikawa et al 2008) **HLS-14** (Suka et al 2013)	**AAHLS (**Chinn & McCarthy 2013)
Tool encompasses use of health literacy skills within context of everyday life	Original – no, diabetes focus but HLS-14 version, yes	This appears to be aim but lots of the questions include communication with HCP
Application of health literacy skills generally, not to a specific LTC, and to multi-morbidity	As above	Yes
Suitable for UK audience/ adults	Designed for Japanese population but translated to English for publication	Tested on UK audience
Focus on health literacy skill level for an individual	Yes	No – several questions which focus on 'getting help/support'
Records self-report of skills enabling classification in to functional, applied (communicative or interactive), critical level of skills	Yes 3 levels of HL tested – communicative (as 2nd) but scoring used to determine score at each level rather than overall level.	Aim to yes – communicative. Authors report critical level not fully discriminated. Communicative level questions potentially leading
Uses a reasonable number of measures & can be completed in less than five minutes	Yes	Yes
Statements or questions easy to read	Not tested with UK audiences	Yes readability tested with participants
Statements or questions have one part only	Yes	Yes but some questions quite long
Available to use (no charge for use and no restrictions on use)	Yes	Yes

The health literacy questions asked in interview one, phase one are presented in Appendix E and were developed using the following process:

- Critical review of four literature reviews of health literacy measures
- Elimination of measures based on applicability to study aims, see Appendix D, Table A.
- Identification of two measures which were most appropriate to the study aims:
  - FCCHL, Ishikawa et al 2008/HLS-14 Suka et al 2013
  - AAHLS, Chinn & McCarthy 2013
- Strengths and weaknesses with regard for tool to meet requirements of study were identified for both these tools, see Table 4.
- Using FCCHL and AAHLS as a basis statements were drafted which aimed to match Bloom's taxonomy of skill level (see section 2.4.2) and enquired about a person's view of

their health literacy skill (subjective measure). See Appendix D, Table B and Table C which illustrate how the statements were drawn from AAHLS, Table B and FCCHL/HLS-14, Table C.

- Final format for phase one developed using an iterative process over three meetings and the expertise of two health promotion specialists (one the researcher now a lecturer, the other now a Professor) and a statistician. The scoring system was devised (see 3.7.1.1).
- Questions were pre-tested using a volunteer – a friend of the researcher who lives with type 1 diabetes, aged 59 and left school with no qualifications. The feedback received led to minor changes to the wording of some questions.
- Questions used in phase one, one participant fed back that ‘never’ response was too strong and suggested ‘almost never’
- I observed responses to the questions in phase one and compared how responses and scores related to participant comments in interview two. I reviewed the questions and made a few changes to the questions prior to phase two, see Appendix E, phase two.

3.7.1.1 Scoring system for health literacy questions.

The AAHLS tool used a three point scale of ‘often’, ‘sometimes’, ‘rarely’. The FCCHL used a four point scale of ‘never – often’, the HLS-14 used a five point scale of ‘strongly agree to strongly disagree’ and scores were summed to give a total score for HL as well as a score for functional, communicative and critical levels of HL. To avoid participants selecting the middle option by default an even-numbered scale was preferred. A four point Likert scale of never (changed to ‘almost never’ in phase 2), sometimes, often and always was used by participants to rate how able they felt to undertake each stated task. For most statements a reply of ‘always’ scored 4 and ‘almost never’ scored 1. Scoring was reversed for statements 1, 2 and 3 in part B.

The statements were structured such that they reflected either a functional, applied or critical level health literacy skill. For example ‘read information about my LTC’ and ‘I can read the words but do not always know what the words mean’ were understood to represent functional level skills; ‘use information to help me manage my LTC’ and ‘I will share the information with others’ are examples of applied level statements; and ‘decide how reliable the health information might be’ and ‘judge the quality of the health information that I find’ were critical level skills, see Appendix E for all statements. The score for each participant was totalled and graphed – see section 5.4. Once graphed it was possible to discriminate four levels of HL skills. A score under 40 was classified as a borderline functional level of skills; a score between 40 - 49 as a functional level; 50 - 59 as an applied level and a score of 60+ as a critical level of HL skills. The application of the scores is presented in Chapter 5.

3.7.2 Social network mapping

A requirement of the study was to understand the resources and people that supported the participants to manage their LTC, that is, their social network. Network constituents can be simply listed but diagrams can provide a method for representing information in a spatial and simplistic form (Bravington & King 2019). Using a diagram to illustrate a person's network appealed as it would be a novel yet straightforward way for people to view their network and it provided me with a record of their network. The diagram method had to place the participant as central and not take too long to complete. The diagram did not need to be complex but would provide a start point for further questioning in interview two. Bravington & King (2019) note the use of convoy diagrams for understanding social interactions. Convoy diagrams comprise three concentric circles to which network members are mapped. The ego is placed centrally in an inner circle and three outer circles represent decreasing levels of closeness to the alter. The method has evolved from the work of Mary Northway, who designed and worked with socio-grams in the 1940s (Hogan et al 2007, Ryan et al 2014). The participant leads on decisions as to who is in the network and where to place alters. The usefulness of the concentric circle tool lies in the visual representation of a person's network, enabling guided discussion of the meaning of network relationships (Ryan et al 2014).

To map a participant's social network stage 1 of GENIE was used to create a diagram of the participant's personal network. GENIE (Generating Engagement in Network Involvement)[2] is a web-based, self-management support intervention which can help people with chronic illness engage with personal support networks and improve self-management processes and outcomes by linking with online and offline support. There are four stages to the GENIE process but only stage one was undertaken in this study. Stage one comprises a mapping exercise normally undertaken on online via the website, a paper-based method was a practical approach for me when working with people in the community in a range of venues. Stage one uses the three concentric circle diagram on to which participants add their network supporter name and note the frequency of contact (for example daily or weekly).

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[2] GENIE is released under a General Public License and is sponsored by EUwise, Seventh Framework Programme, University of Southampton Faculty of Health Sciences and the National Institute for Health Research Wessex CLAHRC.

During interview one a paper copy of the concentric circle diagram was used as a prompt for participants to list and position the people or other resources that supported them to manage their LTC. I explained that, '*you are in the middle, the inner circle is people who are closest to you, help you the most with your LTC, then bit further out, bit further out'*. I also demonstrated this on the diagram. This language was purposefully non-leading and non-judgemental to encourage participants to be open and honest about the positioning of others. I also aimed to use language which encouraged participants to report on the network available to them on an everyday basis rather than the network accessed during acute times of poor health. Only one of the participants took the opportunity to populate his own social network diagram. For all others I wrote generic names, rather than real names, in the circles as directed by the participant and noted the frequency of contact.

3.7.2.1 Scoring system for network diagram

Once interview two was completed (because participants could add names to their network diagram in interview two if they wished) the final diagram was used to create a score indicating the size of the network. The size of each network was calculated using the method explicated for GENIE, i.e. seeing a supporter every day scores 10, at least once a week scores 5, at least once a month scores 1, less often scores 0. The scores were added up to give a total score for each participant's network, the larger the score the larger the network. The calculation process was not an exact process as the frequency of contact did not always fit neatly in to daily or weekly. For example, some men visited the Men's Shed every day that it was open, where this was at least three times a week the Shed was scored 10. Following calculation of the total score for each participant four categories of network size were elucidated, see Table 5.

Table 5 Network size scoring system

Network total score	Category of network size
<18	Very small
19 - 28	Small
29 - 49	Moderate
>50	Extensive

3.7.3 Social network questions

To complement the social network mapping, which illustrated who provided LTC support, the social network questions were aimed at understanding the type of support received. A review of social support measures (see Appendix F) led to the decision to utilise a 4-item measure reported in Jetten et al (2012). The authors suggest that the measure can assess emotional support, companionship, instrumental support and informational support, which appeared ideal for this study.

The intention was to score the answers, where a 'never' response scored one and an 'always' response scored four, however this was not undertaken. There were several reasons for this; one being that the four questions were not understood by participants in phase one. Consequently the questions were substantially changed between phase one and two (see Appendix G). A further problem was that calculating an overall score for 'level of support' did not produce a meaningful result. For example, the different types of support were not necessarily of equal importance to participants, yet this is an assumption that, ideally, is made when scoring (Bowling 2002). Finally, the answers to the questions and the scores did not assist with any useful analysis of each participant's social network. The questions elicited only a partial view of participant's overall perceptions of the support available to them and did not illuminate participant's actions to manage their social network. Fortunately the in-depth interview did elicit this network information.

3.7.4 Field notes

Once in the field I found it was essential to make observational notes either before I left a venue (sat in the car) or as soon as I returned from interviews. Arthur et al (2014) note the importance of field notes which for me, prior to interviews, enabled development of the recruitment process and at the analysis stage added context to participant's answers. The types of notes made and their justification are presented in Table 6.

Table 6 Overview of field notes

Time point	Notes made	Justification for note-taking
Before interviews	How I gained access to the club and potential participants (or not, if unsuccessful)	Contribute to understanding of recruitment process – what worked and what did not. Keep a record of potential participants
Before interviews	People interviewing – anything to look out for or note (e.g. recently bereaved)	Ensure ethical recruitment and safety and comfort of participants if recruited Notes to contribute toward understanding of participant's situation
After interview one	Time and date for interview two Any points to note, e.g. talkative/not talkative, impact of venue Comments made after recorder turned off	Practical arrangements to ensure interview two occurred. Notes contributed towards an understanding of the participant's situation. Impact of venue – did it enable open discussion?
After interview two	Any additional points to note – e.g. reaction to questions, talk or information gained from the group that is relevant	Notes contributed towards an understanding of the participant's situation and of the atmosphere/context of the club.

3.8 Interview two

Interview two was a semi-structured interview which facilitated an in-depth exploration of self-management of LTCs with each participant. The aim was to generate new knowledge by encouraging participants to re-consider what they did and why (Hall 2013, Yeo et al 2014). This section explores the origin of and the justification for the interview guide and the process of undertaking interview two.

3.8.1 Designing the interview guide

To devise the semi-structured interview guide I re-visited the research question and specific questions (section 3.2) and the relevant literature (as Chapter 2) to establish the topics to be covered. The interview guide had to cover all the necessary aspects, avoid repetition and maintain a focus on the specific research questions (Arthur et al 2014). There were three sections to the guide; using health information; drawing on support; and managing an LTC. Questions for each section were derived from appropriate evidence. A first draft of the interview guide was tested for acceptability through interviewing a relative aged 72 who lives with two LTCs. The feedback received was that the questions were acceptable and made one 'think differently', an apt outcome for an interview guide. The guide submitted for ERGO approval, and used in phase one, included citations where literature was drawn upon to draft questions (see Appendix H). The guide was simplified for phase two (see Appendix I). Simplification reduced unnecessary repetition with interview one and made the guide easier to apply during interview two.

3.8.2 Undertaking interview two

Interview two took place between two days and two weeks after interview one. Time between each interview was necessary to enable me to listen through interview one and determine any aspects which needed to be clarified or explored further. The length of time between each interview was simply a pragmatic approach dependent on my and participant's availability. Participants were informed of the two interview process and during interview one I would remind people of the opportunity to re-visit their answers. Interview two started with re-visiting one or two points made in interview one which led naturally in to further questions about either their social network or their use of health information. The interview would continue with whichever aspect had not already been covered and then finish with questions about control over their LTC, particularly the importance of managing and their confidence to manage. I would end each interview by thanking them and offering the voucher (see section 3.5.1).

As interview two was my opportunity to hear participants' understanding and perceptions of using information and drawing on supporters to manage their LTC(s) I had to strike a balance between being objective and building trust. At the start of the interview I aimed to build rapport and exhibit confidence in the process. Enabling participants to reveal potentially difficult aspects required a certain amount of neutrality in terms of being non-judgemental, showing that I was not going to be shocked and allowing the participant to talk. Interviewing is hard work as one must listen carefully *and* make decisions about the next question to ask; at times I moved on to the next question rather than probing answers fully. Yeo et al (2014 p184) advise that 'getting below the surface' requires the use of 'why' questions and it may have been appropriate to use 'why' at some points during an interview to encourage participants to expand upon their answers. However, in health behaviour conversations the use of 'why' questions are discouraged as being confrontational and I resisted the use of why questions (Wigley & Wilson 2009). Importantly I valued participant's contributions, wanted to make best use of their time and therefore did my best to interview effectively.

3.8.3 Summary of changes made to data collection tools for phase two

When reviewing the data collection tools at the end of phase one it was helpful to keep in mind Presser et al's (2004) suggestions to appraise the respondent's reactions and answers to questions and judge whether questions were enabling the uncovering of findings pertinent to the research question. As I aimed to recruit people who experienced low health literacy skills it was important that questions were understandable. Each data collection tool was reviewed and changes made, if necessary, as outlined below.

> Health literacy skill questions: each question was appraised to identify whether it was being understood and answered as expected. Listening to interview one enabled me to consider whether participants were answering honestly and accurately and identify whether the wording of each statement was working or causing problems (Bowling 2002, Presser et al 2004). For Phase two one question was added to Part A and the wording of question 8 in part A was changed. No changes were made to Part B questions. A small wording change for the Likert scale – changing never to 'almost never' – was undertaken based on feedback from participant 5. See Appendix E.
>
> Social network mapping: no changes were made between phase one and phase two.
>
> Social network questions: as explained in section 3.7.3 the questions provided in phase one were not answered well so were expanded upon for phase two. See Appendix G and section 3.7.3.
>
> Interview guidance: for phase two unnecessarily repetitive questions were removed and the interview guidance was stream-lined – see Appendix H for phase one guide and Appendix I for phase two interview guide.

On completion of the data collection phase I had varied and rich data from two interviews, one structured and one semi-structured, with each participant. The next phase of the study was the data analysis stage, which is narrated in the following section.

3.9 Data analysis

The data analysis process focused on discovering and interpreting findings for the three main aspects of the study: self-management of an LTC, application of health literacy skills and the role of a personal social network. Taking a transactional view of the pragmatic paradigm (Greene 2007, Denscombe 2014) I critically reviewed the requirement to understand self-management from two perspectives; for processes I as the researcher was interested in, and from the participant's perspective of living with an LTC. From my viewpoint comprehension of participant's health literacy skill levels and the size and structure of their social network would enable comparison of participants with differing levels of HL skills, for example, in terms of how they manage their LTC. From each participant I wished to understand how self-management of an LTC occurs every day. Accordingly there were two aspects to data analysis and presentation. The first aspect was the calculation and collation of findings from the data collection tools used in interview one (section 3.7). The second aspect was the thematic analysis of participant explanations of LTC self-management. A critical final stage in the analysis was synthesising the two aspects, through abstraction, interpretation and explanation (Spencer et al 2014). The stages of data analysis enabled and required full immersion within the collected data as the decision was made to analyse without the use of analysis software.

Aiming to ensure that data analysis was rigorous, systematic and transparent (Lathlean 2010) I selected the Framework method of qualitative analysis. The Framework approach is often used within applied research and was therefore suitable for a health promotion and pragmatic approach to research (Lathlean 2010). The Framework method enables a logical structure to data management, organisation and explication which I personally found helpful and which was relevant for a study which used a deductive and inductive approach to data analysis (Ormston et al 2014). The Framework approach has parallels with thematic analysis, both methods can be applied to analysis of data which presents the perspective of different participants and the researcher (Spencer et al 2014, Nowell et al 2017).

There are five stages to the data management aspect of the Framework method (Spencer et al 2014), familiarisation with the data, coding the data to derive an initial themed framework, indexing then charting the data and identification of concepts and descriptive themes across all data. This prepares the data to enable what Spencer et al (2014) term abstraction. During abstraction links across data are identified permitting an interpretation of the explicit (participant derived) findings and implicit (researcher derived) findings; where the explicit findings arise from what the participant says and the implicit findings arise from application of theoretical and substantive knowledge. The stages of analysis are discussed in detail below.

3.9.1 Stage one: familiarisation with the data

All interview recordings were transcribed by a third person. The transcriber signed an anonymity agreement (see Appendix J). The recordings were sent electronically to the transcriber via a secure system (University SafeSend), no identifying information, such as the full name of a participant, was shared and recordings were deleted from the transcriber's computer once the transcription was received and checked by me. I listened to the interview audio while reading the transcript to ensure all necessary detail was included and accurate. Identifiers, such as place names, were replaced by pseudonyms, alternative terms or vaguer descriptors, the objective being to achieve a reasonable level of anonymisation while avoiding overly harsh editing

(Denscombe 2014). Checking the transcripts against the audio recordings enabled immersion within the data before commencing stage two.

3.9.2 Stage two: identifying a themed framework

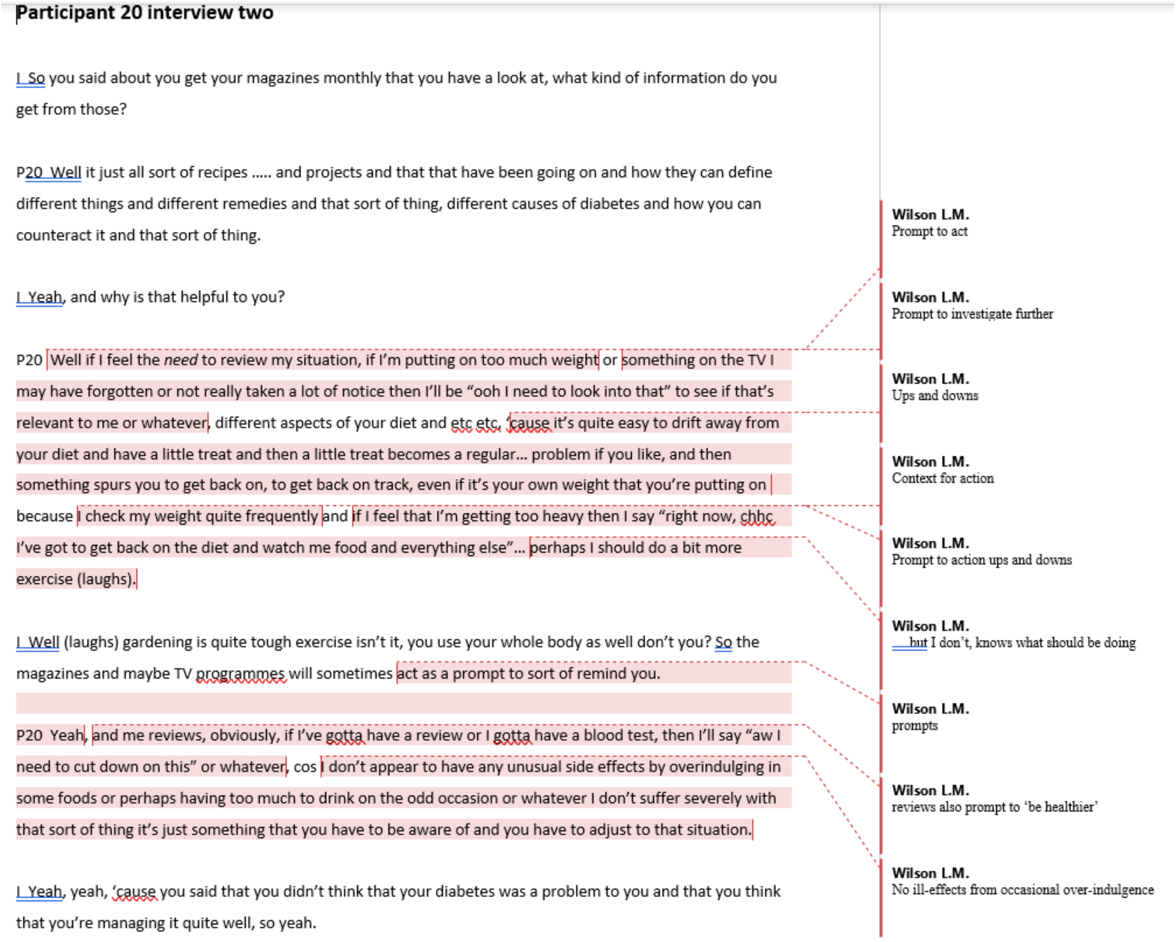
Across the three over-arching study themes of self-management of an LTC, a personal social network and health literacy skills, potential data codes were identified deductively from the study research questions and sub questions. Examples of the codes used and the justification for the deductive codes and the link to theory are sign-posted in Table 7. As data analysis progressed other codes arose inductively and these are indicated in Table 7 as ‘emerged from data’.

Table 7 Themed Framework of codes

Over-arching theme: self-management of LTC			
Code	**Justification for code**	**Theory link**	**Section of thesis**
Prompt to do something	To self-manage need to notice changes/symptoms/use meds	Wyke et al (2013)	2.2
Acting	To self-manage need to do something	Ong et al (2011)	2.2
Control	Understand whether person feels in control/autonomy to self-manage	Laverack (2016)	2.3
Importance	Underpins whether people act or not	Miller & Rollnick (2013)	2.3
Confidence	Underpins whether people act or not	Miller & Rollnick (2013)	2.3
Over-arching theme: personal social network			
Code	**Justification for code**	**Theory link**	**Section of thesis**
Types of support	Understand type of support provided/offered	Thoits (2011)	2.5
Support from similar others	Know similar others are important for self-management	Thoits (2011), Gage (2013), Grace (2020)	2.5
HCP interactions	Known to be important for self-management	National Voices (2014)	1.3, 2.2
Talking helps	Emerged from data - inductive	N/A	
Giving advice (phase 2)	Emerged from data	N/A	
Humour/irony/self-mocking	Emerged from data	N/A	
Tactics that help	Emerged from data	N/A	
Over-arching theme: health literacy skills			
Code	**Justification for code**	**Theory link**	**Section of thesis**
Sources of information	Understand how many & types of sources drawn on	Yamashita et al (2019)	2.4
Barriers to using information	So can compare barriers for participants living with low/high HL skills	Nutbeam (2001, 08)	2.4
Facilitators for using information	So can compare participants living with low/high HL skills	Nutbeam (2001, 08)	2.4
How information helps	Emerged from data	N/A	
Tactics that help	Emerged from data	N/A	

3.9.3 Stage three: indexing

All interview transcripts were indexed by annotating the text using the 'comments' facility available in Word. See Figure 2 for an example. The deduced codes (Table 7) were kept in mind while indexing nearly every line of an interview however the comments at this stage were not limited to aspects of the data that fitted within the codes. At the indexing stage comments were used to enable an initial interpretation of each section of participant's data and to illuminate the unique aspects of self-management, HL skills and social network for each participant.



Participant 20 interview two

I So you said about you get your magazines monthly that you have a look at, what kind of information do you get from those?

P20 Well it just all sort of recipes ….. and projects and that that have been going on and how they can define different things and different remedies and that sort of thing, different causes of diabetes and how you can counteract it and that sort of thing.

I Yeah, and why is that helpful to you?

P20 Well if I feel the *need* to review my situation, if I'm putting on too much weight or something on the TV I may have forgotten or not really taken a lot of notice then I'll be "ooh I need to look into that" to see if that's relevant to me or whatever, different aspects of your diet and etc etc, 'cause it's quite easy to drift away from your diet and have a little treat and then a little treat becomes a regular… problem if you like, and then something spurs you to get back on, to get back on track, even if it's your own weight that you're putting on because I check my weight quite frequently and if I feel that I'm getting too heavy then I say "right now, chhc, I've got to get back on the diet and watch me food and everything else"… perhaps I should do a bit more exercise (laughs).

I Well (laughs) gardening is quite tough exercise isn't it, you use your whole body as well don't you? So the magazines and maybe TV programmes will sometimes act as a prompt to sort of remind you.

P20 Yeah, and me reviews, obviously, if I've gotta have a review or I gotta have a blood test, then I'll say "aw I need to cut down on this" or whatever, cos I don't appear to have any unusual side effects by overindulging in some foods or perhaps having too much to drink on the odd occasion or whatever I don't suffer severely with that sort of thing it's just something that you have to be aware of and you have to adjust to that situation.

I Yeah, yeah, 'cause you said that you didn't think that your diabetes was a problem to you and that you think that you're managing it quite well, so yeah.

Wilson L.M.
Prompt to act

Wilson L.M.
Prompt to investigate further

Wilson L.M.
Ups and downs

Wilson L.M.
Context for action

Wilson L.M.
Prompt to action ups and downs

Wilson L.M.
but I don't, knows what should be doing

Wilson L.M.
prompts

Wilson L.M.
reviews also prompt to 'be healthier'

Wilson L.M.
No ill-effects from occasional over-indulgence

Figure 2 Example of indexing

From the indexing process in phase one (five participants) comments for each participant were categorised to a range of codes. The codes in Table 7 provided a basis for the generated codes although some codes were expanded, for example different types of support were coded separately and, as already explained, some codes arose inductively. Hennink et al (2016) posit that code saturation occurs when no additional issues are being identified through the coding process. Guest et al (2005) and Hennink et al (2016) suggest that the majority of codes are identified from interview one and code saturation can occur by interview eight. Forty-nine codes were identified in phase one (five participants) and only three additional codes were identified at the start of phase two analysis. This is perhaps to be expected as the interview questions for phase two were deliberately focused on the research aims and topics but also indicates that code saturation was achieved. Fifty-two codes were applied to analyse all the interview data, that is, interview one and two for phase one and two. Three new codes were identified in phase two, four codes were not used and two were merged. In total data for forty-six codes were tabulated for each participant.

3.9.4 Stage four: charting

For each participant indexed sections of interview responses were mapped to the forty-six codes, in a table. Three or four participants were charted adjacent to each other so that patterns across participants could begin to be revealed, see the example in Table 8.

Note; blue font in Table 8 represents data from interview one, black font interview two, exclamation mark indicates laughter, sections in brackets are my comments, words in capitals indicate words emphasised by participant.

Table 8 Example of charting stage of analysis

Over-arching theme: personal social network			
Code	**P18 Male arthritis only**	**P19 M Diabetes, depression, Parkinsons?**	**P20 M Diabetes, glaucoma, cataracts**
Instrumental support/advice	X wife X wife nags X wife reminds to do things – (particularly if out of routine)	X brother-in-law X wife X father – when fluent x shed x sister-i-l x dog – picks up when not well (particularly previous dog) x wife gets as much info as she can x wife took in info and helps me eat healthily x wife says got to take meds, got to eat, she makes sure it happens x wife steps in when 'black dog' comes x need a car	X wife first port of call X other family NOT supportive X healthcare staff x magazines x support with doing things – never needed x advice – always with the wife! X wife mentioned shed – not interested to start as likes gardening
Negotiating support		x (not asking) don't get support – down to me not asking, I need, I don't ask, I think that's a man thing (independence)	
Context for support	X office manager (deals with paperwork then chats to him) X wife makes him build word up – like school, frustrating (p5) X can't talk to wife about sporting injuries X don't talk in detail about medical things with family & friends	X probs with understanding info X don't get support – down to me not asking, I need, I don't ask, I think that's a man thing (independence) X shed like work canteen without the work X I don't work – I'm not allowed X wife takes stuff in (for me) goes in one ear and out the other! X I have a sweet tooth (needs help with h. eating) X forget to eat X d quite stable, don't have issues X doesn't ask as not wanting to bother others/don't think its important/laziness/not feeling up to it X depression descends	X wife – watching me all the time X if wife noticing (putting on wt) others might be noticing too X I do look at it (emotional support) with the fact I know I'm getting older X getting to lunchtime and not done anything so shed opportunity to 'get out' X do thoroughly enjoy shed X camaraderie X don't see children or grandchildren X go to bowls with wife

3.9.5 Stage five: identification of descriptive themes across all data

From the charts (as Table 8 above) it was possible to look across examples of responses for each participant and for each code. Commentaries on or summaries of the findings for all codes were prepared as descriptive themes, see example in Figure 3, below. Having identified the health literacy skill level for each participant and the size of their network, from interview one data, it was also possible to elicit patterns in terms of participants with, for example, a functional level of HL skills and/or participants with a large, diverse network. Commentaries on the data findings for each descriptive theme were developed and examined as a basis for the abstraction process.

Descriptive theme: Informational support

Overall – mainly HCPs and similar others. Also – LIMIT to how much info people wanted – especially if lived with LTCs for a long time and/or worried about what they would find (eg 3, 4), someone they trusted red = critical HL skills, blue = applied HL skills, green = functional HL skills

1F – family (look up stuff tog) & friends (some similar others)
2F – not open to advice from HCP due to previous exp, friends
3F – nurse, HCP (needs things explained, dyslexia?)
4M – doesn't ask for it but it is given – lived with LTCs for long time, had info in past from HCP
5M – stroke club
6M – partner (ex NHS) and internet (also HCP – v reliant on them actually)
7M – HCP, pharmacist, relative, similar others
8M – wife (both wives NHS background), HCP
9M – internet, likes to be informed so can tell others (but does not act on info himself)
10F – HCP, friends and family
11F – HCP
12F – 'had it for so long don't tend to look at it (info)' HCP originally
13F – Nurse, similar others (at clubs)
14M – HCP but doesn't remember it all/mishears
15M – Pharmacist and similar others
16M – similar others and HCP
17M – confident about getting info from relevant source, 'I know pretty much what there is to know'
18M – wife
19M – similar other, wife, brother-in-law
20M – HCP, Diabetes UK magazine (similar others)
21M – sister, wife
22M – partner

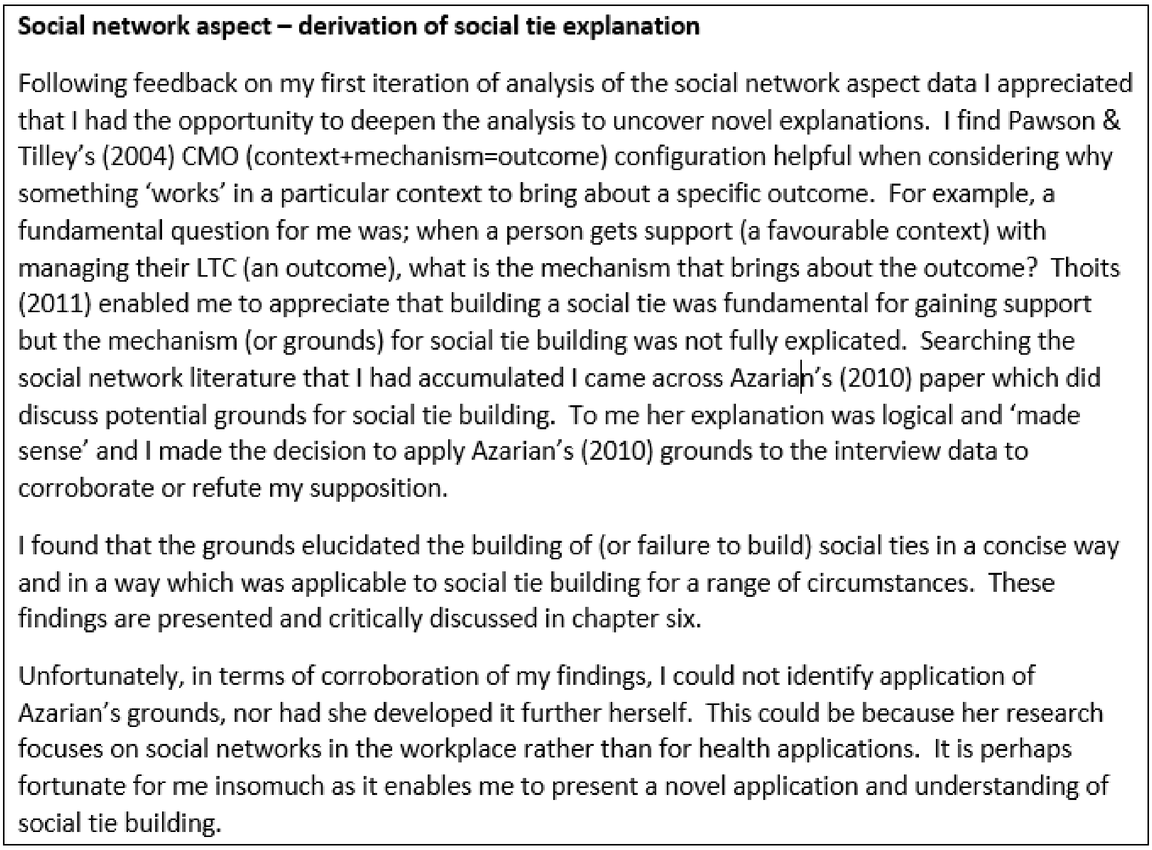
Patterns in terms of HL skill level, functional = one, sometimes two sources drawn upon (exception 19M), applied = two or three sources drawn upon, critical = no clear pattern

Figure 3 Example of summary for informational support descriptive theme

3.9.6 Abstraction

Interpretation and abstraction were iterative processes requiring movement between data summaries, theory and individual participant data. Starting with the summaries of descriptive themes (as stage five above), keeping theory and the charted interview data in mind new understandings of, and explanations for, the findings were inductively elicited. As the write up of the findings continued emerging explanations were back-checked to the original interviews, examples of the explanations were elicited from the interviews and theory was read and explored to build abstractions between the findings and the literature.

Drafts of the findings chapters were read and commented upon by my supervisors, the discussion and feedback enabling me to focus my interpretations for the health literacy aspect data and expand my interpretation of the social network aspect data. Following the feedback theoretical frameworks for health literacy skills and personal social networks were developed, the respective framework being critically discussed at the start of the findings chapters. Tables and diagrams were used to iteratively summarise theoretical ideas identified from the literature and link these inductively to interpretations and understandings of the interview data, see examples in Figures 4 and 5. This process enabled me to build connections between theory and the findings and to develop explanations for the findings, which are presented in Chapters 4, 5 and 6.



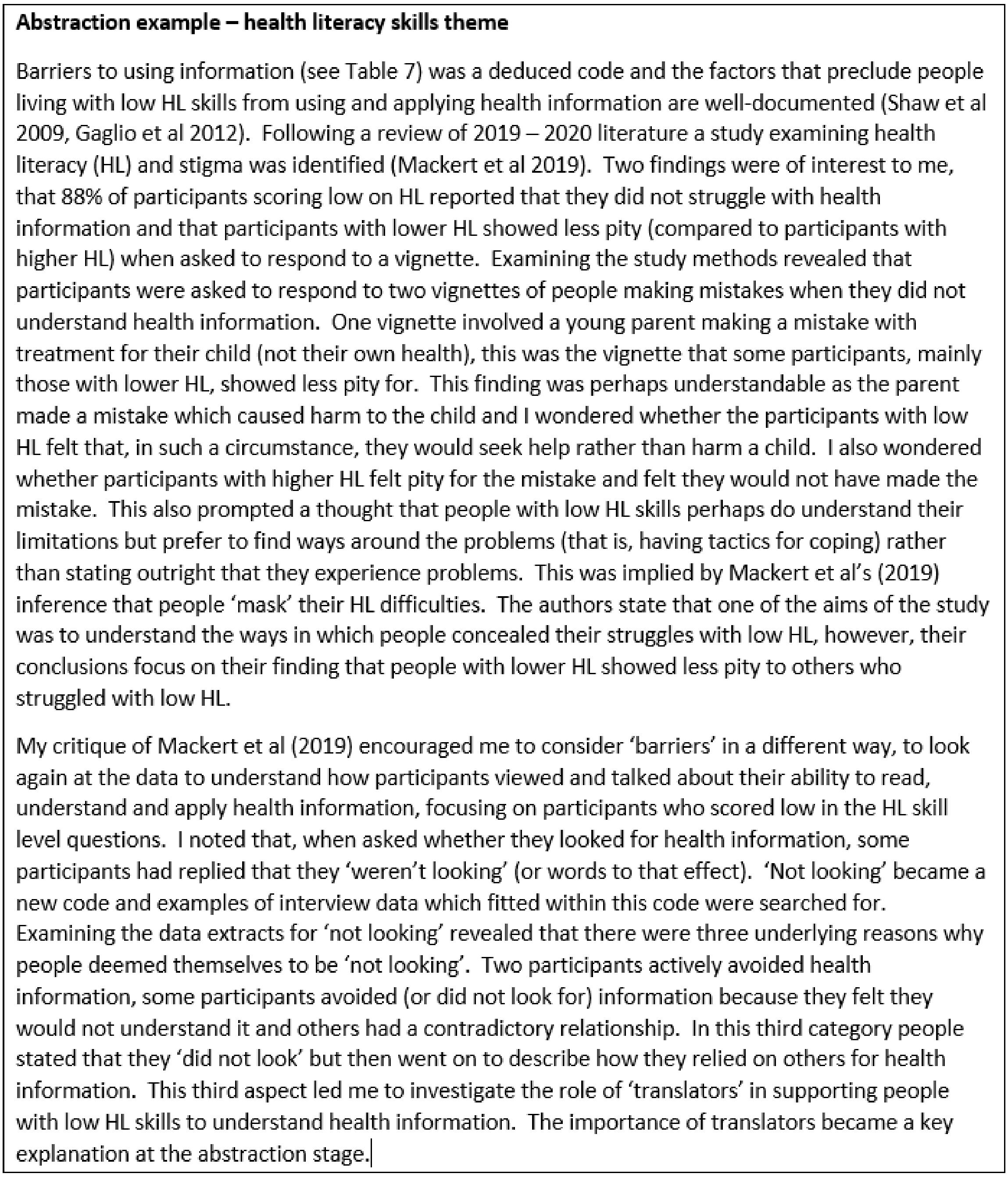
Social network aspect – derivation of social tie explanation

Following feedback on my first iteration of analysis of the social network aspect data I appreciated that I had the opportunity to deepen the analysis to uncover novel explanations. I find Pawson & Tilley's (2004) CMO (context+mechanism=outcome) configuration helpful when considering why something 'works' in a particular context to bring about a specific outcome. For example, a fundamental question for me was; when a person gets support (a favourable context) with managing their LTC (an outcome), what is the mechanism that brings about the outcome? Thoits (2011) enabled me to appreciate that building a social tie was fundamental for gaining support but the mechanism (or grounds) for social tie building was not fully explicated. Searching the social network literature that I had accumulated I came across Azarian's (2010) paper which did discuss potential grounds for social tie building. To me her explanation was logical and 'made sense' and I made the decision to apply Azarian's (2010) grounds to the interview data to corroborate or refute my supposition.

I found that the grounds elucidated the building of (or failure to build) social ties in a concise way and in a way which was applicable to social tie building for a range of circumstances. These findings are presented and critically discussed in chapter six.

Unfortunately, in terms of corroboration of my findings, I could not identify application of Azarian's grounds, nor had she developed it further herself. This could be because her research focuses on social networks in the workplace rather than for health applications. It is perhaps fortunate for me insomuch as it enables me to present a novel application and understanding of social tie building.

Figure 4 Social network abstraction example



Abstraction example – health literacy skills theme

Barriers to using information (see Table 7) was a deduced code and the factors that preclude people living with low HL skills from using and applying health information are well-documented (Shaw et al 2009, Gaglio et al 2012). Following a review of 2019 – 2020 literature a study examining health literacy (HL) and stigma was identified (Mackert et al 2019). Two findings were of interest to me, that 88% of participants scoring low on HL reported that they did not struggle with health information and that participants with lower HL showed less pity (compared to participants with higher HL) when asked to respond to a vignette. Examining the study methods revealed that participants were asked to respond to two vignettes of people making mistakes when they did not understand health information. One vignette involved a young parent making a mistake with treatment for their child (not their own health), this was the vignette that some participants, mainly those with lower HL, showed less pity for. This finding was perhaps understandable as the parent made a mistake which caused harm to the child and I wondered whether the participants with low HL felt that, in such a circumstance, they would seek help rather than harm a child. I also wondered whether participants with higher HL felt pity for the mistake and felt they would not have made the mistake. This also prompted a thought that people with low HL skills perhaps do understand their limitations but prefer to find ways around the problems (that is, having tactics for coping) rather than stating outright that they experience problems. This was implied by Mackert et al's (2019) inference that people 'mask' their HL difficulties. The authors state that one of the aims of the study was to understand the ways in which people concealed their struggles with low HL, however, their conclusions focus on their finding that people with lower HL showed less pity to others who struggled with low HL.

My critique of Mackert et al (2019) encouraged me to consider 'barriers' in a different way, to look again at the data to understand how participants viewed and talked about their ability to read, understand and apply health information, focusing on participants who scored low in the HL skill level questions. I noted that, when asked whether they looked for health information, some participants had replied that they 'weren't looking' (or words to that effect). 'Not looking' became a new code and examples of interview data which fitted within this code were searched for. Examining the data extracts for 'not looking' revealed that there were three underlying reasons why people deemed themselves to be 'not looking'. Two participants actively avoided health information, some participants avoided (or did not look for) information because they felt they would not understand it and others had a contradictory relationship. In this third category people stated that they 'did not look' but then went on to describe how they relied on others for health information. This third aspect led me to investigate the role of 'translators' in supporting people with low HL skills to understand health information. The importance of translators became a key explanation at the abstraction stage.

Figure 5 Health literacy skills abstraction example

3.10 Strategies for ensuring quality and rigour

As previously discussed this study is design-based and the methods are directed by the research question, hence the requirement to understand the latent constructs of health literacy skills, personal social networks *and* to reveal an in-depth understanding of the self-management process. The first section discusses the validity and reliability of the data collection tools used in interview one, taking the meaning for these terms from Knight (2002) as ways to understand whether the tools are valid and reliable methods for collecting data to understand the latent constructs within the research question. The second section presents the criteria posited to enable judgement of the trustworthiness of the overall study design, methods and implementation.

3.10.1 Interview one data collection tools

As the definitions and scope of health literacy vary (Liu et al 2020) a health literacy skills level measurement tool was developed to address the requirements of the research questions. Developing a new tool was both a risk to validity - in that it may have been preferential to use a scale for which construct validity had already been shown - and a way to improve validity, because the new tool had content and criterion validity for the definition of HL skills specified in this thesis (Browne & Green 2005). An ordinal scale enabled ranking, which achieved the aim of the study to rank the HL skill level of participants. HL skills were defined and the type of skill representative of increasing levels of complexity of skill were clearly stated (2.4.2), all tasks which contribute to content and criterion validity (Browne & Green 2005). Face validity was checked through asking two colleagues to contribute to the development of the scale. It has been possible to pilot the new measurement tool for HL skill level in this study, however further testing would be required to ascertain the construct validity and reliability of the scale (Bowling 2002).

The use of convoy diagrams to map personal social networks is an accepted data collection method (Bravington & King 2019), aided participants to discuss their supporters and the visualisation of each participant’s network contributed to the qualitative data analysis. The scoring system categorised participant’s network size: the reliability of the scoring system has not been established but the score has legitimacy within this study as it enabled ranking and cross-case comparison for social network size.

The social network questions (Appendix G) appeared to have face validity but when applied in phase one were ambiguous and unclear for participants. The adapted phase two questions were answered by participants (Appendix G). The scoring system was not used as scoring did not provide any additional insight to the data and participants discussed their social network in-depth in interview two. In conclusion, the HL skills questions and the convoy diagrams did enable the latent constructs to be understood and the research questions and relevant research sub-questions to be addressed.

3.10.2 Criteria for trustworthiness

I have taken a pragmatic stance and drawn on Denzin (2009) who acknowledges that research is political – in that it considers how power is achieved and distributed, and moral – in that it must be conducted with rigour. Within this study it has been important to safely enable access, as participants, for people who may lack power as an outcome of their level of education and/or the health condition(s) with which they live. In terms of rigour, as a doctoral study the work is subject to institutional and academic requirements, and I as the researcher am incumbent to boundaries of time, personal knowledge and resources. Judgements about the quality of design, methods and implementation are therefore accountable to the differing viewpoints of participants, the University, potential audiences and the researcher. I have selected to evaluate this study in terms of credibility, dependability and authenticity as these aspects enable consideration of rigour, trustworthiness and moral value (Denzin 2009, Lewis et al 2014, Connelly 2016).

3.10.2.1 Credibility

Credibility can be understood as the internal validity of a study (Denzin 2009) and can be judged through indicators such as whether the study is trusted or believed by readers and by the participants. Various methods can be applied to strengthen credibility, three methods have been selected and are discussed below: peer-review, triangulation and member checking (Holloway & Wheeler 2010).

Riese (2019 p673) posits that researchers will inevitably apply their own view while simultaneously requiring ‘multiple vision’ to appreciate the views of participants and future audiences for the research. When working alone it is not always possible to be aware of the significance of knowledge, advice or situations until after an event or opportunity however peer-review can support reflection in and on actions (Holloway & Wheeler 2010). Peer-review was achieved for this work by discussing the study plans, implementation and findings with my supervisors. Their feedback raised my awareness of alternative approaches or explanations and aided my understanding of potentially inappropriate subjectivity.

Triangulation can improve the scope, depth and consistency of methods (Holloway & Wheeler 2010); thereby, Morse (2017) posits, enhancing validity and advancing the application of findings to practice. Flick (2002) suggests that theoretical triangulation requires a range of theoretical perspectives to be drawn upon when designing the data collection methods. As discussed in Chapter 2 I have drawn on theory to understand and define the aspects of health literacy skills and personal social networks and these two aspects are theorised from differing paradigms. The divergent theoretical bases and the aim to understand self-management as a process led to the decision to apply methodological triangulation whereby two approaches to data collection were taken (Flick 2002). For example, as I aimed to recruit people who had left school with no O level qualifications it could have been assumed that such people would be living with a low level of health literacy skills. However, to improve accuracy, and as health literacy skills are an unobservable human attribute, or latent construct (Bovaird & Embretson 2008), it was necessary to measure the construct using a health literacy skills measurement tool. The measure of HL skills revealed a range in the level of HL skills for participants who left school with no qualifications. To complement the measure the participants' views on their use of health literacy skills for self-management was ascertained through a semi-structured in-depth interview. The comparison of the findings for the HL measure and the qualitative findings enabled a critical stance, particularly where findings diverged. For example, one participant lived with dyslexia and scored very low on the HL measure however the interview data revealed that he used technology with confidence and was numerate. As Fielding & Fielding (2008 p560) state, the use of different methods facilitated a 'fuller picture' of the data and the findings.

Member checking is a method used to ascertain the authenticity of study findings for the study participants (Holloway & Wheeler 2010). Member checking can comprise an implicit process during interviews or an in-depth explicit process whereby participants are asked to comment on the accuracy of transcripts, researcher interpretations and sections of the research report. In this study member checking was an implicit process and therefore limited to eliciting participants' views during the interviews and briefly discussing my emerging findings when visiting the clubs. As data collection proceeded I added useful tips for self-management to the support contact sheet that I offered to participants and the clubs (Appendix C). More in-depth approaches to member checking were not practical for reasons of time. For instance, finding appropriate settings for recruitment and undertaking two interviews with each participant took up a significant amount of research time meaning there was not enough time to re-visit clubs to check findings. In addition, studying on a part-time basis meant there was a considerable time lag between interviewing and identifying the final conclusions. However, as discussed in Chapter 7, future work will enable the sharing of findings with others, including people living with LTCs and health care professionals, permitting the development of the findings and their application and elicitation of the authenticity of the findings.

3.10.2.2 Dependability

For the criterion of dependability Connelly (2016) posits the qualitative researcher view that methods should be fully explained to enable potential replication and confirmation of the study. Holloway & Wheeler (2010) argue that replication of a unique study is not possible, however methods should be applied in a consistent way and be repeatable, enabling others to arrive at similar findings, interpretations and conclusions. In this chapter I have attempted to detail the process followed, such that others could repeat the methods I applied. Again, in future work I would wish to repeat aspects of the data collection, particularly further testing the health literacy skill measurement tool. As Dewey suggests that research findings are a means for furthering investigation and questioning our practice, rather than a definitive 'answer' (Hall 2013), I am content that the need for further investigation has become an important recommendation from the study findings.

Holloway & Wheeler (2010) reiterate the importance of reflexivity for ensuring the dependability of qualitative approaches. Hence I have included within this thesis reflections on my previous experiences, my beliefs and values and how these have impacted my decisions about the methods, analysis and interpretations applied within this study. Awareness of my role, actions and assumptions have been enhanced through knowledgeable support and input from my supervisors.

3.10.2.3 Authenticity

Authenticity requires judgement in terms of whether the research is worthwhile and potentially empowering (Lewis et al 2014), particularly for the participant population. I have strived to achieve authenticity through application of strategies listed by Holloway & Wheeler (2010) as including fairness to participants, being truthful to participants narratives and working to empower participants. Fostering empowerment for management of health and wellbeing, within the context of living with a long-term condition, is an important aim for this study, as is understanding self-management from the viewpoint of participants. The participant population of people living with an LTC are held as central to the study design, ensuring that the findings are relevant (i.e. authentic) to the experience of self-managing an LTC. Fairness was achieved through recruiting in settings with which participants were familiar and ensuring informed consent to participate. Truthfulness has been discussed in the sections above. Ultimately however, a final test of authenticity will only be possible when, as explained in 3.10.2.1, a future process of member checking the study findings with people who live with LTCs and health care professionals takes place.

3.11 Chapter summary

This chapter has evaluated the pragmatic philosophical position which underpins the design of the research study and justified the approach in terms of the questions being asked, the type of data required to answer the questions and the purpose for which the findings will be used (Denscombe 2014). The methods of participant recruitment, the development and implementation of the data collection tools and the approach to data analysis have been discussed and critiqued. It has been important to plan an ethical approach to the research, to protect the participants and ensure that possible distress from discussing self-management of an LTC is minimised. The following three chapters present the study findings and the final chapter, Chapter 7, sets out the thesis discussion and conclusions.

Chapter 4 The Participants

4.1 Introduction

This chapter is the first of three chapters which present the study findings. Chapter 5 presents the findings for the health literacy skills aspect and the findings relevant to the personal social network aspect are presented in Chapter 6. This chapter introduces each participant, explaining a little of their context and presenting an overview of all the findings; it also explores four tactics for self-managing an LTC that were identified, providing an insight in to some of the actions participants undertook to achieve their self-management goals.

4.2 An introduction to the participants

This section provides a brief introduction to each participant, enabling an understanding of their situation and context in advance of discussing the study findings. A table presenting the main characteristics of each participant is displayed below. The data set out includes participant number, gender, age, self-reported LTC type, health literacy score and category - discussed in Chapter 5; social network score and category - discussed in Chapter 6; and postulated LTC self-management tactical style - discussed in this chapter.

Participant labelling follows a structure of P for participant, number indicating order in which they were interviewed, and M for male or F for female.

Table 9 Participant characteristics

Partici-pant number and gender	Age	LTCs – self-report (years lived with)	O level (or equiv)	Health literacy score Part A Part B & category	Social network size score & category	Self-management tactic(s)
1 F	62	Diabetes (20) Arthritis (10) Stroke (5)	Yes Stroke	24 26 Applied	42 Moderate	Socialiser & partner-guided
2 F	70	Spinal stenosis (20+) Arthritis (10) Migraines (65)	No	24 20 Functional	36 Moderate	Living with it
3 F	54	Arthritis (6) Diabetes (8)	No	19 16 Borderline functional	61 Extensive	Socialiser
4 M	67	Arthritis (50) Heart failure (5) Back problem (8) Cancer (4)	Yes	24 25 Functional	41 Moderate	Living with it
5 M	60	Stroke (4)	No	23 24 Functional	51 Extensive	Socialiser & partner-guided
6 M	59	Diabetes (48) Weight problem (52)	Yes Dyslexia	33 24 Applied	33 Moderate	Technician
7 M	68	Diabetes (16) Heart bypass (9)	No	25 27 Applied	32 Moderate	Was partner-guided
8 M	67	Arthritis (4) Diabetes (recent) Cancer (3) Asbestosis (18) Damaged spine (43)	No	37 27 Critical	32 Moderate	Socialiser, technician & partner-guided
9 M	62	Diabetes (2) Arthritis (5) Depression (5)	No Dyslexia	14 17 Borderline Functional	15 Very small	Technician
10 F	49	Diabetes (14) High BP Depression (3)	Yes	30 25 Applied	41 Moderate	Socialiser
11 F Sister to 12	67	Arthritis (2)	No	25 25 Functional	15 Very small	Living with it

Table continued over.

Table 9 Continued

Partici-pant number and gender	Age	LTCs (years lived with in brackets)	O level (or equiv)	Health literacy score Part A Part B & category	Social network size score & category	Self-management tactics
12 F Sister to 11	59	Arthritis (29)	No	27 20 Functional	26 Small	Living with it
13 F	70	Diabetes (10) Underactive thyroid (50)	No	25 24 Functional	21 Small	Living with it
14 M	66	Diabetes (4) COPD (7) Depression (7) Heart condition (9)	No	20 25 Functional	36 Moderate	Socialiser & partner-guided
15 M	70	Diabetes (15) Arthritis (15) Cataracts (10)	No	30 26 Applied	36 Moderate	Partner-guided
16 M	68	Arthritis (2) Diabetes (10) COPD (10)	No	34 28 Critical	26 Small	Technician
17 M	66	Arthritis (1) Atrial fibrillation (26) Pulmonary embolism (35)	No but later went on to H.E.	30 32 Critical	31 Moderate	Technician, partner-guided & socialiser
18 M	62	Arthritis (1)	Yes Dyslexia	24 23 Functional	15 Very small	Socialiser - even though not currently drawing on for LTC self-management
19 M	54	Diabetes (2) High BP (12) Depression (18)	Yes (but now struggling to read)	25 20 Functional	38 Moderate	Partner-guided
20 M	69	Diabetes (14) High BP (14) Glaucoma (18)	No	28 24 Applied	16 Very small	Partner-guided
21 M	68	Diabetes (12) Atrial fibrillation (5) Prostate cancer (7)	No	24 24 Functional	20 Small	Living with it
22 M	69	Arthritis (10) Diabetes (17) Bowel prob (2) Heart prob (3+) Lung prob (1)	No	23 26 Functional	26 Small	Partner-guided

4.2.1 Overview of findings to be presented

The following table, Table 10, provides an overview of the findings presented in this chapter and Chapters 5 and 6.

Table 10 Findings overview

Chapter	Findings presented
Chapter 4	Tactics for managing an LTC • Socialiser tactic • Partner-guided tactic • Technical tactic • Living-with-it tactic
Chapter 5	Participant's health literacy skill levels • Borderline functional • Functional • Applied • Critical
	Acquiring health information • 'I'm not looking' • 'I'm not savvy' • 'Somebody like me'
	Using health information sources • Finding these helpful *and* contradictory • Looking for 'someone I can trust'
	Over-arching findings • Requirement for translators • Search for trustworthy sources
Chapter 6	Size of participant's social networks • Very small • Small • Moderate • Extensive
	Building social ties • The club as a context for building ties • The relevance of similar others • Building ties with other resources • When mis-matches occur
	Negotiating social ties • Ignoring unhelpful others • Giving advice • The use of humour
	Over-arching findings • Importance of others, particularly similar others, for providing a new perspective to self-management • Grounds for social tie building as striving for affinity, utility and reliability

4.2.2 Comments on saturation

Holloway & Wheeler (2010) posit that recruitment of participants needs to be appropriate, in that participants should experience circumstances relevant to the research aim, and adequate in terms of generating enough data to answer the research questions. Table 9 reveals that the sampling was appropriate in that all participants lived with an LTC and the majority experienced a functional level of HL skills. In terms of adequacy it is helpful to consider whether enough data was collected to achieve saturation, when twenty-two participants were recruited and forty-four interviews were undertaken. Hennink et al (2016) usefully identify two aspects to data saturation, code saturation and meaning saturation. In section 3.9.3, stage 3 of the Framework method of managing data, it was discussed that code saturation was deemed to have been achieved as forty-nine codes were identified in the first five semi-structured interviews, the same codes were applied in phase two and only three additional codes were identified in phase two.

In terms of meaning saturation, that is, considering whether enough data has been collected to fully illuminate descriptive themes and abstracted findings, Hennick et al (2016) suggest that the volume and depth of data required will depend upon the nature of the code, descriptive theme or finding. Some codes and descriptive themes are reasonably concrete or can be elicited in an objective way. For example the question, 'and how important is it to you to manage your LTC?' was asked and got (usually) a direct reply which could be coded as 'very', 'somewhat' or 'not' important (see 3.9.2). With other aspects of the findings it was reasonably easy to see patterns in the data and therefore fewer examples were required to illustrate the finding. For example, the use of irony and self-mockery to generate humour (see 6.10.3). All participants used humour at some point during the interview but the many examples showing how the participants did this are interesting but are not required to advance the finding.

Some codes, or understandings within the data, are subjective and/or context specific or more difficult to elicit and may require a large volume of data to enable interpretation. Other codes were identified by me as researcher rather than being deduced from participant's actual comments. For example, the code 'gaining a new perspective' was identified inductively through noting participant comments *and* drawing on theory regarding the ways in which empowerment is generated and understood. It was therefore necessary to take a broad view of all the data to identify comments applicable to the code. Taking a pragmatic view, it is likely that meaning saturation has not been achieved for all findings (Hennick et al 2016) and some findings will require further investigation. However I believe that code saturation was achieved and that a sufficiency of findings relevant to the research questions have been identified and presented.

The following section presents findings which illuminate the tactics participants applied to enable self-management of their long-term condition.

4.3 Tactics for managing an LTC

In Chapter 2 self-management of an LTC has been defined as a dynamic lived process (Kendall et al 2011) through which a person undertakes actions to promote their health, manage illness and manage life with an LTC (Audulv et al 2012). Bury's influential work (1991) theorised that people living with an LTC strive to find meaning in their illness, and developing a personal narrative enables them to make sense of their situation and gain control over the condition, the symptoms and the treatment requirements. As discussed in Chapter 2 Bury (1991) posits three aspects to the narrative: the coping aspect - how a person learns to tolerate or put up with their LTC; the style - the way the LTC is presented; and the third aspect – the strategies they use - considered in this section. Strategy is described by Bury (1991 p461) as '*what people do*' to manage their condition. Bury (1991) recognises difficulty with using the term 'strategy', which implies a rational and long-term approach, hence using the term *tactics* rather than strategies in this thesis, to indicate decisions made based on what is available to people and their personal preferences.

In this study four tactics for self-managing an LTC were identified from the data by analysing the actions participants undertook to achieve their self-management goals. As shown in Tables 9 and 10 these tactics were labelled in such a way as to be indicative of the four different approaches: hence - the socialiser tactic, the partner-guided tactic, the technical tactic and the living-with-it tactic. Some participants drew on more than one tactic. The following sections discuss these four analytical categories in more depth, supported with examples from the participant data and with reference to literature and findings to be discussed in later chapters.

4.3.1 The socialiser tactic

The socialiser tactic was exemplified by actions including being proactive in asking others for help. Participants using this approach included P1F, P3F, P5M, P10F, P14M and P18M. All participants discussed the role of others in the process of self-management, this is debated in Chapter 6, but the 'socialisers' were unique in recognising and talking enthusiastically about the contribution of a range of others to the task of self-management. P3F was an example of a 'socialiser', she had no immediate family but she organised the women's club which met four times a week and she was an active member of her church and a choir; she is further discussed in the next two chapters.

P18M drew on a small social network to support him with his LTC but he appreciated the importance of support from others explaining:

> P18M … *health wise yes* [others are helpful] *and that's why the groups that we run here are so important because there's like that camaraderie…*

P18M enjoyed the ‘camaraderie’ of working with others and understood that being social was important for good health. He went on to explain his belief in more depth:

> P18M *How does it* [being social] *help? It helps, I don’t think we’re supposed to be on our own I think that we, we strive for company, well not all the time I’m quite happy being on my own sometimes but I think I do like being in a group I think because well just what I said, maybe we need we need to offload I think*

P18M found it helpful to talk and ‘offload’ to others. He also recognised that there was a balance to be had between having time on his own and having time with others. Azarian (2010) and Cummings et al (2017) acknowledge that people balance agency and dependence when seeking support, consequently maintaining social ties for self-management of an LTC is an active process requiring decisions about who and when to ask for support (Vassilev et al 2016). Building of social ties is discussed in Chapter 6.

4.3.2 The partner-guided tactic

A second way in which participants managed their condition was to depend on or encourage support from their partner (or husband or wife). Participants for whom their partner appeared to play an integral role in self-management included P15M, P19M, P20M and P22M. P15M and P19M discussed their wives’ important contributions:

> P15M … *I ceremoniously, religiously takes me medication, well the wife makes sure I take the medication you know what I mean? (…) She makes sure I don’t go eating the wrong stuff for starters and she’s always like checking me out with me, mind you I ain’t done it for a couple of days, checking my blood sugar levels and all that lot, different things and reminding me about what I gotta do …*
>
> P19M …*it’s like some of the medication I take it slows your metabolism and everything down so I don’t feel as hungry and I don’t eat as much and she says “you’ve got to take your pills, you’ve got to eat you’ve got to eat with this metformin,” she makes sure it happens…*

For P15M and P19M their wives provided prompts which reminded them about the requirements of their LTC and ‘made sure’ self-management ‘happened’.

For some of the participants who used the socialiser tactic their partner was a significant support for self-management too, this included P1F, P5M and P14M. Having experienced a stroke and living with diabetes P1F explained how her husband helped her to manage:

> P1F … *he helps me a lot, like, I’ll potter around and do the dusting and he’ll do the hoovering something like that umm he always reminds me to take my tablets and that especially at teatime when I have to take one and he’ll say ‘have you took your tablet?’*

P1F's husband provided her with instrumental support and helped her with reminders about her medications. As will be explored in Chapter 6, participants usually had affinity with their partners and partners were available to support in many ways, including by providing prompts for self-management actions.

4.3.3 The technical tactic

Taking a technical approach was elucidated when participants reported that they enjoyed investigating the best way to manage their condition and were confident with using digital technologies. In this study a technical approach to self-management was only explicitly discussed by men, including P6M, P9M and P16M. The quote below illustrates how P6M was using digital resources to help him understand his diabetes:

> P6M *once I was diagnosed with it OK so I went onto the net I wanted to find out about it because it's a progressive disease so I wanted to know more and more about that about how progressive it was obviously there's new thinking now that you can be in remission of it depending on what you do and certain diets and things that've come about…*

Digital technology enabled P6M to attain his desire to understand what he could do to manage his diabetes and to know about potential new treatments or approaches.

P9M lived with dyslexia and he used digital resources with confidence too:

> P9M ….*I couldn't figure out which one* [of his medications] *was giving me the grief, I'd done the reading up on all of them, as you do these days on Google or Wikipedia or all the other and it came to the conclusion that any one of my tablets, the arthritic one or the diabetes one **OR** the statins, but the statins were the number one candidate you see so I thought well the only one way to do it was to take them all off and umm keep them, let them get out of my system for like 3 months….*[**bold** represents his emphasis]

P9M's use of technology to manage difficult side-effects of his medication led to him stopping taking statins and cutting back on his diabetes medication. P9M is discussed in the following chapters as he is a particularly interesting case. He enjoyed being unusual, he proudly told me he was a '*basket-case*', and he experienced poverty, yet he did apply tactics to manage his health.

People living with LTCs make decisions about treatments or behaviours they are expected to follow and the subsequent impact on their 'normal' daily life (Bury 1991). Self-managing an LTC is a constant balance of social wants and needs, a judgement of the perceptions and willingness of others and medical requirements. If a person experiences low levels of health literacy skills their medical knowledge and understanding may be limited, potentially making it more difficult to make decisions about the balance between 'normality' and self-management (O'Connor et al

2019, Schrauben et al 2020). In such circumstances the involvement of others, or resources such as the Internet, are fundamental, a finding which is discussed in Chapters 5 and 6.

Two of the participants, P8M and P17M, who both had a critical level of health literacy skills (see Chapter 5), used all three self-management tactics being socialisers, partner-guided and taking a technical approach. P8M had lived with health problems for a long time and drew on a wide range of tactics to manage his health:

> P8M … *we're* [he and wife] *well, you know, err versed with exactly what's wrong with us what the pills do and everything* (…) *we've read this through backwards and forwards on all the paperwork they give you (…) I did the Demystifying Chemotherapy the whole day course absolutely* [motions excellent] *(…) she* [GP] *said "I'll tell you what" she printed off the report from the X-ray "yeah, read that" she said "just get on with that"…*

Understanding what was happening with his body and his treatments was important to P8M and he drew confidently on information given to him by health professionals. His preference for information from HCPs is discussed in Chapter 5 and in Chapter 6 his understanding of the club as a significant place for '*just talking*' is explored.

4.3.4 The living-with-it tactic

Some participants talked about '*just living with'* their LTC, which seemed to reflect an acceptance, stoicism or tolerance of the condition and the self-management requirements. Participants exhibiting this tactic included P2F, P4M, P11F, P12F, P13F and P21M and one common finding was that they all discussed 'getting on with' managing their condition. In contrast to the three tactics described above this tactic was not just action-oriented, it also reflected a mind-set which appeared to assist participants with reconciling themselves to the inevitable decline in their health because of the LTC(s) they experienced. Participants who were 'living-with-it' were managing their condition(s) but had also recognised that the management aim was to prevent further deterioration rather than improvements in health. Hence the potential rationale for participants applying this tactic is discussed in some depth following the presentation of illustrative data.

This quote illustrates P2F's philosophy toward support for her health:

> P2F …. *like I go to slimming club every so often when I get so* ***fat*** *that umm but I don't take any notice of what they give me I just go home and don't eat so much so no as far as I'm concerned I'm living with my condition I've had it for so long that I'm living with it so all I'd be doing is wasting somebody's time* [pause] *there's nothing that anyone could offer me that would make it any* [pause] t*hat's just mine* (…) *I'm not a spring chicken, it's not as if I've got my whole life ahead of me, that 'you must get this under control' and all that…*(her emphasis)

Living with it for P2F represented acceptance of her conditions and a knowledge that there was not much more that could be done to improve her health. She felt that further, presumably medical, interventions would be a waste of other's time, she perhaps reflected a wish to have quality of life.

P4M was resigned but stoic about his situation:

> P4M …*my philosophy* (…) *I know it's not going to get better and that's the starting point OK let's go from there* (…) *got to make the most of how you are that day.…*
>
> P4M *I want to be able to do the things I used to do and I can't once you accept that then I am still working to the limit of what I am capable of although it's not obviously not to the limit of what it was ten or twenty years ago but I still want to be or do the best I can at whatever it is I do…*

For P4M doing things to the best of his (current) ability was important to him, and something he could strive to achieve despite his health problems.

P12F talked about 'living with' her arthritis:

> P12F *It's just an ongoing condition I think I've just come to terms, I'm gonna have to live with it, just take my painkillers and my 'brufen and you know. Obviously I've had both knees done so they* [HCP] *had said to me it's got to a state where whether my weight was big or not it still you know but they don't seem interested anymore because of my weight put it that way so I sort of don't bother.*

Having had knee replacement surgery P12F was now able to 'live with' her condition. A tentative conclusion here though is that her ambivalence toward managing her weight was a result of a difficult HCP interaction. She felt that the HCP did not encourage her to lose weight and therefore she too 'didn't bother'.

P21M took a fatalistic approach to his health explaining:

> P21M *I don't worry about ummm about dying or anything like that y'know so it's a matter of oh, alright I'll manage it to a point and if anything happens well it happens if you know what I mean*

He indicated that HCPs maybe did not fully understand his point of view:

> P21M *the doctor's good he'll tell me what I should do and what I shouldn't do but of course you can't make me do it and I'll try it but then I'll think "this food's bland, porridge"*

P12F and P21M's comments reflect a Francis et al (2019) finding that clinician expertise was rated within LTC care but that patient expertise was not, particularly if a patient made an informed decision not to comply. As there is no one approach to managing an LTC Bury (1991) states that the term compliance is of little relevance to chronic illness, instead suggesting that negotiation between HCP and patient is necessary to understand and balance clinical guidance and medical goals with the person's health goals and preferences.

Investigating the role of hopelessness in multi-morbid LTC management Coyle & Atkinson (2018) question the privileging of positivity and the medical focus of curing or coping. P2F and P4M discussed a recognition that they could expect further deterioration of their health, rather than a cure. They were realistic and potentially this tactic had become their way of coping with their situation. Mok et al (2004) posit that when people experience illness and disability they act to let go of factors they cannot control - for P2F further interventions - and focus on things that are within their control - for P4M doing things as well as he can now. Both participants talked about accepting that 'not much more [could] be done' to improve their health, what Mok (2001 p74) explains as, 'accept[ing] suffering as part of life'. That is, an external force (in these cases their level of health and its trajectory) is beyond human control but individuals can decide to accept this and change how they perceive their own circumstances. Mok et al (2004) found that acceptance of illness enables people to let go of things they cannot control and focus on things that are within control; they also found that focusing on positive or at least neutral thoughts acts as a distraction tactic and helps people live with their illness. Finally, Mok et al (2004) suggest that a transformation of thoughts and expectations, for instance from 'hopeful' to acceptance of 'the way things will be', can assist people with accepting the trajectory of their illness and using such tactics can enable people to feel empowered.

4.4 Self-management tactics, a summary

Self-management of a long-term condition necessitates priority setting, decision-making and action, in the context of meeting one's personal wants and needs, while managing social circumstances, the symptoms experienced and treatments and behaviours required (Bury 1991, Bratzke et al 2015). Amid complexity participants described using tactics which potentially enabled them to gain or maintain some control over the process of LTC self-management. Four tactical approaches to self-managing an LTC were identified including, being sociable, being partner-guided and taking a technical approach to self-management. The fourth tactic was termed living-with-it (an LTC). For P2F, and P4M and P21M, there was 'not much more that can be done' so they were 'living with it'; for them *living with it* represented a limit to their sense of future. Although a first impression of this tactic might be one of inaction this tactic could, surprisingly perhaps, be a way for a person to gain a sense of control over their health. Mok et al (2004) and Coyle & Atkinson (2018) posit that the replacement of 'hope for a cure' with, instead, acceptance of deterioration, can enable people to maintain feelings of control and empowerment.

The next two chapters explore in depth the contribution of health literacy skills, an individual-level capability, and a personal social network, a system-level factor (Chen et al 2018) to long-term condition self-management for the study participants.

Chapter 5 Health literacy skills: findings and discussion

5.1 Introduction

In this thesis the decision was made to investigate health literacy as an individual cognitive ability, that is, to understand the skills of health literacy that each participant possessed. Health literacy skill ability is defined as the degree to which an individual can obtain, understand and apply information required for health-related decisions and actions. Defined in this way the skills of health literacy are key to self-management as people living with a long term condition and who wish to manage the condition require information[3] and knowledge to enable them to do so (Yamashita et al 2019).

The first section of this chapter examines the theoretical framework for the health literacy aspect of the data analysis. Next, each participant's health literacy skill ability, deduced using the health literacy skill questions in interview one, is presented and examined in relation to data from interview two. In sections 5.5 and 5.6 barriers to acquiring information and participant's awareness of their struggles to obtain and understand information are presented and discussed. The chapter concludes by considering the overarching findings - that participants seeking trustworthy information and requiring translators to de-code health information.

5.2 Using health literacy skills: theoretical framework

Within this thesis managing a long term condition is recognised as a complex process requiring, amongst other factors, scientific knowledge of medical information and comprehension of healthcare systems in order to understand the treatment and management regimes stipulated by HCPs (Bratzke et al 2015). To become knowledgeable one can draw on other's knowledge encoded in the form of information (Wilson 2000) and to be health literate is to possess the ability to de-code health information and to use it to further one's learning (Egan & Gajdamaschko 2003). Put simply, health literacy skills enable the 'de-coding' of health information in to health knowledge, and appropriate knowledge can then be applied to, in the case of living with an LTC, self-managing one's health.

As explained in section 2.4.2 health literacy ability can be postulated as existing across a hierarchy (Nutbeam 2008, Ishikawa et al 2008) such that someone who is able to read information but not

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[3] Throughout this chapter the word 'information' is used to indicate 'health information'

de-code it and only use it to inform their actions with assistance can be described as having a low or functional level of health literacy skills. A person who can read information and make decisions based on the information and what they already know can be described as having a moderate or applied level of literacy. A person who can read information, make decisions based on the information, judge whether the information is reliable and teach another person about the information would be said to have a high or critical level of literacy.

Health information about how to self-manage a condition enables someone to know how and when to act, even if they decide not to act (Miller et al 2011); however accessing health information can require the use of the full range of health literacy skills. Ideally, to self-manage, a person would know what information they require, where to source the information, read or hear and understand the information, apply the information to their own situation and judge the quality of information (Gaglio et al 2012). A critical level of health literacy skills may enable a person to undertake that entire process. Conversely a functional level of HL skills may restrict a person's ability to de-code health information, resulting in them being unable to interpret, understand and apply information to the self-management process.

In this thesis it is posited that the choice to use one's knowledge to inform actions (or not) is an attribute of the person's motivation rather than health literacy ability. HL skills enable the de-coding of health information into knowledge; motivation, comprising importance and confidence (Miller & Rollnick 2013), determines whether that knowledge is acted on. A person who views health knowledge as important and who has the confidence to enact the knowledge is potentially able to act on the advice, irrespective of their HL ability. However HL ability will impact motivation - people with lower levels of HL skills, for example - might not understand the importance of information or may experience low confidence in their ability to use information successfully. Thus the two aspects, HL ability and motivation, are intimately linked.

In the following sections individuals' HL skill level as the ability to *de-code* health information in to personal health knowledge is the focus of the discussion. The data findings will be discussed in terms of the tactics people use to acquire health information when their HL ability is low and the barriers and facilitators to using health information for self-managing an LTC when HL ability is limited. When HL ability is such that a person is unable to de-code health information the findings will explore the use of 'translators', that is, other people or other resources (such as the Internet or videos) that can 'translate' information in to a form which is understandable (Liu et al 2020). Throughout the following sections the data findings will be considered contingent on each participant's HL skill level, as categorised in section 5.4.

5.3 Participant's education levels

To meet the aim of the study to investigate how people living with low health literacy skills self-manage a long term condition I identified people who could be experiencing low health literacy skills through using a proxy measure of having left school without any qualifications. The rationale for this is explained in section 3.4, here I discuss the education levels of the participants.

Sixteen of the participants (73%) had left secondary school without O level qualifications. At first glance it appears that all sixteen participants will experience low education levels however the reality is complex. O levels were undertaken at age 16 and before 1972 young people could leave school at the age of 15, i.e. before they completed O levels (Department for BIS 2012). People currently aged over 58 (as of 2020) are more likely to have been encouraged to leave school at age 15 to commence work, rather than undertake O levels, and some of the participants mentioned this as their experience; the outcome of having no qualifications can be a result of circumstance rather than ability. Having left school with no qualifications people can later make the decision, or have the opportunity, to undertake further education and this can raise their level of skills. Participants P17M and P8M left school with no qualifications, P17M later trained in a professional role and P8M had undertaken qualifications in the armed forces. As will be discussed in the following section both these participants scored highly in the HL skill questions.

Six of the participants (27%) had achieved O levels or equivalent in school, however four of these participants reported difficulties with reading and using health information. There can be a situation where people have qualifications but experience difficulties with specific learning skills. Two participants, P6M and P18M, had O level equivalent qualifications but lived with dyslexia, a learning difference which affects reading and writing skills (British Dyslexia Association 2020). P19M experienced what he called '*word salad*' which impacted his ability to read and retain information; this was possibly a result of anti-depression medication and Parkinson-type symptoms. P1F had experienced a stroke which she reported as having curtailed her ability to read and retain information.

In summary, twenty of the participants had either left school with no qualifications or experienced difficulties with reading and using health information. As explained in Chapter 3, in interview one I applied the health literacy questions which enabled me to score and derive each participant's health literacy skill level. The results of the health literacy scoring for each participant are discussed in the next section.

5.4 Participant's health literacy skill levels

One research objective was to identify the level of health literacy ability (that is, functional, applied or critical) for each participant, by applying the health literacy ability questions in interview one. The development of the health literacy ability questions was discussed in detail in section 3.7.1 but, to briefly recap, Bloom's hierarchy of cognitive skills (Heick 2020), Nutbeam's (2008) three levels of HL ability and Ishikawa et al's (2008) HL measures informed the HL ability questions.

Categorisation of the health literacy skill level for each participant was derived from the score attained for the health literacy questions in interview one (see section 3.7.1 and Appendix E). The skills assessed included reading, finding and accessing health information, interpreting information, applying that information to self, sharing information with others and judging the quality of information (Nutbeam 2008, Ishikawa et al 2008, Chen et al 2018). A score under 40 was classified as a borderline functional level of skills; a score between 40 - 49 as a functional level; 50 - 59 as an applied level and a score of 60+ as a critical level of health literacy skills. Health literacy skill scores for the participants are presented in Table 9 and Figure 6 below. The proceeding four sections discuss the HL level findings for the participants.

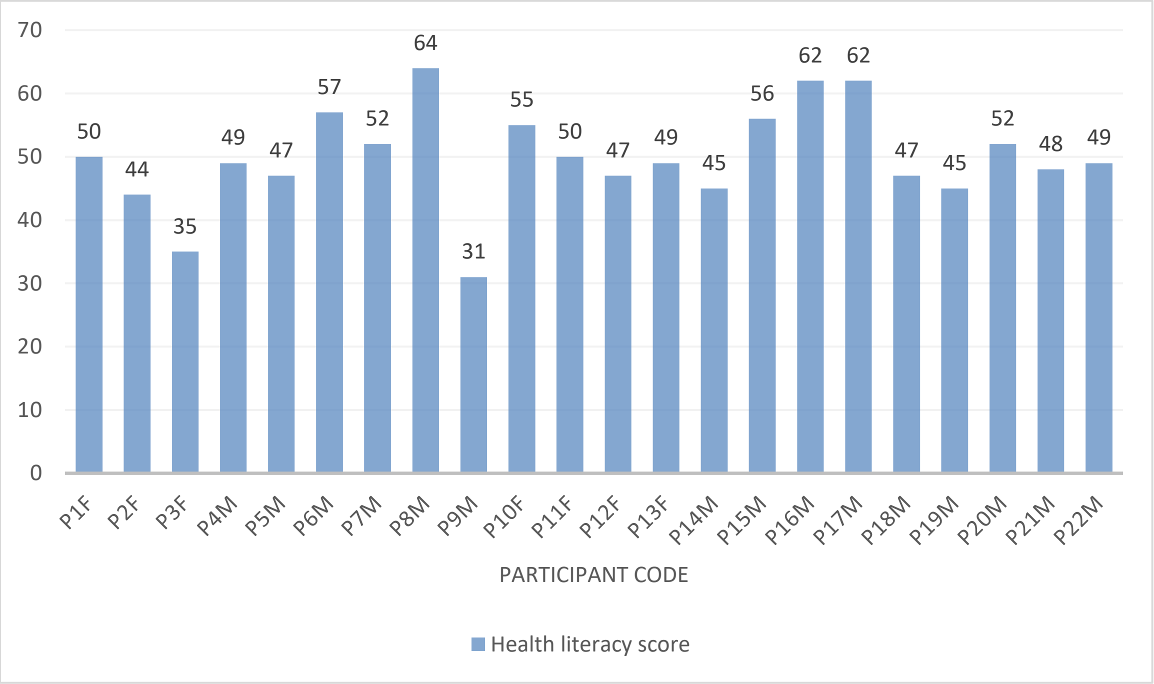

Figure 6 Participant health literacy skill scores

5.4.1 Borderline functional health literacy skills

Two participants were placed in this category, P3F and P9M scored less than 20 on both components of the health literacy questions and had an overall score of 35 (P3F) and 31 (P9M). Looking at the bar graph of HL skills scores (Figure 6) the decision was made to classify scores below 40 as a level of skills lower than functional, hence the term borderline functional. P9M reported living with dyslexia and acknowledged problems with reading:

> P9M *well all my school days I was a dummy 'cos I couldn't read and write properly and unfortunately school teachers don't recog, in my day they didn't recognise dyslexia*

He reported his numeracy skills as very good, describing how he confidently calculated and compared the prices of foodstuffs to save money:

> P9M (…) *at least I work on the price per kilo unlike my friends who say, "well that's £2.99 and that's only £2.50"…*

Budgeting was very important for him as he experienced poverty.

P3F did not discuss dyslexia but I observed her avoiding reading information by passing it to others to read. She explained her difficulties with reading on a lack of appropriate glasses:

> P3F *No, no I won't Google anything I don't read the packet well I can't see actually that's a lie I've got my new glasses Friday*

It was difficult to determine whether these two participants experienced a very low level of health literacy skills and could not read and understand health information or whether there were other reasons for not accessing information. For P3F the lack of glasses may have prevented her from reading but she also described feeling anxious about the information she might find:

> P3F *I think that can be worse looking because it makes you feel worse great big long words that really probably don't mean an awful lot to me*

She was concerned about the information distressing her and expressed apprehension about not understanding, which seemed to be additional reasons for avoiding reading health information.

P9M experienced dyslexia and explained that looking for health information was not important to him:

> P9M *…that's assuming that I would be looking (laughs) I think I could find it if I bothered to look, so that's the problem – that I don't look, I know it's out there and I can use Goo.., Internet easily to get information up, if*
>
> Interviewer [interrupts] *so you're able to but you*
>
> P9M [interrupts] *I haven't bothered*

He reported not being bothered about finding health information but was keen to explain how he now used technology to get around his difficulties with reading, spelling and understanding words:

> P9M *I'm Internet based I couldn't write it down by hand because of my dyslexia*

P9M did have some skills for finding health information through the Internet, but he answered negatively to most of the health literacy questions. This is perhaps a reminder that skill assessments only describe what someone can do, or wants to do, at a specific point in time (Duncan & Schwab 2015). It was difficult to know whether P9M had a low level of HL skills or whether he was answering negatively due to low mood or feelings of a lack of control over his health. McKenna et al (2017) posit that the use of health literacy skills is associated with feelings of being in control, or not, for managing one's health, however in this study motivation is seen as associated with but independent from HL skill ability. In the case of P9M it could be that low control, importance and confidence were restricting his motivation to apply health literacy skills for managing his health.

5.4.2 Functional health literacy skills

Participants were deemed to experience a functional level of health literacy skills if their overall score was between 40 and 49. Eleven participants were in this category, including seven people who had left school without qualifications: P2F, P5M, P12F, P13F, P14M, P21M and P22M.

P11F was placed in this category although she scored 50 overall. Her replies to the health literacy questions were based on the experience of one episode of uncomplicated arthritis during which she received verbal information and demonstrations of the exercises she was asked to undertake. She struggled to apply the interview one questions to her experience:

> Interviewer [reads out Q1 part B] *When I read medical or health information that I am given I find lots of words difficult to read* [answer options being almost never, sometimes, often, always]
>
> P11F *I don't know what to do 'cos I understood it so I'd have to be always*
>
> Interviewer *so you understood all the words.*
>
> P11F *Yeah cos she* [hospital HCP] *sat down and explained it all to me… very good*.

Her answer revealed that she understood the information she had been given because it had been explained to her; she struggled to answer the initial question. In interview two she talked about her dislike for reading:

> Interviewer *Do you read for pleasure? Like novels or magazines or?*

> P11F *No, hate reading.*
>
> Interviewer *You don't like reading at all?*
>
> P11F *No.* [pulls a face and interviewer laughs]

She, and her sister P12F, talked about their understanding of written information being different to others:

> P11F *I'll ask my sister or daughter if I'm not sure, 'cos sometimes I don't understand forms I'll read it and it's weird 'cos I'll look into it different than someone else I think that looks think that says different things to what that other person looking at it thinks*
>
> P12F [sister to P11F] *If I look at information and then I read it I always take two meanings to it if you know what I mean I don't quite understand things and sometimes I needs to talk to someone to get an understanding of it, if you know what I mean?*

They both felt that they did not always interpret written information in the same way as other people and, if information was important to them, required support to understand it.

All the participants with functional levels of HL skills expressed some type of difficulty with understanding, using or applying health information, further examples of which are presented and discussed in this chapter. As discussed in section 5.2 functional HL skills enable someone to find and read health information but may not be such that the person can understand how to interpret and act on the information. As action is an integral part of self-management of health (Lorig & Holman 2003, Green et al 2015) it is useful to understand the tactics used by the participants to manage their condition when they found health information difficult to interpret. Participant's tactics will be discussed later in this chapter and in Chapter 6.

5.4.3 Applied health literacy skills

This group, consisting of six participants, attained scores of between 50 and 59. In section 5.2 it is posited that participants with an applied level of health literacy skills can access health information, understand and interpret the information *and* apply the information to their decisions for self-managing their health.

P1F and P10F had achieved O levels and CSEs respectively, P7M wrote for a hobby. P15M had no formal qualifications but he was happy to visit the pharmacist if he had a question and picked up information at the pharmacist:

> P15M … *go to the chemists or something I'll look at a bit of literature, I'm always looking and I pick up something, cos you don't know you might pick up something that you don't know might'n you*

P15M was proactive in asking questions:

> P15M ……*I do, I listen out or something or I think "I'll go and inquire about it" you know what I mean?*

P20M had left school with no qualifications but he had attended a DESMOND course[4] and subsequently received and read a monthly Diabetes UK magazine:

> P20M …..*things are that easy to currently look up on online if you need to I personally don't really feel that need I mean I can get the magazine and I can look at the magazine and I flip through it through the headlines and if I think it is pertaining to me I will read it, if it's type 1 or insulin or anything like that then I just flip through it as it doesn't pertain to me*

P20M was not keen on using the Internet for health information but the Diabetes UK magazine was a helpful source of information for him.

P6M, who self-reported as dyslexic, scored 57 and had a range of tactics for getting health information and support with his diabetes, including using technology:

> P6M *Yeah I get a lot of my information from the 'net and a lot of that is because that's my field of workin' with the IT and computers and things so I can get a lot of detailed information…*

He did not hold back on contacting the GP or the practice nurse to discuss his symptoms and treatment:

> P6M *So I'm poppin' actually in to see 'em* [HCP] *today (…) it's just because my blood sugars have dropped which is really really good, OK, it's because of this strict diet that I'm on and I just wanna make sure they haven't come down too far*….

It was important to P6M to manage his health - 'this strict diet'. Monitoring his health, reading information and drawing on his HCPs enabled him to meet his health-related goals.

As previously discussed (section 2.4.2) the argument is made in this thesis that the intermediate level of health literacy skills, between functional and critical, should be labelled 'applied' rather than interactive (Nutbeam 2008) or communicative (Ishikawa et al 2008). This is not because the skills for this level are particularly different from those explained by Nutbeam (2008) and Ishikawa et al (2008), rather it is because the labelling 'applied' better represents the definitive skills. Applied HL skills are those of interpreting and applying health information to one's decisions and actions, rather than interacting or communicating with others. The findings explored above reveal that having applied HL skills enabled the participants to approach others for information

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[4] DESMOND is a Type 2 diabetes structured education programme which is available in a range of formats and is offered to people living with, or at risk of, Type 2 diabetes. www://Desmond-project.org.uk

(the pharmacist or HCP) and use written sources (magazine or Internet). So, even when these participants felt they did not fully understand health information they had tactics they could draw on to aid their understanding.

5.4.4 Critical health literacy skills

Three participants, P8M, P16M and P17M, who had left school before achieving O levels, were characterised as experiencing critical health literacy skills as they achieved scores of over 60 for the health literacy questions. P8M had gained armed forces qualifications and both his wives had been HCPs. He wanted to know as much as he could about his health and he was pro-active in asking questions:

> P8M …. *I mean I will ask questions even my GP knows that (…) I'll ask her questions, we always ask questions instead of "oh thank you very much" and walk out well "what happens if this/that?" or "is there anything else we can do?" so we like to be well informed about what's wrong in there*

He and his wife went to appointments together so that they could both take in the information, ask questions and discuss things at home, they also looked things up together:

> P8M *you know the wife and I talk and she'll have a look when I've had an X-ray or a review or whatever and we'll just talk between us normally more of the in-depth side of health and things like that*

P8M was proud of his approach to managing his health, he recognised that others did not always want or use the type of information that he found so helpful:

> P8M *I've spoke to lots of people in the past (…) they seem to be the type of person who goes to the doctor and accepts what the doctor tells them, they're not willing or they don't want to know exactly what's wrong with them I do and the wife does and I think that makes you manage your health better and you feel healthier for it for knowing exactly what's going on in your life health wise*
>
> Interviewer *So having that information, having that knowledge, and knowing what's happening helps you to-*
>
> P8M [interrupts] *Makes it more manageable*

P8M not only recognised that information assisted him with managing his health, he understood that simply accepting HCP advice was not enough to manage successfully; he was prepared to ask questions of HCPs and discuss different scenarios with his wife.

P16M found explanations from HCPs useful and when requirements were explained to him it helped him to act, although he implied that he would not necessarily follow the advice to the letter:

> P16M *well before I knew it, I wasn't, you know, I was eating all the wrong stuff* [laughs] *and everything y'know so that didn't help, once they* [doctor/nurse] *explain it to you then you sort of take action then it's quite good some of it*

He was confident to look things up, including the meanings of words, on the Internet:

> Interviewer … *you're pretty confident about using your computer to find information?*
>
> P16M *Oh yeah, yeah to find anything yeah, it's very good actually, gives you some good insight into it* [diabetes] *really*

P16M found it helpful to have 'insight' in to his LTC.

P17M had finished school without any qualifications but later went on to train as a social care professional. He was happy to be proactive when requiring advice, and, like P8M, recognised that others may not be so confident to do so:

> Interviewer *OK, so you're relatively confident about getting information if you needed it from some sort of source.*
>
> P17M *Yeah, pretty confident yeah, I mean umm if I had any issue I would, I'd be asking people for information about it and I know not everybody's like that…..*

When asked whether he drew on any strategies discussed with previous clients in his job role he talked about how he had discussed coping skills with his colleagues:

> P17M *I was always very supportive to other staff in respect of coping with work, there was one guy who found dealing with stress difficult and I tried to support him with that and umm look at strategies at how he could manage it…..*

Participants in this category of health literacy ability evidenced critical skills in that they were able to access information, apply the information accurately to themselves and could judge the quality of the information. They were also confident about sharing information with others and understood the boundaries of doing so.

5.4.5 Health literacy ability: summary

The health literacy ability questions used in interview one enabled the identification of the level of health literacy skills that each participant experiences. Thirteen participants (60%) had functional levels of health literacy skills, with two of these having lower than functional skills. Six (27%) had applied levels and three (14%) had critical levels of HL skills. The low education level indicator of not achieving O level qualifications is a reasonably reliable population indicator of a low level of health literacy skills (Finbråten et al 2020, Cudjoe et al 2020) but a somewhat crude indicator of HL ability for individuals. One reason for this is that people continue to read, learn and develop other skills throughout their life (Duncan & Schwab 2015). Three participants, P8M, P16M and P17M, were judged to have critical health literacy skills, although none of these participants had achieved O levels at school. However, nearly three-quarters of the participants with functional or lower than functional HL skills had left school with no qualifications and had not undertaken any formal further education.

The method of classification of participant's level of HL skills, the health literacy questions asked in interview one and the scoring system, has been effective in enabling discrimination of participants as possessing either functional, applied or critical levels of HL skills. As discussed in the findings above the qualitative data for participants supports the classification of specific HL skills as: functional, for example reading; applied, for example applying information to own situation; or critical, for example judging the quality of information. Participants with functional levels of skills described difficulty with higher order skills and participants with critical levels of HL skills described using concomitant skills such as providing information to others. Participant explanations gathered through interview two have provided support for the HL skill classification for each participant. Further discussion and findings relating to the hierarchical nature of health literacy skills and the specific level of skills experienced by participants will be presented in the following sections.

5.5 Acquiring health information

This section and section 5.6 present findings pertaining to participant's perceptions and experiences of acquiring and using health information for long-term condition self-management. Each sub-section commences with a brief discussion of appropriate theoretical underpinning principles. Examples from the data are presented, then related to theory, and the implication of each finding is debated.

5.5.1 Acquiring health information – the explanation of: 'I'm not looking'

Yamashita et al (2019) suggest that health information seeking is driven by need, so we might expect individuals to seek out information when they have a health problem. It seems common-sense for people to search for health information when they live with a long-term condition, as their condition requires them to self-manage their health. However, the actions of the study participants were more nuanced than this and one example of their response is explored in this section. When asked ‘do you look for information about your LTC?’ three types of response were identified - conscious avoidance, avoidance because of not understanding the information and a contradictory response.

Participant P4M consciously avoided looking:

> P4M *If I wanted to but I don’t bother sorry it’s not something I go looking for information on or whatever it’s just something I put up with never yeah I don’t actually go looking*

P4M did not discuss any use of information to manage his health and reiterated in interview two, ‘*I’m not looking, I don’t need any more advice*.’ He was living with considerable disability and ill-health and explained:

> P4M *For somebody* [else] *(……) for them going out and looking for information and trying to implement what they find* [is relevant] *to me I just get on with it I think as you get older umm all the options and all that could be done and what have you, you just get sick to death of the treatment and spending time in hospital you just say “I’ll put up with it”*

P4M described a situation where more information, and subsequent intervention, was perceived as not helpful for him, and not wanted, so he was ‘not looking’ and ‘put up with’ his poor health.

Two participants provided examples of avoiding looking for information due to finding information difficult to understand. As presented in section 4.3.4 P3F discussed her belief that looking for information was not helpful for her health and that she found information difficult to read and interpret. P14M also described how he avoided looking for information because he found it confusing:

> Interviewer *So you wouldn’t really sort of yourself go and look for information?*
>
> P14M *No, I tried it but it’s the same again* [doesn’t sink in].

The explanation of ‘not looking’ for P3F seemed to reflect her experience of having difficulties with searching for information and not wanting to find information that was likely to be negative or scary. P14M was ‘not looking’ because he found information difficult to understand and, as will be explained in the next section, he depended on his wife to ‘translate’ and assist him with using information.

Participant P9M provided examples of the contradictory response, that is, he initially seemed to be categorised as ‘not looking’ for information but then went on to talk about drawing on sources of information. In section 5.4.1 a quote from P9M illuminates how he was ‘not looking’ for information but that, if he could be bothered, he could look up information on his phone. He understood that it was not common-sense to have information and not act on it but this was his choice:

> Interviewer *I think there's a lot of people who find it difficult to manage*
>
> P9M *oh yeah but not deliberately like I do, yeah mine's a deliberate choice (…) mine was a conscious decision to say "sod it, I don't want to play with these"* [tablets]

Later in the interview he went on to explain:

> P9M … *but I know about my condition and I don't want to know about it so I ignore it I put it in to that 'I know about but I don't care box' or whatever you like to call it*

His comments reflected ambivalence about change, he knew what he could be doing but he had made the choice to not act, possibly, as will be explored in later sections, because he perceived change as too difficult. 'Not looking' reflected his (current) choice to not act.

Miller & Rollnick's (2013) concept of motivation comprising a person's judgement of the importance of making a change and their confidence to make a change is useful here. For example, P4M's circumstances whereby he was *living with* his conditions (see Chapter 4) meant that, potentially, it was now not important for him to search for more information about his conditions and thus his health literacy skill level was somewhat irrelevant to this choice. In terms of confidence, as illustrated above, P3F and P14M reported lacking confidence to understand information so avoided looking for information; this lack of confidence could possibly arise from their low level of health literacy skills limiting their ability to de-code information. It could also be that the health information they were given was complex and they were unable to de-code it and they ignored it or 'didn't look'. Gaglio et al (2012) posit that desire (or motivation) for information will vary for each person and according to their circumstances, for example by HL skill level, or the context, for example a health care setting. As previously explained, health literacy ability determines whether a person can de-code health information and sometimes underpins motivation for change; however motivation is not a constant. Rather than each person being 'motivated' or 'not motivated' to acquire health information the reality was a complex balance by the participants of wants, needs and skills.

Yamashita et al (2019) posit adults with a high level of HL skills may acquire necessary health information and reach a situation where they do not need more, that is, where it is no longer important to have more information. P17M (critical HL) provided an example of this situation, which led to him turning down an information session provided by health care services:

> P17M *the hospital have tried to promote umm information giving sessions ummm for example the drug I'm on they were gonna do a lecture on that and I thought well that's all*

> *very well but I've read their leaflet from the hospital* (laughs) *and I've looked online is there really anything I don't know about this drug and I declined the offer*

This participant was confident about his knowledge and deemed that it was not important for him to hear the information again as he would not learn anything new.

The implication of these findings is that 'not looking' does not have a straight-forward meaning of never accessing or never wanting information. Interestingly during the interviews participants often revealed using more information sources than they initially gave themselves credit for. Although 'not looking' was the opening response given by some participants when asked directly about information seeking they all went on to discuss accessing at least one information source. It is possible that a response of 'not looking' may reflect a low level of health literacy skills and a lack of confidence in one's own skills. In addition, irrespective of health literacy ability, forgoing or ignoring health information may be an outcome of perceiving that one has *enough* knowledge (Yamashita et al 2019).

5.5.2 Acquiring health information – the explanation of: 'I'm not savvy'

In Bloom's taxonomy of learning skills (Heick 2020, see Table 2) remembering is the first level of learning skill so it follows that an inability to remember information may be an onerous barrier to gaining knowledge. Some of the participants reported that they found remembering information difficult and for a few this may have been as an outcome of their condition. For example P1F and P5M, who had experienced strokes, when asked about taking in information and acting on it replied:

> P1F *Well I take it in but I don't always keep it there ermm I'd say I often try and you know do what it says on there if I remember it* (laughs)
>
> P5M *Not really, because it goes in and then like tomorrow I'll only remember half of this*

Despite their attempts to 'take in' information P1F and P5M found it difficult to remember information.

P9M and P19M reported experiencing periods of depression and discussed problems with remembering information. When asked 'are you able to remember information about your LTC?' they replied:

> P9M *err not always I mean that is err hit and miss with me cos of my memory problems sometimes it will stick but err like I can someone can tell me something and I'll say "yep, fair enough" and then ten minutes later I've forgotten what was said same with written*

> *information at least on the computer you can go back you feel a bit someone will say, "I just* ***told*** *you that" yeah yeah well it didn't stick and it's getting worse unfortunately*

> P19M *so I get sometimes word-salad so all the words just get mumbled* [sic] *or I can read a little bit of a book I can read a page get down to the bottom and I've forgotten what it was up the top things like that*

The quotes above illustrate the frustration these participants experienced when they could not remember information. All four participants went on to describe how other people or resources supported them to manage their LTC, including by translating health information in to a form that they could understand and apply. Participant P9M was, as previously explained, '*not bothering*' to manage his LTCs, he experienced loneliness, depression and poverty and gained the lowest score for health literacy skills of all twenty-two participants. However he too had his 'translator', the Internet via his phone or computer. The role of translators is discussed further in the following sections.

Comprehension of information is the second level of skills in Bloom's taxonomy (Heick 2020, see Table 2). One third of the participants, when asked if they found that they, 'could read health information but did not always know what the words meant' (Q3 part B of HL questions), replied that they often or always experienced this. Not understanding was described in different ways by participants and P14M (functional HL) encapsulated a few in his first interview:

> P14M *I go* [to HCP] *they tell me and then after that it's like I don't really remember half of it because there's so many medical terms and it just* [pause] *it's like they fill my head with too many things at once so it doesn't give me* [pause] *it doesn't sink in*

He talked about not remembering but in this instance it was less to do with his memory and more about there being too many 'medical terms' and not enough time for explanations of information, time that he required to enable the information to 'sink in'. In a meta-synthesis Schulman-Green et al (2016) found that when discussing self-management approaches medical jargon or rushed communication confused patients.

P14M struggled with understanding information that he read:

> *P14M* (…) *err I might know the word but* [pause] *it's the context it's been written in see I'm not that savvy I can read but y'know I read and I thinks 'what's that mean?' and I have to ask*

He could recognise certain words but the context, potentially medical contexts, meant he did not understand the words. He judged himself as 'not savvy' and required support to understand the meanings of words. He was able to ask his wife to help him:

> *P14M* (…) *my wife 'cos I'm like* ***a scatterbrain*** *my wife deals in all these sort of things like she gets* [grabs a bit of paper] *like that comes with some tablets and she reads it through and I say "what's that about, what's that mean? " then she informs me 'cos she is more patient than I am 'cos I wouldn't know what half the words meant so I do take it* ***in*** *you know what I mean* [his emphasis]

P14M judged himself as a 'scatterbrain' who did not know what words meant but his wife was 'more patient' and could 'deal with these things'. P14M's wife was able to read and de-code health information and thereby translate it to a form that her husband could understand, he could then take the information in.

In circumstances such as having trouble with remembering health information or being 'not savvy' enough to understand health information people may need to draw on others who are accessible, for example family members, to support them to de-code the information and translate it in to a form which they can understand. In support of this supposition Shin & Sham (2019) discuss how people draw on different supporters, for example an HCP or a family member, to help them to understand information and improve their knowledge. In the examples above P9M used digital technology to support his understanding and P14M drew on his wife to 'deal with' information that he found difficult to take in. The next section discusses a finding which illustrates that participants were aware of difficulties they sometimes faced when using health information but did not wish to feel alone in experiencing these difficulties, I also explore other tactics used to counteract difficulties.

5.5.3 Awareness of difficulties with health information: 'somebody like me'

When recruiting participants and during interviews I had to take care to encourage people with low HL skills to contribute and open up about their experiences; I did not wish for them to feel shame or embarrassment. Participants did share their tactics for dealing with low HL skills. P2F (functional HL), for example, preferred written information because she could take it home, read it in her own time and share it with her daughter:

> P2F (…) *so I think the health care people ought to realise that my generation not everyone's got a computer or a supersonic phone that they can do all these things with* (…) *there must be other people like me that can't access all this but they can read a book or a pamphlet, like I did yours* [referring to participant information sheet] *I put it in my knitting pattern and when I got home I opened it and I just read it through and I showed it to my daughter*

Having more time and sharing the information assisted P2F with understanding. She later explained how even 'mundane' information was important:

> P2F (…) *so very often they ought to put things down which seems very mundane to a lot of people but somebody like me I cannot stand buttons and dials*

P2F expressed a preference for information in a straight-forward format.

P6M had an applied level of HL and took a technical approach to managing but he too found some medical terms confusing:

> P6M *umm sometimes what they're saying and what it does maybe not so clear because they're giving you medical terms and somebody like me wouldn't understand medical terms - So if I tell them* [HCP] *things like, in computer terms, like of the inside of a microchip, they're gonna be lost – and that's likewise when somebody's written something down so when you line up a medical thing and technical thing and you line the two up you're like well actually I don't understand whether that's going to help me 'I haven't got a clue on that' it's the same thing*

P6M recognised that healthcare workers might struggle to understand the technical terms used in his profession and concluded that it was the same situation as him not being able to understand medical terms. '*Somebody like me*' was a term used by P2F and P6M which seemed to reflect their attempts to remove the detriment of 'not understanding' by showing that they were not alone, that others were like them. P2F and P6M also explained that, in certain contexts or environments they may not understand health information but in their home environment they could draw on tactics which helped them to de-code and understand information. Langewitz (2020) posits that HCPs giving patients a lot of information at one time risks overloading the person, resulting in helplessness and this had perhaps been the situation that P2F and P6M had experienced.

P19M (functional HL) explained his tactics for de-coding information, emphasising that information was most helpful when explained in 'layman's terms':

> P19M *I find some websites out there for medical stuff is so in-depth it's not really you can spend more time looking up the answers to other things because you don't know what the heck they're talking about whereas with Diabetes UK I found that one to be very, very straightforward and simple in that you can do searches on different items say take for example Metformin or whatever and you can put that in the search and it will come up with stuff and it's relevant and it's said in a way that you can understand it really you don't need to keep looking everything up (…) so it's quite a layman's terms.*

Some of the male participants enjoyed taking a technical approach to self-management and were confident with using the Internet. P6M explained how he used the Internet to help him understand medication information:

> *P6M (…) because I get my information from the net, is the point of fact I can see the packet* [medication] *look at the company, look at the drug, turn around and "is that what it says?" go on the website and check it if need be, which, there is more information on their website than there is on the box obviously it's clearer on the website than it is on the*

> *- well I think it is - and how many people actually **read** the leaflets? So, I've learned to do that now*

P6M found the medication information provided via a website easier to understand than the written leaflet provided with the drug. Being technical and using technology enabled P6M and P9M to overcome dyslexia:

> P9M *I'm Internet based, I couldn't write it down by hand because of my dyslexia and put words all over the place, I can't even read me own writing, but fortunately with spell-check and grammar-check I can get a word, letter out that looks reasonable**-ish**.*

Ironically it was P9M, who had the lowest HL ability of all participants, who clearly explained how technology was helping him to get around his difficulties with understanding:

> P9M *this concept of modern technology can over-ride your questions, if you said, if it wasn't for the computing system you've got on your phone, then it* [reading and understanding words] *would be difficult, but because I have those facilities it's not difficult anymore*

Importantly, technology enabled 'somebody like me' with dyslexia to mitigate their health literacy difficulties and become savvy. There was perhaps a wish for the tactics they used to get around their difficulties to be acknowledged, as P9M explained, 'I have those facilities it's not difficult anymore.' In addition participants looked for recognition, and perhaps reassurance, that other people like them ('somebody like me') also struggled to understand health information or did not have access to technology; as P2F reported, basic information was not 'mundane' but helpful. Mackert et al (2019) suggest that experiencing low HL can lead to feelings of shame and stigma. It seems possible that shame does not come from the low level of HL skills but the feeling of helplessness engendered, perhaps in health care contexts, where 'somebody like me' who is 'not savvy' is not given the time and explanation that would assist in understanding health information. Shaw et al (2009) and Gaglio et al (2012) found that, when receiving health information people preferred circumstances that: created opportunities for them to ask questions; enabled an explanation of how the information applied to them; and provided a summary of the information. The research findings indicate that, in the absence of these conditions, participants found other ways to cope with self-management information. For example, P6M, P9M and P19M used technology to translate information in to a form that they understood and P2F made time to read information and discuss it with her daughter. By using these tactics these participants were able to *become* savvy.

5.6 Using health information sources

Within this thesis the focus on health literacy skills as an individual ability is tempered with the recognition that such skills are used within social contexts and are therefore inextricably linked with personal social networks. This section presents findings which elucidate how participants drew on health information sources, including resources such as the Internet and people such as HCPs. The section therefore explores the use of health literacy skills in social contexts providing something of a link between health literacy skills as an individual characteristic and the personal social network as a contextual phenomenon. As using information sources will include receiving information from others the findings in this section represent the 'social' aspect of using health literacy skills. The section starts with a critique of literature to illuminate the theoretical stand-point taken in this section. The following sub-sections present the study findings for participant's experience of using information sources including the television, the Internet, HCPs and 'similar others' (a person who is experientially similar to the ego, Thoits 2011).

5.6.1 Using information sources: theoretical framework

To self-manage effectively people require accurate information and information that is relevant (Shaw et al 2009, Gaglio et al 2012) and the source of information can determine the accuracy and applicability of the information. For example, for LTC self-management accurate information would be expected to be provided by health care professionals (HCP) and evidence-based websites such as NHS sites or organisations such as Diabetes UK. These sources can be classified as expert knowledge sources (Shin & Sham 2019) and should be accurate but may be complex in terms of content and its meaning and implications for a person, as illustrated by the data findings in the previous sections. In contrast, information gained by the person themselves or from family and friends, could result in information which is relevant but may be of dubious quality. Chen et al (2018) found that people with low health literacy skills were more likely to access sources that were easy to access but unreliable and Chapman et al (2019) found that reliable health websites were difficult to access with inaccessible language and a lack of visual content. These conclusions indicate that 'the problem' may lie with the inaccessibility of certain sources rather than a lack of people's motivation to access sources.

Yamashita et al (2019) suggest that health information can comprise facts provided by others, what they classify as a passive way of gaining knowledge, or people can actively learn about their condition. People experiencing a functional level of HL skills may find it easier to receive knowledge via passive formats such as instruction from a health care professional. In support of this association Gaglio et al (2012) found that people experiencing low health literacy and living with an LTC reported face-to-face communication with HCPs as their preferred method of receiving information. People experiencing an applied level, or higher, of HL skills might be predicted to actively seek out knowledge by investigating or studying a topic, in addition to gaining information from HCPs. Yamashita et al (2019) found that older adults (aged 50+) with good HL skills sought information from a variety of sources and the more education participants had received the more likely they were to use books and the Internet as sources of information.

The sources of information that the study participants drew on are discussed below in terms of participant's HL ability and in terms of their perceptions of trustworthiness. Chen et al (2018) suggest that a lack of trust in a source may be a barrier to the use of a source however there are many other aspects of health sources that create barriers to access. I wanted to understand the factors that enabled my participants to use a source. When interviewing I took the stance that participants would want to use trustworthy sources, in that they would want to have confidence in the information they were receiving (Champlin et al 2017). I kept in mind that, because of their HL skills level, some participants may have found it difficult to judge the quality of information and accordingly they found it problematic to accurately judge the trustworthiness of a source. The findings, discussed below, provide an account of the ways in which participants searched for trusted sources of health information while managing the 'problem' of judging quality. This culminated in some sources being perceived as 'helpful yet contradictory' and trust being placed in information gained from health care professionals and experientially similar others (Thoits 2011).

5.6.2 Television: 'helpful' *and* 'contradictory'

In this, and the following section, two sources of health information - television and the Internet - are discussed. The findings illuminate the difficulties of sourcing straight-forward health information for the complex process of LTC self-management.

Television was a useful source of health information for some participants:

> P12F … *if say an advert comes out and it's says oh "about arthritis" like they do programmes on it like at the moment they was doing one on diabetes I'll sort of watch that so if things have come up before I have thought "oh yeah I will watch that" because it gives you an insight into it's better to look at something rather than reading it to be truthful because I think it goes in more…*

P12F preferred watching the television to reading. Her experience was that watching programmes gave her an 'insight' into other's experiences and this helped her to 'take it in' and build her understanding.

One television programme had a particularly important impact on P7M:

> P7M *I got to a stage where I was forgetting to take the tablets and I didn't really want to know and that sort of thing and then I umm watched a programme on the TV and err it was about diabetes and this particular chap was having his leg off and I thought to myself, "I'm not having that" and umm yeah that's when I started taking notice and that's it ever since I've been as good as gold as you might say*

In health promotion practice elicitation of fear is generally used with caution as the evidence of effectiveness of such approaches is inconclusive (Green et al 2015). However, presenting amputation as a possible consequence of diabetes, within a programme about diabetes management, appeared to have had a fear-provoking but ultimately beneficial impact on P7M as it encouraged him to better manage his medication.

A few participants did not trust the television as a source of reliable information or found the information presented contradictory. One participant with functional HL explained how he found contradiction difficult to deal with:

> P22M *I have watched some of 'em* [TV programmes] *but, they all seem to contradict theirselves don't you find with a lot of things, same when I've looked on the Internet for anything, one says one thing one says another, there's nobody that sort of says yeah I know it's gonna be this or, there's nothing definite, it's sorta, it's like anything on the Internet, like even the weather, like the other day one says it's going to rain and the other says it will be sunny all day*

P22M wanted information to be 'definite', if he had a question he wanted a straight-forward answer. However, messages about complex phenomena, such as the weather or LTC self-management cannot be presented as definite or fixed (Gaglio et al 2012). Participants with low HL skills appeared to deem complex messages as contradictory, possibly because they found the messages difficult to make sense of. For some participants it was perhaps easier to not trust the information and ignore it, rather than attempt to de-code it.

5.6.3 The Internet: 'helpful' *and* 'contradictory'

Gaglio et al (2012) suggest that the Internet has enabled ubiquitous access to health information and, where digital media is also interactive (Levin-Zamir & Bertschi 2018), health information provided via the Internet has the potential to be accessible and usable by all. Most of the participants discussed using the Internet at some point during their interview and the men who took a technical approach to LTC self-management particularly enjoyed using the Internet. The Internet was an important source of information for P9M, as previously discussed (section 5.5.3) he enjoyed using his phone to look things up and he mentioned using NHS sites. Other participants with functional HL skills did discuss using a personal computer, tablet or phone to seek health information, but this was sometimes with reluctance:

> P13F *I'd look on the internet, look on the internet (…) Yeah I've got a laptop so if not the kids have got laptops and everything haven't they so I've got a tab* [tablet] *so I'd look it up, to see what the problem, what causes the problem more or less, yeah that's it, been doing it so long (laughs)* [managing diabetes] *I don't take no notice.*

> P20M *(…) I'm not a lover of the Internet, I'm not really technically minded I do get lost and frustrated quite quickly, if I can't go like that* [bangs table] *and the information is there then you've gotta start looking for it and you press another button and you lose it and things like that I get frustrated at that and my wife does all the computer things*

Both participants could use the Internet to look up information but P13F (functional HL) felt that she was managing her diabetes and did not require more information and P20M (applied HL skills) became frustrated when he could not access an immediate answer. Arcury et al (2020) found that people who experienced what they called 'computer stress' could, not surprisingly perhaps, become disenchanted with using computers. Arcury et al (2020) also identified certain factors that encouraged people to use the Internet, which included having several devices, which was P13F's experience, having support from others, as P20M had from his wife, and, having adequate or better HL skills.

Participants with applied HL skills appreciated the access to information that the Internet gave them but they were aware that they had to be cautious when using Internet sources:

> P6M *so I can get a lot of detailed information* [louder] ***however*** *you get what I call the fake news and the fake adverts on there "take this, take this, hello" and I know sometimes that isn't gonna work, so you want proof of things OK so if I see that there is proof of things then I'll have a look at that and see what's going on*

> P7M *I do go onto the diabetes website but I mean you just use your knowledge really, umm I don't… If I think something is wrong on the net, or something like that, I just disregard it. There are bits on the web that actually say "if you use this and if you use that it can stop your diabetes" and all the rest of it, but I've found that the majority of those sorts of sites are American…but they're saying "you can have this for so much" and it could work out to hundreds of pounds and I'm just not interested because it's a big* ***con*** *at the end of the day… you know, I don't go there.*

Using the Internet required P6M and P7M to know what was useful and what was of limited quality or 'fake'.

Participants with critical HL skills used the Internet in conjunction with several other sources of information. For P8M, the context being that he experienced multi-morbidity, he understood that the information could be unreliable and perhaps of limited use to him now:

> P8M *I very rarely use the Internet because there's so much on the Internet errmm I'm a bit wary of some of the information I have done in the past and I will sort of weigh it up with what I've been told by either a GP or a specialist, I will look at the Internet and think "chop that, I'll stick with that"* [motions stick with what given by HCP]

The other two participants with critical HL skills used the internet with confidence to support their knowledge and understanding:

> P16M …*mostly I would get on the computer, just put it in (…) I always check it* [words he does not know the meaning of] *in the computer but I don't normally have any problems with that*
>
> P17M …*I'm a bit like that I'm afraid any word that comes up that I haven't seen before I get on the phone and look up what it means* [laughs]

Kim & Xie (2017) found studies which concluded that, even with high levels of HL, people could experience a lack of confidence in their ability to find and judge the quality of online health information. The amount of information available via the Internet, and its potential lack of reliability, can be burdensome (Arcury et al 2020) and the relative recency of digital information means that people aged 55+ did not have the opportunity to learn, as young people or in school, the skills now required to navigate digital sources. Chapman et al (2019) and Kim & Xie (2017) conclude that the readability level of online health information can be high and is a barrier to access for people with low HL skills. Kim & Xie (2017) posit that lack of access to online sources of health information and support will increase health inequalities, particularly for older people.

Potentially, rather than trying to improve people's health literacy skills, it could be possible for interactive media sources to be developed that enable access and understanding for all. For example, digital sources that translate complex health information in to flexible, appropriate and interesting information could be made available (Arcury et al 2020, Levin-Zamir & Bertschi 2018 and Kim & Xie 2017). Levin-Zamir & Bertschi (2018) found that complex information provided digitally could be presented verbally, enriched with animations, and hence become accessible to people with low HL skills.

5.6.4 Health care professionals: 'somebody I can trust'

When considering during interview one who *supported* them to manage their LTC all the participants included at least one HCP within their personal social network diagram. However, when asked who they got *information* from very few participants explicitly mentioned an HCP as a source of health information. The three participants with critical HL skills did discuss having information-sharing dialogues with HCPs. Findings have already been presented showing how P8M was confident to ask questions of the GP or consultant and how P16M felt that explanations from the GP and the nurse, in conjunction with him looking things up on the Internet, had helped him to manage his diabetes. When asked, 'do you look for information?' P17M replied:

> P17M *umm I've read leaflets, umm I've read stuff on the Internet and of course I've had discussions with the consultant and the relevant nurses*

P17M used a range of health information sources with confidence, a finding that supports Yamashita et al's (2019) conclusion that people with critical HL skills sought information from a variety of sources.

Participants, including those with functional HL skills, appeared to understand that HCPs could be a source of information for LTC self-management. For example, when P3F (borderline functional HL) was asked if she would encourage others to find information via the Internet she replied:

> P3F *Probably not I certainly wouldn't advise Googling it 'cos I think that is dangerous and I think if I was to advise it would be the local GP or the local practitioners too 'cos some GPs are really good and nurses and that…*

P3F perceived the Internet as 'dangerous' and understood HCPs to be 'really good' and perhaps more reliable. P4M (applied HL) explained explicitly why he chose specific sources of health information:

> P4M *when I need advice I would go to somebody who I can trust who knows what they are talking about umm whether if it's a doctor or whatever then you are going to go to the one that's in the field that you want to see them in*

He was able to articulate what P3F maybe implicitly understood, that HCPs 'know what they are talking about' and could be trusted sources of health information.

When requiring health information participants may have wanted to see someone they trusted however getting to see an expert and then understanding what the expert said were potentially two barriers to deal with. Wanting to speak with an expert brought complications if the expert was difficult to access:

> P1F ….*I'd like to see the diabetic nurse* [sic] *a bit more than once a year I know that 'cos I do get questions and I think you know I don't know really (….) and it's so hard and you think sometimes you want to ask things but again you ring up you try and ring your GP just to ask you can't really ring just to ask a question you know like I need to speak to the diabetic nurse at the moment because she gave me a blood test three months ago….*

P1F found only seeing the nurse once a year frustrating, she wanted to ask questions and she wanted timely feedback on how she was managing her diabetes, but it was 'so hard', that is, not available.

Sometimes the trusted expert was accessed and then the barrier was that the information was inaccessible:

> P14M *…. if they can take all the medical jargon out and tell me and* [Interviewer interjects with 'explain'] *explain it "look if you take these this is what it'll do to ya, if you don't take 'em this is what could happen" that's the way I work I'd rather be told straight like if they says "well if we do this and do that" I say "well, will I die or won't I?" if they say "yeah if you don't do it you will die" then I'll do it then y'know what I mean? That sort of attitude…I mean I might sound a bit morbid and things like that…It's just me, it's just what's inside there* [taps self]

Here and as previously discussed P14M described himself struggling to understand medical terms and to some extent blamed himself for a lack of understanding, 'it's just me'. Nevertheless he appreciated that if information was presented in a simplified form and in a way that was relevant to him he was more likely to understand and act on the information. He required 'medical jargon' to be translated and expected and hoped that HCPs would enable this.

Langewitz (2020) discusses a finding that trust in an HCP can be detrimental to information recall and decision making as patients who trust their HCP may then accept information without question. When asked whether she took in information and acted P13F (functional HL) answered:

> P13F *Yes, yes I did that I always just try to and do what they* [HCP] *say there's no point in going if you're not gonna do what you're told*

However, she later described a situation where she had followed instructions for some while and then been told she was overdosing:

> P13F *I had a problem when I went last time apparently I've been on too much metformin, I mean I've been on the same dosage for years and all of a sudden apparently I've been overdosing, I said, "how can I overdose when you've described* [sic] *it for me? you've give it to me" how can you overdose if the surgery the diabetic nurse give it to ya? So they've docked me half down so which I don't mind but if I was told that I should but I only do what they say with the tablets I've got I do what they say you know that's what I do*

P13F had understood that to manage her condition she should 'do what they say', she had therefore been trusting of her HCPs and followed what they prescribed. She was somewhat shocked to find out that the dose was too high, particularly as she was doing what they told her. Rademakers & Heijmans (2018) report that patients with low HL skills are likely to be passive in HCP encounters. This could be a consequence of trusting the HCP or lacking the skills to question, or a combination of both factors. In alignment with Shaw et al (2009) and Gaglio et al (2012) the findings discussed above indicate that HCPs can do more to ensure active dialogue with patients.

Finbråten et al (2020) suggest that HCPs should tailor health information to the individual's HL level, devote time to explaining the information and draw on a range of ways of explaining the information. This type of approach was very important for P3F, who had borderline functional HL and no family. She talked about meeting with her new '*diabetic nurse*':

> P3F… *she's new* (…) *and she's really good, she* ***explains everything*** *to me* (…) *so she tried to we're trying to do it that I don't have fruit for a meal I have it as part of a meal you know after something so it all gets soaked up but we won't know until November when we do the next blood test it's every three months this particular one so* ***she*** *has explained* ***everything*** *about my diabetes to me which I think is really good* [Participant's **emphasis**]

For P3F the clear explanations were important but so was the ability to speak with the nurse on a regular basis and monitor, together, the outcomes of changes. Goal setting, monitoring and regular feedback and encouragement are known to be beneficial for achievement of health behaviour changes (McAlister et al 2008, Hughes et al 2020) and can be facilitated by HCPs.

P6M, who had an applied level of HL, was very proactive with health information (see 5.4.3) and assured me that he was confident with managing his diabetes but he regularly looked to HCPs, and others, for help:

> P6M ….d*ecision making, yeah, I'd generally make my own decisions I'd discuss it with partner, close friend if I need to call on him and we'll discuss something see if it's a good idea, bad idea whatever and it's like myself OK so last week I thought "right I've gotta ring the doctor just to see if I can get an appointment" 'cos the bloods have come down, which is really good but I don't want them to come down too low though for the amount of insulin I'm having so I just wanna adjust and see do I need to adjust that or they* [HCP] *gonna say let's let it run for a bit….*

P6M's juggling of information from his partner, a friend and the doctor is perhaps an example of what Shin & Sham (2019) discuss as a gaining of 'thick' knowledge through combining one's own experience, comparison with others and expert knowledge. Shin & Sham (2019) posit that lay knowledge enables people to gain a sense of control over their condition by complementing and adding to the expert knowledge, contributing to people understanding how expert knowledge relates to them and their situation. P6M recognised that he was fortunate as his partner was another source of expert knowledge:

> P6M *My partner is very good 'cos she's ex-medical anyway but I probably know a little bit more now about that than she does* [laughs] *'cos I do monitor what goes on*

P6M enjoyed being an expert in his conditions; he was interested in technology and monitored his health closely. It seemed important too that he now knew more than his partner, even though she was 'ex-medical'.

Yamashita et al (2019) suggest that HCPs can be a preferred source of health information for people regardless of their health literacy level, and Chen et al (2018) posit that HCPs are trusted because they have professional training and credentials. Implicitly trusting an expert source is not without its drawbacks, patients can be passive and reluctant to question HCP's advice (Rademakers & Heijmans 2018) as demonstrated by P13F. In addition, gaining access to and advice from HCPs can be difficult as the examples above demonstrate. Shaw et al (2009) and Gaglio et al (2012) also conclude that people, particularly those with low HL skills, can find HCPs difficult to access, that consultation time can be limited and the information provided is difficult to understand and apply. The participants with critical HL skills, and some of the participants with applied HL skills, employed tactics that enabled them to get around some of these barriers, they did their own research, went prepared to consultations and asked questions of HCPs. HCPs could do more to ensure that health information giving is done in such a way as to be useful and accessible to *all* patients, and this would be particularly helpful for people living with low levels of health literacy skills (Shaw et al 2009, Gaglio et al 2012).

5.6.5 Similar others: 'somebody I can trust'

As Thoits (2011) explains a 'similar other' in network theory is a person who is experientially similar to the ego, the ego being the 'abstract initial actor' (Berkowitz 1982 p51) i.e. the participant. In this study a similar other is categorised as a person who is living with an LTC, usually the same LTC as the ego. The influence of similar others on self-management is discussed in more detail in Chapter 6 but their importance for providing and translating helpful health information is discussed here.

When asked about useful sources of health information P7M explained:

> P7M *umm, basically talking to other people who have the same condition and it's very helpful that way and I did mention that umm one of the family's got class 1 diabetes so he's been very helpful as well and he's younger than I am, it's a shame really but it's been very helpful*

P7M found it helpful to talk with similar others and gained useful information, he was also empathetic of their situation, particularly for the person he described as 'family'. Thoits (2011) suggests that family members who are also a similar other can provide particularly effective informational support, and this was P7M's experience.

P19M drew on support from others as he experienced ‘*word salad*’ and found remembering information difficult, his preferred source was a similar other:

> P19M *Well my brother-in-law is type 1 diabetic and he has been all his life and he is a member of Diabetes UK, in the sense that he’s an active member and he goes around and he gives talks and stuff like that all over* (…) *so most of the time I get it* [information] *from him but I also get it from Diabetes UK or my doctor.*

For P19M the family member was a knowledgeable and trusted similar other, comparable to two other trusted, expert sources, a relevant charity and a GP. When asked whether he could remember information P19M replied:

> P19M *I would say ‘often’ because my wife is also diabetic she got diagnosed after me ermm but again she remembers all this sort of stuff so she pushes me along as well*

P19M’s comment that his wife’s support ‘pushes him along’ reflects encouragement to manage his diabetes, possibly because she was helping him to appreciate the importance of managing the condition and building his confidence to act (Miller & Rollnick 2013). Also key is that she ‘remembers stuff’ - because he did not. For P19M having a range of similar others to draw on as sources and translators of health information was helpful for understanding how to manage his condition:

> P19M *again, if I don’t understand it I’ve got different resources like my brother-in-law or my wife or Diabetes UK to bounce it off*

By Diabetes UK he was referring to a monthly magazine which he received, it included examples of people managing their diabetes. He found it helpful to draw information from different sources and ‘bounce it off’, or use it, to build his own knowledge and understanding.

Shin & Sham (2019) suggest that interactions with similar others can enrich the ego’s knowledge by enabling the translation of scientific information in to information which is personalised and contextualised for the ego. P19M struggled to remember information and appreciated the support his relatives provided with translating medical and health information. Grace (2020) found that experientially similar others tended to be empathetic of the ego’s situation and were likely to have relevant tactics that could be attempted by the ego. P7M shared tactics with his experientially similar relative and consequently empathised with the relative’s situation. Shin & Sham (2019) conclude that information from similar others is perceived by the receiver as important and relevant, i.e. has utility, and these perceptions can build a sense of control in the receiver. The translation of health information by experientially similar others appears to be particularly helpful for people who are living with a long term condition as it can aid them with learning how to manage their condition. In this thesis the provision of informational support is defined as a product of a personal social network, that is, informational support is provided by others. The finding that similar others can be an important source of informational support is explored further in Chapter 6.

5.7 Chapter conclusion

The health literacy questions (interview one) and the scoring system enabled categorisation of participant's health literacy skills. Thirteen participants (60%) had functional levels of health literacy skills, with two of these judged to potentially have lower than functional skills. Six (27%) had applied levels and three (14%) had critical levels of HL skills. A majority of participants experienced a functional level of health literacy skills and some reported being able to read health information but not always understanding or remembering it. When HL skills are limited people may be unable to de-code information and require information to be translated, that is, de-coded by another and then relayed to them in a form that they could understand (Egan & Gajdamaschko 2003). Participants found it helpful if others, including experts such as HCPs, experientially similar others or other supporters such as partners or family, de-coded and 'translated' health information into a more relevant and understandable form. Participants who enjoyed using technology (P6M, P9M, P16M) used technology to help them de-code and understand health information.

It was perhaps not their low level of HL skills that was the main barrier to health information for participants, the barrier appeared to be the frustration and helplessness they experienced when they did not understand information and could not get assistance with de-coding. Participants were aware that they struggled to understand information and described this as 'not looking' or being 'not savvy'. They aimed to demonstrate that they were not alone in their struggles with information, explaining that other 'people like me' experienced these problems too. Importantly, participants did have tactics for getting around their difficulties with health information: they made use of translators, including wives, husbands, children, experientially similar others and technology, and tried to get access to reliable sources such as HCPs.

Participants with functional HL skills asked for scientific concepts to be explained in clear, simple terms, as exemplified by a comment from P18M:

> P18M *I'm a visual person so what the best thing, what would* ***really*** *help, if someone said about the illness I had, like a picture, a picture there that would explain something…*

Kickbusch (2001) posits that many people learn through listening and watching rather than reading and writing, that is, by listening to or watching teachers or translators, people can be supported to understand information and gain knowledge.

Participants, particularly those with applied HL skills or better, understood that sources of health information needed to be trustworthy:

> P10F *I'd rather use something what was reliable then I know I'm getting the proper information.*

Trust was placed in HCP as 'the experts' but some participants found getting access to HCPs was problematic and when they did get access then, for some, the information they were given was difficult to understand. Helpful HCPs translated medical information by taking time to explain it and helped participants to relate information to their situation.

Although participants found some information sources, for example the television and the Internet, easy to access and helpful they also realised that such sources were not always reliable and these sources were described as 'contradictory'. Contradictory sources were those which claimed to provide information but which were judged as untrustworthy or difficult to understand. One very helpful source of information, and informational support, was experientially similar others; this is discussed in more depth in Chapter 6.

The conclusions drawn so far lead into a brief consideration of how health literacy skills contribute to empowerment, where empowerment is viewed in this thesis as a process whereby people gain control over their health and well-being (Laverack 2016). Participants with critical HL skills (for example P8M, section 5.4.4) described making their own decisions based on information from a range of sources, a finding also reported by Yamashita et al (2019) and Finbråten et al (2020). Participants P8M and P17M, in particular, discussed ways in which they maintained their autonomy while achieving their health goals and, potentially, experienced empowerment. In contrast, participants with low levels of HL skills described relying on others for support with health information and some reported feeling helpless at times (P14M, section 5.5.2). In such circumstances participants endeavoured to find support with becoming empowered rather than helpless. For example technology enabled empowerment for those participants who were 'savvy' with technology. Similar others assisted some participants, enabling them to understand, interpret and apply information to their own situation. In summary, although having an applied or critical level of HL skills can enable someone to self-manage their LTC, the social context for self-management is fundamental too, with indications that social context can enable, or disable, self-management, irrespective of an individual's level of HL skills. An understanding of how health literacy skills are connected to and overlap with the provision of social support from a personal social network is beginning to be compiled and will be further developed in Chapter 6, which presents the findings for the social network aspect.

The frustration of dealing with medical information, wanting to draw on trustworthy information and the process of translation that he required from his wife was explained by P14M and encapsulates the points made in this conclusion:

> Interviewer *So you don't necessarily decide how appropriate it* [information] *is for you, you sort of rely on…*
>
> P14M *Well I do, I'd like to, if given the information like my wife gives it to me instead of like* [pause] *If I've gotta read it's very difficult because I don't know* [pause] *don't get me wrong I can read and I can write I'm not the best writer in the world but sometimes if I don't understand the word or I don't understand the meaning of the word or what context it's in that is well my wife will explain it to me, the context as well*
>
> Interviewer *…I'm trying to find out how people get around problems, so you're describing really well*
>
> *P14M* [interrupts] *I've got a secretary I've got a secretary!* [laughs]

Chapter 6 Personal social network: findings and discussion

6.1 Introduction

This chapter presents and discusses the findings for the personal social network aspect of the research. The first section presents the theoretical framework for data analysis which has enabled the identification of the presented findings. To facilitate an understanding of the context for social tie building, participant's personal social networks for self-management support are described in terms of their size and the supporters in the network. Following this the grounds for social tie building are discussed, using examples from the findings to illustrate how participants sought to achieve affinity and gain utility from ties that they deemed reliable. The chapter concludes with a section which presents three tactics described and used by participants to enable them to negotiate their social ties and draw on the ties most helpful to them.

6.2 Building social ties: theoretical framework

Azarian (2010) suggests that typologies of social networks should go beyond the aspects of strength and frequency and 'explicate the … grounds of connectivity' (p331) that is, the mechanism behind the social tie. As Pawson & Tilley (2004) posit, a mechanism is what brings about an effect or, in their words, how resources '…permeate into the reasoning of the subjects.' (Pawson & Tilley 2004 p7). Reasoning or perceptions about a social tie, from the ego's perspective, could be positive, negative or neutral (Shumaker & Brownell 1984) and it could be deduced from this that positive or neutral relationships may be acceptable to the ego and negative or harmful relationships will be avoided. In support of the importance of ego's perceptions of social ties Hinder & Greenhalgh (2012) posit that what people know is not limited to an understanding of what they know themselves but includes their understanding of other's ways of thinking and knowing. Azarian (2010) argues that understanding social tie building requires an appreciation of the substantive knowledge and mutual expectations of actors within the network, i.e. the relational factors and the context which shapes perceptions and actions; Shumaker & Brownell (1984) suggest that people do not constantly evaluate their relationships but that a researcher asking about relationships and perceptions can trigger an evaluation. The supposition that people have perceptions about how others may support them and that research inquiry can enable perceptions to be voiced is a fundamental aspect of Dewey's pragmatic approach to inquiry (Garrison 1994), pragmatic inquiry being the paradigm guiding this study.

This chapter draws on Azarian's (2010) discussion of social ties which posits that an understanding of the mechanism for connectivity can be elucidated. She recognises that ties are dynamic as people manage the need to belong (for example, identification with a group) and the wish to be recognised as an individual (for example, being a whole person, not 'a diabetic'). In a study exploring the experience of living with and managing chronic pain Cummings et al (2017) described participants *not* wanting to be viewed as self-pitying (being independent) while simultaneously recognising that they depended on others for emotional and instrumental support (being dependent). When seeking support from others to manage an LTC an ongoing balance between agency and dependence is required; as Vassilev et al (2016) suggest, maintaining social ties is part of the dynamic process of self-management.

A person with an LTC may require support, wish to relate to others and therefore seek out and draw on connections with others, that is, build social ties. Azarian (2010) describes the grounds for social tie development as affinity, utility and loyalty. Affinity can be described as the wish to like someone and have something in common with them. Utility can be described as gaining a practical purpose from the relationship, for example instrumental, informational, decisional or emotional support. Loyalty or reliability describes the expectation that the other person will wish to respond and/or can be relied upon to respond and that, by responding, both parties will gain. Azarian (2010) uses these three terms in the context of ties for economic purposes so, in this chapter, the term reliability is used instead of the term loyalty, it feels more appropriate to, and better describes, ties for health support. Loyalty implies a faithful adherence to commitments which was not - as will be demonstrated - what participants necessarily sought when requiring self-management support. Rather they sought someone or something that could be *relied upon* to deliver what they wanted. Importantly Azarian (2010) suggests that the loyalty (reliability) category of ties enables the engaging parties to increase their power and authority, which has a fit with the supposition that social support for health self-management can bring about empowerment.

Azarian (2010 p326) discusses the search and selection process for affinity, utility and loyalty as a matching process, stating, '… a social tie is but a relatively durable match of mutual expectations…', thus implying that the matching process is an attempt between parties to find a shared experience which brings benefit to both parties. Potentially then, for people living with an LTC, matching could bring about what Vassilev et al (2014) and Ould Brahim (2019) discuss as the collective, rather than individual, process of creating a supportive environment for self-management. Thoits (2011) critiques matching models of stress-buffering from the 1980s for focusing on the identification of the demands or need created in stressful situations and whether the support provided matches the need. Thoits (2011) suggests that as difficult circumstances will create more than one type of need, for example emotional *and* instrumental needs, it is more helpful to locate social support matching within a personal social network rather than within situational need. An additional argument is that what people *need* and what they *want* can differ (Green et al 2015); the analysis presented in this chapter operates from a basis of attempting to understand what the participants wanted, rather than needed.

Drawing all these theoretical perspectives together it can be surmised that the quality, strength and utility of a tie is a product of the ego's perception. In other words, the way in which the alter and the support from a potential or actual tie is understood and regarded by the ego is important for social tie building. Also, beliefs about a tie, for example a feeling that a tie can be relied upon, could bestow faith or confidence within the ego and make tie-building more likely.

In summary these findings are presented premised on the idea that a social tie for self-management support will be created when an ego perceives a match is achieved in terms of the ego's wants and the tie's provision, the match being judged by the ego in terms of affinity, utility and reliability.

6.3 The context for social support: the size of participant's self-management networks

As explained in the methods chapter, Chapter 3, the three concentric circle method was used to map network members (Hogan et al 2007 and Ryan et al 2014), and participants were specifically asked to list the people and resources they drew on for support with managing their condition. The size of an ego's network was then determined by taking in to account the number of supporters listed and how often a supporter is seen (see section 3.7.2). The score for the size of social network for each participant in this study is presented in Table 9 (Chapter 4).

Neubert (2008) posits that a pragmatic approach to research requires the context of inquiry to be delineated, hence the size and structure of each participant's personal network is described below as an indicator of their context for LTC self-management rather than as a tool for measuring the capacity of support provided. Shumaker & Brownell (1984) also emphasise the importance of describing the context for social support; accordingly some characteristics of each participant (ego), including demographic factors, LTCs and health literacy skill level are provided in Table 9. Participant's description of their network was mapped on to social network diagrams, some examples of which are provided in the following subsections. As recruitment occurred in community clubs participants had access to potential supporters beyond family and friends; the clubs provided an opportunity for contact with others.

The size of a participant's network was calculated using the method described in 3.7.2.1 and four categories of network size were elucidated: very small, small, moderate and extensive. These categories are presented below, with examples of network diagrams for P11F, P21M, P10F, P14M and P3F, and a discussion of two participants, P11F and P3F.

6.3.1 Very small personal network

P9M, P11F, P18M (who have functional health literacy skills) and P20M (applied HL skills) had network scores <18; their social networks for self-management of an LTC generally consisted of one or two others and the club. Participant P11F's social network is displayed on the following page (Figure 7) and discussed as an example here. When asked who she felt she could depend on for support she replied:

> P11F *If I need to talk to someone or if I need somebody (…) my sister and my daughter is always there for me I'm lucky in't I?*

P11F described a reliable but small social network for managing her health:

> P11F *when I'm poorly it's my daughter and my sister (…) Ohh I'm not ill like I'm very rarely ill I should say (…)*
>
> Interviewer *Crochet club?*
>
> P11F *oh, I wouldn't ask them for help, is that what you mean?*
>
> Interviewer *yep*
>
> P11F *I don't need to*

P11F felt she did not need a lot of support with her health as she was '*very rarely ill*'. However it transpired that the club had been very important for her following family bereavements:

> P11F *When I lost my son as well and I didn't wanna go out for ages and, and that's why we joined down here because I got in myself sorry about this I'm crying* (…) *I don't think I'd be the person that I am now if… 'cos I was staying in and not wanting to shower or and that's not me I like to dress up and have a shower and look nice… so that's why I do it I come down here*…

She explained how important the club was to her and how it had helped her; coming to the club had taken her out of herself, out of her grief. The importance of the clubs as contexts for meeting others, who were or could become social ties for self-management, is explored and discussed later in this chapter.

For all network diagrams: circles represent level of support for LTC self-management provided by the alter to the ego, as judged by the ego and with the inner circle representing most helpful support and outside the circles representing the least helpful support.

E = every day contact, W = weekly contact, M = monthly contact, I = intermittent contact (less frequently than monthly), U = unhelpful

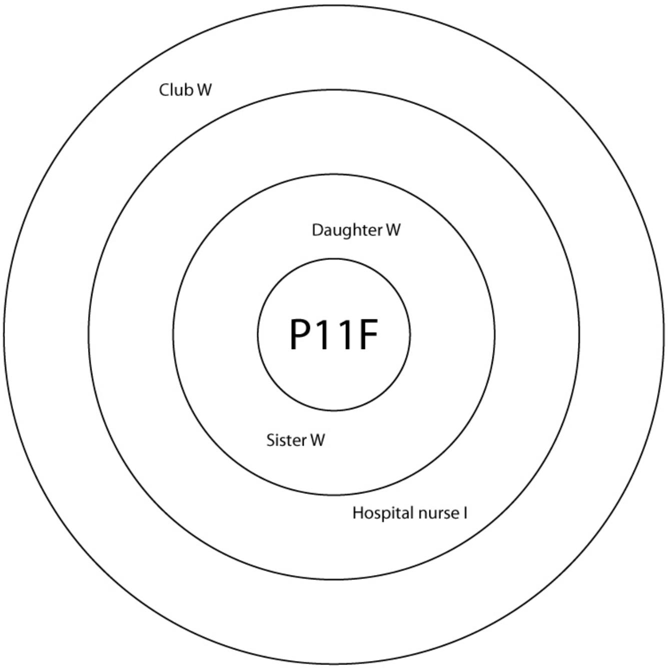

Figure 7 Personal social network diagram for P11F

6.3.2 Small personal network

Those scoring 19 – 28 were P12F, P13F, P21M and P22M (functional HL) and P16M (critical HL), (5 participants) and they were deemed to have a small network. For P12F her small network consisted of family, her husband, children and sister, and the club. P13F was widowed, saw different members of family through the week and attended three clubs. P16M had no partner but he had a close friend he spoke to every day and he visited the club most week days. P21M had a borderline very small/small network. P21M was very close to his sister and saw her once a week, he was estranged from his children and he was a carer for his wife (see Figure 8, next page). P22M's small network consisted of his partner, the club and a neighbour. Some of these participant's network ties are discussed later in this chapter.

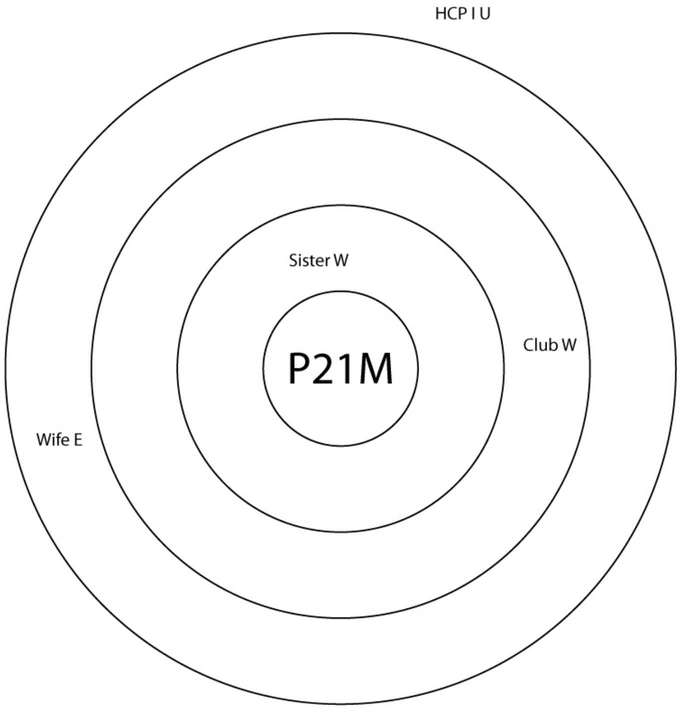

Figure 8 Personal social network for P21M

6.3.3 Moderate personal network

Half (11) of the participants described a moderate network, scoring 29 – 49. These were P2F, P4M, P14M and P19M (functional HL), P1F, P6M, P7M, P10F, P15M (applied HL), and P8M and P17M (critical HL). Moderate networks generally comprised a partner, children and/or other family (e.g. in-laws), friends, at least one HCP and the club. All these participants lived with multi morbidity, including some with considerable disability (for example P2F, P4M, P8M, P14M and P17M) and their contact with a range of health services contributed to their moderate sized networks. For examples see network diagrams for P10F, Figure 9 and P14M, Figure 10, following page.

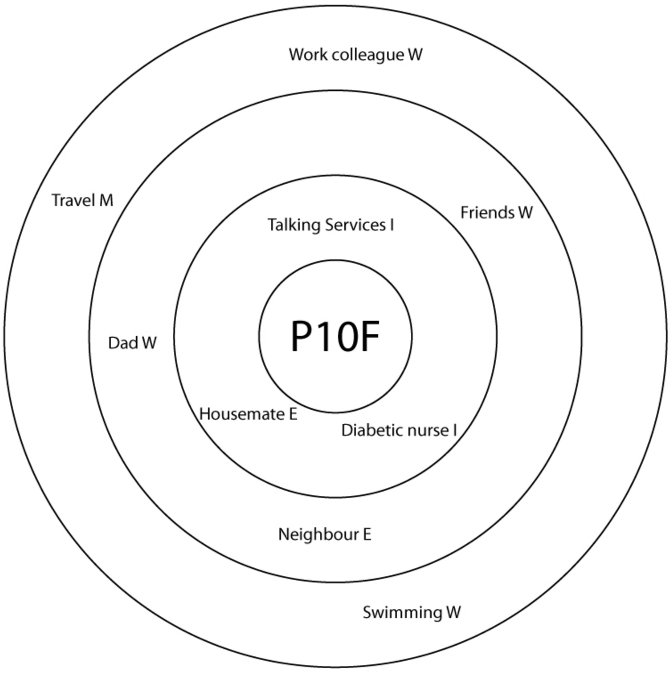

Figure 9 Personal social network for P10F

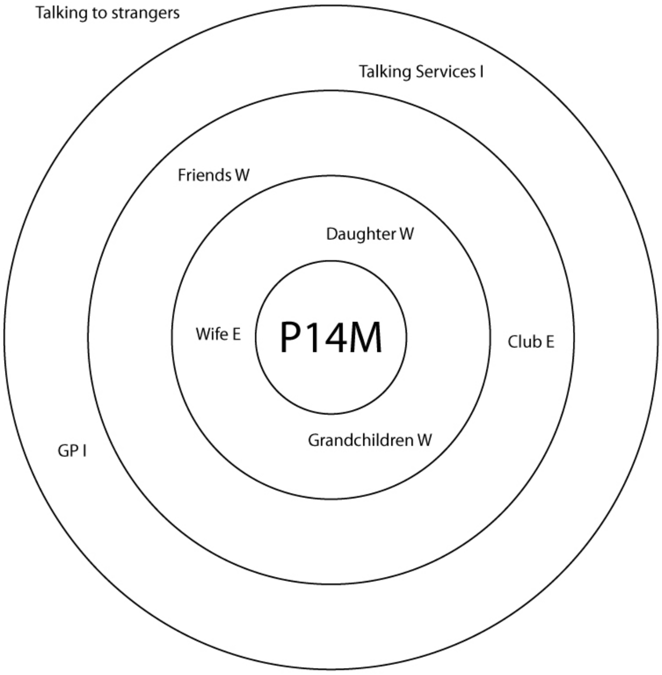

Figure 10 Personal social network diagram for P14M

6.3.4 Extensive personal network

Extensive networks were deemed as those scoring >50 and two of the participants were in this category, P3F (borderline functional HL skills, see Figure 11) and P5M (functional HL skills). P5M's extensive network reflected the support that had been put in place for him since he experienced a stroke. He also had a supportive family, friends, bi-weekly opportunities to meet others who had experienced stroke and attended a men's club on a regular basis.

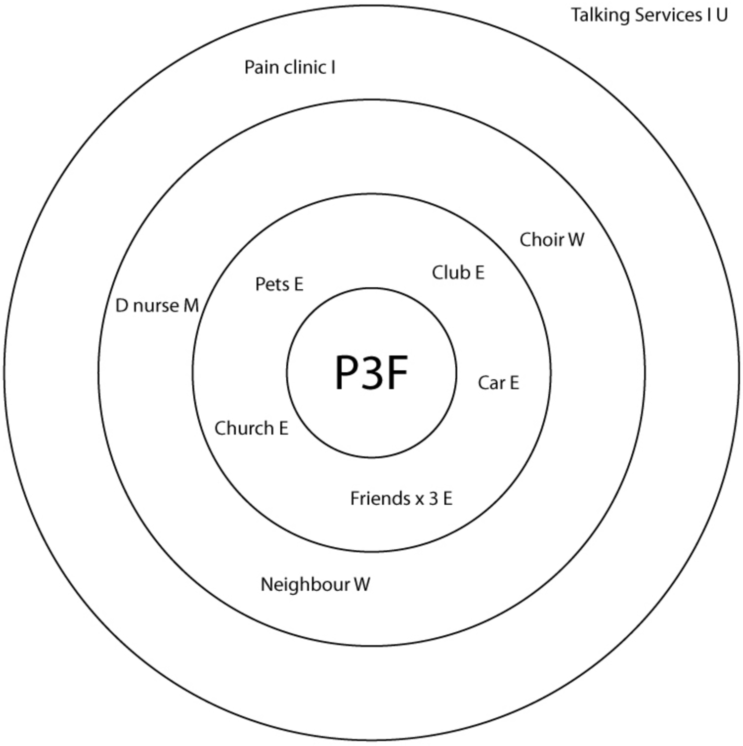

Figure 11 Personal social network diagram for P3F

As can be seen from her social network diagram P3F had no family but ran one of the clubs and was active in her local community. She brought a unique perspective of a person who was a recipient of support *and* a provider of support (Thoits 2011), and she discussed both roles in her interviews. Sometimes, managing her diverse network and dealing with the burden of other's problems became arduous:

> P3F *They come in here and they talk about their ailments and everything, one particular person used to come here with all her ailments and I don't want the group to be like that (…..) And I think sometimes that's me being selfish because I have got aches and pains as*

> *well and you just sort of get on with it and I suppose I should really see other people's ways as well but I don't know it's hard isn't it?*

Her comment that 'it's hard isn't it' seems to reflect a range of emotions for her. She wanted the group to be a positive experience for the women but she found negative attitudes difficult to understand and burdensome. She took a stoic attitude to health - 'get on with it' - and could not find affinity with 'other people's ways' which did not fit with how she perceived the club should operate. With women she more easily related to - i.e. could build affinity with - supporting them was an important part of her life and she described many examples of how she helped others. At one point she summarised one of the reasons that she found helping others an important tactic for managing her LTC:

> P3F *Sometimes that helps me though, providing for other people takes my mind off the pain and the problems, that* [providing support] *does help me to do that.*

Cattell (2001) found that people who supported others through community initiatives and had large networks could become fatigued; for P3F though it seemed that, overall, the benefit she got from co-ordinating the groups and from supporting others outweighed the difficulties of having to manage negative others. Contrary to the idea that more supporters equal more support for self-management, Vassilev et al (2016) found no association between extensiveness and size of social network and well-being and suggest this could be because of the added burden of managing a diverse network. In the case of the two participants P3F and P5M their large and diverse networks could be a consequence of their morbidity level and, although potentially burdensome, the extensive network was perhaps necessary for management of their LTC.

6.3.5 Personal network size: summary

The size of an ego's network is one aspect of a personal social network, one which determines the number of supporters available to the ego, the variety or homogeneity of support available and the substitutability of support and supporters (Vassilev et al 2016, Morris & Sanders 2018). P11F discussed a small number of supporters, felt she did not need more support with managing her health and was confident of future support if she required it. In contrast, P3F experienced considerable disability and had created access to a diverse and extensive personal network for LTC self-management.

In a review of quantitative evidence examining health literacy and social contexts Sentell et al (2017) record inconclusive findings due to wide variation in definitions and measures used. Most of the papers measured an association between the two constructs, however the findings were mixed, leading the authors to simply conclude that people deal with health issues in a social context, draw on health literacy skills and social support and that further research is required. In my small study no obvious correlation for health literacy ability level and personal social network structure was noted within the data. Network size appeared to be potentially related to ego's LTC self-management wants and needs, the availability of others and ego personality, for example outgoing or introverted. However the nature of the study design and data collected do not allow conclusions to be drawn for these aspects of network size. All participants drew on social support for self-management of their LTC(s) to a greater or lesser extent and, as will be discussed in the following sections, the tie selection process appeared contingent on context and participant preferences and perceptions rather than health literacy skill level. However, a significant consideration is that, people living with low health literacy skills are likely to require more support with LTC self-management (Van Der Heide et al 2013) and, for them, access to situations where social support might be offered is particularly important. Participants in this study were attending community clubs and the impact and benefit of a social situation where they could meet with others is discussed in the following sections.

6.4 The Club context as an opportunity to: 'talk a bit'

The participants were either members of a community club (Men's Shed or Crochet Club) or worked in a community club venue (P10F, P18M). All participants therefore had the opportunity to meet with people other than their family or friends. Kelly et al (2019) note evidence which supports Men's Sheds as enabling mental and social well-being and derive possible health pathways for these outcomes. This study contributes to understanding the mechanisms underpinning what Kelly et al (2019 p1155) posit as: 'improved social networking skills', leading to 'increased social bonds and meaningful relationships', that result from the 'provision of space for socialisation and interaction'. The following two sections present findings which illuminate how the club context provided participants with opportunities to build social ties and enable discussion of health and wellbeing.

6.4.1 The Men's Shed

The importance of the men's club for providing an opportunity to talk was explained by P8M:

> P8M ….s*o we get a lot of people here who just sort of naturally you know like we're talking now you sort of pair off, "you alright?" "yeah, yeah" "no you're not" and they'll sort of "well, well mmmuh" and just have a chat that's it y'know - so that's what we do here basically (…*) *Yeah, it's just another ear outside either a professional or the family, just a friend*

P8M described how the club provided opportunities for the men to talk to each other, in his interview he explained how the club supported members who experienced bereavement or mental health problems. In the extract above he also explains how some men might be initially reluctant to engage in talk. There was a sensitivity toward others at the men's club, some participants would talk openly about their health, while recognising that others might not find this so easy to do. P15M and P22M, who were members of Men's Sheds but at different venues, both explained:

> P15M *sometimes people don't like talking and saying about it* [health] *but, nah, to me it's just like* …[easy]
>
> P22M … *I don't mind talking about me illnesses and that to people I know it's meant to be private I don't class things like that as private everybody's the same aren't they? We always talk about that down there* [downstairs in the club]

Shumaker & Brownwell (1984) suggest that people may be unable or unwilling to voice the support they require but it seemed that at the club some men talking about their health enabled an environment where, 'we always talk about that'. Not all the men were as open to talking as P8M, P15M and P22M. P21M described quite complicated rules for topics he would or would not talk about at the club:

> P21M *Well um I wouldn't go into personal details y'know with them downstairs, I mean they're all great acquaintances if you like but none are friends because y'know once we've finished here we're away and we don't see each other but um… how can you explain it… they are just like-minded people who are quite willing to sort of talk about things but you know as I say nothing personal we don't discuss the families or that but we y'know I mean if someone's got an illness we'll talk about it and that*

For P21M there appeared to be a distinction between 'friends' and 'acquaintances' in terms of the topics of conversation and talking about 'family' did not appear to be appropriate to him however discussing 'illness' was. As will be presented in section 6.8.1 P21M revealed that he had what might be described as problematic relationships with his wife and children and possibly this was why he did not wish to discuss his family at the club. When discussing his health at the club, nothing was 'taboo':

> P21M *I mean I could go down and tell 'em anything and people would discuss it "oh I've had that" or "my mate had that" y'know there's nothing sort of taboo, they're really, really good down there, saved my sanity I think.*

Shumaker & Brownwell (1984) and Allen et al (2020) discuss that anonymous self-disclosure, via for example talking over the Internet or to strangers, reduces or eliminates a sense of indebtedness that people can feel when asking for and receiving support. For P21M it seemed that club members being 'acquaintances' who he only saw at the club provided him with a relationship that gave utility without the need for affinity and loyalty or reliability. In addition the club members provided utility through enabling him to discuss any health problems and being or knowing others that had experienced his situation.

In a comparable way P20M explained in interview two that the club was helpful for his health because:

> P20M … *there's more people in the same situation who will talk a bit about things…*

However in interview one P20M had discussed some difficulty for him in talking to others about his condition:

> P20M … *I don't converse with other people, very, very rarely anyway and I don't really know that many people with type 2 apart than come in here and speaking to the other people round the table that have got it, apart from that, but then men are like that aren't they, they don't talk about their conditions as such…*

Although he stated that he did not 'converse' with others he did have the opportunity at the club to speak to others with the same LTC as him. It seemed, for P20M, that talking specifically about his health was not something 'men did' and would ordinarily find difficult or avoid, however he spoke enthusiastically about the opportunity the club gave him to do 'the social thing':

> P20M …. *I do thoroughly enjoy it* [the club] *while I'm here I do enjoy it even if it's just doing the social thing where you're just sitting around and a lot of banter going around, jokes and whatever, camaraderie which is what you miss from work you see …..*

For P20M the relaxed environment of the club comprised 'sitting around' and 'banter' which replicated the work environment and enabled 'camaraderie'. Shumaker & Brownell (1984) suggest that certain contexts can provide an opportunity for contact with others without forcing interaction and this can promote social comparison and role modelling. The men's clubs seemed to create a context which enabled a specific form of affinity between the men, as described by P20M and P21M, but without it being overt 'help', as alluded to by P8M at the start of this section. By attending the club the men could perhaps: find affinity with others, as they had in a work situation; gain utility from others who lived with the same health problems; and could rely on others to empathise.

6.4.2 The Women's Crochet Club

Six of the seven women (not P10F) attended the same club, the Crochet Club, where, four mornings a week, between five and twelve women sat round tables and, as P3F who organised the club explained, "*well we all sit there and natter*…".

For the women attending the Crochet Club the benefit they gained and the way in which support was given was exemplified by a comment from P12F:

> P12F *It's like if you mix with other people they got their problems in their lifes and you hears them and you feels better and it's just making conversation and helping one another out with whatever problems they've got or you know like giving lifts and things like that if you can do it it's just having that chat and socializing. Gives you a better mind.*

P12F describes an initial experience of what Mok et al (2004) describe as downward comparison - which can enhance an ego's self-esteem - however she goes on to describe how 'making conversation' can lead to 'helping one another' which ultimately 'gives you a better mind'. In a similar way to the men's club the Crochet Club provided an environment which enabled contact without forcing interaction (Shumaker & Brownell 1984, Kelly et al 2019). This appeared to enable the women to 'feel better' and even 'help (…) one another' to manage 'problems'.

Five of the women described other club members as friends. P13F did not explain club members as her friends; she attended three clubs and found that these clubs were a useful source of women who lived with the same LTC:

> P13F *You always bet there's always someone there with the same problems as you, and it's always handy to listen for hints*.

P13F revealed how she 'listen(ed) to hints'. Potentially this tactic of maintaining some emotional distance (Shumaker & Brownell 1984, Allen et al 2020) enabled her to gain utility without having to build affinity. She went to three different clubs over the week:

> P13F *You see in the three days I see different groups so it's not all the same people all the time which is nice innit to meet different people?*

The context for her not building affinity with particular people and not needing to do more than 'listen for hints' was that she kept herself well and she was confident that family members would help her if she required help:

> P13F *…. so I'm afraid I'm one of these who just gets on with it, I ain't got time, I've not got time not to be not well, I hate being not well, hate it, but no I just gets on with it* (…) o*h yes if they* [family member] *needed help same way they would me if I needed help all I've gotta do is ring them and they'll be there*

For P13F, and for P11F (see 6.3.1), who were both widowed, it seemed that family could be relied upon ‘if I needed help’, which perhaps meant in imagined future times of crisis or disability (Coyle & Atkinson 2018). They were perhaps not fully aware of the significance of the club, until asked to evaluate this by me as a researcher; then P11F explained how she had joined the club at a time of crisis after her son died and P13F recognised that being ‘well’ was important to her and, although she did not currently require support with managing her health, hearing how other’s managed was helpful. As Jeffries et al (2015) and Kelly et al (2019) posit, the club provided the women with opportunities to interact and socialise, which expanded the self-management support and advice available to them.

6.4.3 The Club context for social tie building: summary

Shumaker & Brownell (1984) posit that relationships are viewed unconsciously and in an automatic way until a prompt, such as a crisis, lack of support or a researcher, leads to evaluation. It appeared that taking part in the interview process enabled participants to vocalise how the club situation contributed to management of their health and building social ties for support was achieved in a variety of ways. Some participants viewed the club as an opportunity for forthright discussions about health and wellbeing while others preferred a covert approach of ‘just listening’, however all participants seemed to benefit in some way from being a member of the club.

Drawing on Dewey’s pragmatism Neubert (2008) suggests that people rely on habitual behaviours, until a new, unexpected situation arises. The ability to react and act differently in new circumstances is important for people living with an LTC: to manage their condition they are required to notice changes, and draw on knowledge, information and support to enable management (Matarese et al 2018). The variety of social interactions available at the club enabled participants to draw on interactions that were most helpful for them. In addition, the club context perhaps provided not just opportunities for gaining support from others but also for participants to view their condition, and its management, through the eyes of others.

The Men’s Shed and Crochet Club findings from the data illustrate different viewpoints and perceptions of club relationships and ways in which support for LTC self-management was provided but overall participants achieved benefit from the interactions. It can be tentatively suggested that the club environment enabled participants to build affinity with club members, that they could gain utility from relationships if they wished and that the club provided a source of reliable, perhaps like-minded, others. As well as like-minded others the club brought the participants in to contact with similar others, and this finding is discussed in the next section.

6.5 Building social ties with similar others: 'they've gone through it'

As previously explained in Chapter 5 this thesis takes the explanation of a 'similar other', as a person who is experientially comparable to the participant, from Thoits (2011). A 'similar other' in this thesis is therefore a person who is living with an LTC, usually the same LTC as the participant. In the previous chapter the importance of similar others as sources of, or translators of, health information was discussed, this section explores the potential mechanism for the influence of similar others for self-management. Similar others will, by definition, have affinity with the ego and, potentially, similar others working together will bring utility to the relationship. Some of the participant's experiences of interacting with similar others are presented and discussed below.

P10F shared her experiences of diabetes with others living with diabetes:

> P10F *Yeah, if they're stuck on something then I'll tell them what I've experienced and see if that helps them. We usually can exchange views on different things, like what meds they're on.*
>
> Interviewer *and why is that helpful to talk to other people about your meds and things?*
>
> P10F *I think it's 'cos they can und… relate 'cos they've gone through it themselves.*

For P10F exchanging views with people who had gone through similar experiences to her was helpful, they did not just understand each other but could 'relate' to each other. Affinity was built because the others had 'gone through it' too. There also appeared to be some utility in that both parties gained from exchanging views about medications. P10F discussed how her housemate provided instrumental support:

> P10F *If she knows I'm not well she'll keep an eye on me and make sure to check my bloods and she knows I've told her what doses of my insulin I need and other injections I need just in case I'm not capable of doing it she can give me a shot*

P10F's housemate looked out for her, providing a safety net for managing her diabetes. P10F explained later in the interview how her housemate also lived with a long term condition:

> P10F *she* [housemate] *works weird hours and she suffers with arthritis so I try to do certain things back to help her, doing jobs in the house, we help each other*

Although P10F and her housemate lived with different LTCs mutual support could occur, helping both of the parties. Affinity existed between the two women and both gained utility from the relationship.

It was discussed in Chapter 5 how participant P19M drew on a relative living with diabetes to translate and provide health information, enabling him to gain knowledge about his LTC. He also read the Diabetes UK monthly magazine and when asked about whether hearing from or reading about other people living with diabetes was beneficial P19M explained:

> P19M *It just* [pause] *it's just sort of the odd things that people might come up with that helps them and you think "well I've had that, maybe I'll give that a go", got nothing to lose, and if it don't work you stop doing it.*

It appears that P19M was willing to try out actions provided as ideas from similar others, possibly because the ideas were felt to be relevant and achievable. Maybe, in addition, hearing or reading about how similar others acted helped him to understand how to act. P19M could explain how his relative translated health information for him but he was not able to explain how this led to him taking action:

> P19M *Dunno really, I just kind of* [pause] *my brother-in-law tells me "this is that, that's that, oh that means this" I think "Oh OK" and I just I dunno just take it on board I suppose, I don't actually consciously think "oh yeah I'll do that with it" it's just a thing of "OK that's not so bad then" just do whatever*

For P19M it appeared that his brother-in-law was a trusted source of self-management information. In addition, this relative translated information into a form which gave P19M, not just understanding, but also the confidence to try to act on the information. Affinity, utility and reliability - what might be termed a *full match* - was achieved for P19M with the relative's support; potentially it was this virtuous combination that contributed to his motivation for acting.

For P12F her husband was an important source of instrumental support and understood her experiences of living with arthritis:

> P12F [my husband] *Helps me get in and out the bath 'cos I can't lift my leg as in I feels like unstable as in that way and like if, shopping he goes and does the shopping and umm, I think that's about, and obviously listening to me when I'm like "oh my knee or my hip, or my foot' but he suffers as well 'cos his hands are really bad with it so he's got an understanding of what it's like, when the weather changes and things like that.*

When asked to articulate the support her husband provided P12F found that she could describe a range of contributions, from doing the shopping, to listening to her and 'understanding'. This appears to relate to Thoits' (2011) theory that significant others, such as a husband, can provide instrumental support and emotional sustenance, which P12F's husband did, while also, as a similar other, providing empathic understanding of her situation.

Significant others, who were also similar others (Thoits 2011, Grace 2020), were beneficial to the participants who experienced that context. By working with such actors the participants gained a full match, namely, affinity, utility *and* reliability. As will be presented in section 6.8 it was not always the case that significant others such as parents or partners provided helpful support for participants; sometimes significant others were available for support but the support provided did not match with what the ego felt they needed.

6.6 Building social ties with similar others at the club: 'you know they understand'

The opportunity to meet similar others in the club situation has already been alluded to (see 6.4) and is explored in more depth in this section. At one men's club I observed participants with diabetes talking together in a group which was led by P6M:

> P6M *we've just had a meetup, the few of us that are diabetic, this morning while I was having a coffee, so I don't know what the percentage of people here that have diabetes, but I would imagine it's maybe thirty percent, forty percent of people, maybe more here (….) so there's a great talk about it, and, you know, what they're dealing with and how they deal with it*

As explained in Chapters 4 and 5, P6M managed his LTC as a technician and felt he was up to date and knowledgeable about diabetes, he was happy to be asked for advice by others:

> P6M …. *I don't like being big headed, now I'll have to turn that on its head 'cos I'll get people who ask* ***me*** *about what they should do and I have this all the time ...*(his emphasis)

P6M enjoyed being viewed by others as an expert source of health information and used his enthusiasm and knowledge to create a support group within the club context. The group within the club gave him an opportunity to be a provider of self-management support, enabling him to build affinity with similar others.

Two participants gave examples of situations where a similar other gave them information that was key to self-management of their condition:

> P15M *I had a terrible problem going to the toilet I couldn't go nowhere it was dodgy (…) I was talking to some old feller who had diabetes, I was talking to all the time and he said to me "what I've done" he said "I've knocked the metformin down from one in the morning to one at night" and I thought "whoah" I phoned the doctor up and err he said I have to see the diabetic nurse, as of yet I haven't seen her but I don't keep going to the loo half as much as I used to*

> P2F …. *but doctors and hospitals give you things but they don't actually tell you what it's for and what will happen if you don't take it. I mean one of the ladies in there* [club] *she*

> *has got a really bad thyroid problem (…) they gave her too much* [radiation] *so now she hasn't got enough and when I said to her (…) "I'm sick of tablets I must stop taking them all" and she said, "do you know you could die if you stop taking those thyroid tablets over a period of time?" and I said "no"*

For P15M the advice to reduce his dose of metformin had a big impact on his quality of life, enabling him to go out without worrying about where the next toilet might be. P2F appreciated that the advice she had been given was potentially life-saving. It also seems that P15M and P2F found the information more timely and more relevant than information provided by HCPs; because the informant was a similar other there was affinity and utility and the advice was deemed reliable to act on.

In line with Grace's (2020) findings, with similar others the participants relayed feelings of affinity, and there was utility in what similar others provided, be it informational, instrumental or emotional support. As P1F explained:

> P1F *just talking about it, it makes you feel better, somebody who's* ***listening*** *who's going through the same thing maybe, you know it makes you feel better just for talking about it as well* (her emphasis)
>
> Interviewer *yeah, yeah and does it help to know that maybe people are experiencing the same things?*
>
> P1F *yeah, yeah that's what I mean, they talk about it and you know they understand 'cos they're going through it as well*

6.7 Building social ties: pets, cars and the Internet

The social network supporters recorded mainly comprised people but some participants also listed pets, their car and the Internet. These resources, and their consequence within social networks for health, have previously been examined and that literature is briefly considered here. Brooks et al (2012) suggest that pets can provide unconditional companionship and note the contribution of pets to the emotional, and sometimes even the practical, work of LTC self-management. In a review Boniface et al (2015) found that poor access to transport, including cars, can limit social capital and lead to social exclusion, both of which can have a negative impact on health. Christie et al (2017) investigated travel needs following serious injury, finding that the need to travel rose due to the requirement to attend medical appointments and the desire to remain in contact with others. Finally, Levin-Zamir & Bertschi (2018) posit that interactive digital media can be a source of social support and Allen et al (2020) conclude that online ties can foster independence and control over LTC self-management. The aim here is to additionally consider the grounds for why the resource was listed and to understand whether this occurred because the resource was a match for participant's wants.

6.7.1 Pets

Pets provided a source of comfort for five participants (P1F, P3F, P5M, P9M and P19M). For P3F, who had no family, her cats were very important:

> P3F *I do get frustrated with myself I feel sorry for myself, doesn't happen that often it's just by sheer determination to keep going and also I think well, I've got to keep going because the cats need me more than anything they are my babies*

As discussed previously P3F lived with considerable disability and chronic pain, caring for her cats provided a motivation 'to keep going' when she was finding things tough. She described in detail how her cats interacted with her:

> P3F *….then Sooty his new place to sit is behind my head on the back of it* [reclining disability chair] *there's a little table either side where I put all my crochet bits and Paws will jump up there for me to scratch him and comb him Tootsie will sit this side until Mr Jiggle decides he's coming up because he'll spit….*

She described how she built affinity with the cats as they responded to her. Her cats were loyal and reliable and perhaps provided utility from the point of view of soothing, comforting and entertaining her. For P19M a previous dog had provided utility too:

> P19M *our old dog we used to have he was a staffy and he picked up on **everything** if I wasn't feeling too good in the middle of the night he'd wake my wife up he wouldn't settle he was a brilliant, brilliant dog*

P2F was something of a contradictory case, she lived in a house with a dog but insisted that it was not her dog:

> P2F ***no** no it's not* [my dog] *umm I have to open the door and let her in but that's it really I don't I'm not really an animal person wouldn't hurt them but you know*

It seemed that P2F did not feel affinity with the dog, '…not really an animal person..' and she did not want the dog to be listed on her social network for self-management.

Building on Brooks et al's (2012) findings that pets provided a unique social support resource to their owners it is possible to establish that pets may provide a social support match and can be a useful social tie for LTC self-management. For people who were 'an animal person' the affinity generated and the sense of loyalty and reliability that a pet could bring was grounds for a positive social tie. In addition there was potential for some utility in the relationship, pets could be comforting, entertaining and observant.

6.7.2 Cars

Being able to drive was listed as an important instrumental resource for P3F, P9M, P16M and P19M. For P3F her '*little car*' was crucial in enabling her to support others and to visit places with friends:

> P3F *Yeah my little car* [quietly] (….) *I wouldn't be able to get out because I can't use buses because I can't get up the step there to get on the bus I don't know when I last used a bus 2008? So my car is my life really a lifeline*
>
> Interviewer *so your car's important for you is it? So that you can do things but* [interrupted]
>
> P3F *important to my friends as well* [laughs] *so they can get out and do things as well. S wouldn't be able to come here without me picking her up she'd have no way of getting down here*

For P3F her car played an important practical role in enabling her to do the things she wanted to do. Her car provided utility and, in addition, assisted her with providing support to others. P3F's car enabled her to build social ties with others, as a recipient and provider of support.

For three participants the unavailability of a car impacted their ability to travel and see their social supporters. P16M somewhat reluctantly revealed that he was not allowed to drive at the time of the interview and this was restricting his ability to travel:

> P16M *Well I can't* [visit my mother] *at the moment 'til I get my vehicle back 'cos I can't actually get over to see her.*

He was missing the independence that driving gave him.

P19M explained that a car was essential in the town he lived in:

> P19M *You've gotta have a car 'cos you can't get around any other way buses are useless (…) I mean I did have my licence taken away from me for three months because of illness and I was reliant on other people to get around it's a nightmare an absolute nightmare to get to here* [the club] *from my house I've got to catch three buses and it'll take me an hour and a half….*

Not having a car and not being able to get to the club was 'a nightmare' to him.

In interview one P9M explained:

> P9M *oh car, yeah, my car, that is a very important part of my life, helps me get to places…*

In interview two he told me that his car had broken down and he was concerned about not having the funds to get his car fixed.

A car, for these participants, had a high utility value and was a very important resource within their social network. However, as shown above, a car was a somewhat precarious resource in that it could be taken away or become unusable, and seriously disrupt a participant's ability to network. There is some support for Boniface et al's (2015) conclusions that a lack of transport can create social exclusion, particularly when, as Christie et al (2017) posit, people live with a condition which limits their transport choices.

6.7.3 The Internet

The Internet was a source of informational support, particularly for 'technicians' (e.g. P6M, P9M and P16M) and this aspect has been discussed in Chapter 5. Two participants, P6M and P22M described the Internet additionally as an opportunity to network with others. P6M was a member of a group, not the club where he was interviewed but another group for which he did not reveal the purpose, which met in person and supported each other online:

> P6M *….so this group is quite good from a spiritual...well not so much a spiritual point of view from an emotional point of view we're all very gelled on the same thing of the way we're thinkin' and what we're doin' (…) they're quite close and because I'm connected to them every day through the net and WhatsApp and all that (…) so it's group support….*

P22M received daily messages from a neighbour and enjoyed keeping in contact with his home town:

> P22M *I talk to them* [neighbours] *every day, on the internet like, they work, I don't work, so they say good morning or whatever, really that's the only friend I got where I live so (…) I'm a member 'cos I come from* [Town name] *and umm I'm a member of their, their remembrance of how the town was years ago I go on there, I love that*

Both participants described 'liking', or affinity, with the communication and interaction they were able to have via the Internet. Considering the tactics of these two participants it would seem that the Internet had a practical purpose, i.e. utility, and was reliable in the sense that it was always available (for a critique of reliability in terms of quality of information see Chapter 5). Additionally, for P6M and P22M, who communicated with others via the Internet, the Internet was viewed as wanted and liked. This adds to Allen et al's (2020) findings that online communities were used to leverage support to fill deficits or substitute for offline support or to build on offline support.

The resources of pets, cars and the Internet have been found to be of particular use to people living with an LTC when they do not wish to or are unable to draw upon family and friends for support for self-management (Allen et al 2020, Brooks et al 2012). In the examples above it has been demonstrated that ties are forged to resources when the resource is wanted, provides utility and is reliable. Matching will not occur if the resource is not wanted, for example, P2F who did not like animals. The matching process can be broken, or never occur, when the resource becomes no longer available (car breaking down) or is not available (access to Internet). Access to these resources can be precarious and unreliable (Boniface et al 2015). Importantly, people living with an LTC, or multi-morbidity, may be most in need of requiring such resources but least able to achieve these (Campbell 2020).

6.8 Building social ties: when mis-matches occur

When enquiring about sources of support for self-management assumptions might be made about the contribution of close family members such as a spouse, partner or children, for example that these actors would be helpful providers of self-management support. However, in line with a range of evidence (Vassilev et al 2013, 2016, 2019, Allen et al 2020) tie-building for self-management support with family members was described by some participants as problematic, to the extent that support that might be expected from family was not or could not be provided. Shumaker & Brownell (1984) suggest that matching of the ego’s support wants with support provision may fail when the expected providers of support are unable to empathise, unable to ‘read’ requests for support, unwilling or unable to provide the requested support or do not conform to what the recipient wants. In terms of the grounds for tie-matching, a lack of empathy would inhibit affinity-building, support not being provided would not yield utility and a reluctance to conform to what the ego wanted could detrimentally impact affinity, utility and reliability. In the data examples below it seems that the ego’s expectations for a family tie did not match with the support received, or the wanted support was not made available, bringing about an incongruity in perceptions for the ego. Considering family ties, it is likely that a temporal factor existed in that the ego’s experiences with the tie were likely to have occurred over many years. Also, potentially, it could be that the *ego* was unwilling or unable to communicate their support needs (Shumaker & Brownell 1984). However temporal factors and how the ego was perceived by alters have not been examined within this study.

Four participants are discussed below, providing examples of family ties which did not meet the ego’s expectations for self-management support.

6.8.1 Participant 21M

On his network diagram (section 6.3.2) P21M placed his wife in circle three and his sister in circle one. He recognised that not putting his wife in circle one was unusual, he stated:

> P21M *I know it sounds silly her coming last but that's the way innit* [laughs] (….) *That's my wife in the outer circle*

It seemed that, in terms of the support he received with self-management, his wife 'came last'. He had been a carer for his wife for more than five years and he explained that:

> P21M *Yeah I mean we'll discuss things to a certain point but um she wouldn't talk about anything intimate but neither do I y'know which is strange when you're married (…) but it's just something we don't do y'know I suppose if I had a real sort of intimate problem I'd have to tell her but y'know she helps me sort of morally* [sic morale-wise] *y'know and uh we get on quite well I wouldn't say we're the best of friends sort of thing you know we have our ups and downs but uh most of the time we get on great*

As he reflected on their relationship, he identified that, even though he was a carer for his wife, they did not talk about 'intimate' things but most of the time did 'get on great'. It seemed that incongruities had arisen in their relationship, that he expected to be 'intimate' and 'best of friends' with his wife but this was not the situation they found themselves in. Potentially his wife, requiring support herself, was unable to support him with his LTC, or he did not wish to burden his wife. He also lacked a relationship with and support from his children:

> P21M *Yeah I've got three* [children] *they're all horrible* [laughs] *but that's by the by*
>
> Interviewer *Yeh I was about to say they're not on there are they* [social network diagram]
>
> P21M *No that's okay I wouldn't let the kids know*

It appeared that he would not discuss health problems with his children and that his children were not very present in his life. His sister was placed in the inner circle of his network diagram and when asked how his sister helped him to manage his LTC he replied:

> P21M *Um, I'd say it's more, more the common sense umm she's quite, well she's very intelligent compared to me she'd tell you the common-sense side of things (…) I could tell her anything and it's not a problem and she'll give me her honest opinion or if not she'll actually look it up herself (…) there's not many people that I can actually unload to apart from me sister*

His sister was the only person *'*I can unload to' and their weekly meetings where they could discuss 'anything' were very important to him; for him his sister was a major support for his health, and a full match in terms of affinity, utility and reliability. His sister perhaps helped him to self-manage *and* to cope with caring for his wife and had subsequently become the most important social tie for him.

6.8.2 Participant 18M

P18M placed his wife in the first circle of his personal social network for self-management support explaining:

> P18M …*she's the one who basically keeps me on my toes so and tells me, "right, OK have you taken this, have you taken that?"*

However when it came to emotional support P18M felt that his friends understood him better than his wife:

> P18M *Yeah… mmmm… emotional support, right I…I.. my wife I struggle with I know this is a bit* [pause] *emotional support, I mean I can talk with my wife obviously about personal things and things like that, but* [pause] *I think I'd rather offload it on a mate then* [pause] *I do talk to my wife but I feel like I've got a for me anyway my my mate or a man would understand where I'm coming from more (…) I've got mates who are really close, that I could, well I say mates, a couple of mates who I'd be prepared to… bare all so*

It appeared that his mates responded to him in a way which encouraged him to 'offload' and 'bare all' and this was helpful for him. He explained that:

> P18M …*with my wife, I can't, we never talk about sports injuries or anything like that she's lived with it (…) with a man you miss the camaraderie of (…) men, just around chatting, banter, things like that, so maybe that's the reason my wife is saying "you're an old man what are you still playing sport for?" I like the team, I like the team*

It seemed his wife lacked empathy with his love of sport and the 'camaraderie' that brought him, meaning there was a lack of affinity on occasion. It was perhaps helpful that he could rely on his wife for certain types of support, that is, utility, and had mates who 'understood where he was coming from', and whom he had affinity with, when he required emotional support.

6.8.3 Participant 22M

When discussing sources of emotional support P22M explained:

> P22M ….*I don't really get emotional support from anybody really, I do it all myself… my partner's not very…umm I don't know how to put it….she could live in a room on her own and she wouldn't care, so she's not very… lovable or whatever you call it um but I've always (pause) we've been together twenty-four years I've got used to it now* [laughs]

For P22M there was a recognition of the incongruity in the relationship he had with his partner, he did not get the emotional support from her that he hoped for or expected, however he accepted this as a function of her personality and had ‘got used to it now’. In interview two he explained a bit more about their relationship:

> P22M *she’s my carer as well so she, she has to make me take my tablets (…) I say (…) “you might pick up another fella” (…) cos I’m 16 years older than her she’s t’riffic she is really*

He appreciated the instrumental support his partner provided and he showed some concern that she might find someone else. P22M had a complicated relationship history, had been unable to have children himself and did not see his stepchildren:

> P22M …*but I don’t see any of them* [stepchildren] *when I was married we split up and then she said, that as far as she was concerned I was dead (…) and err stopped me seeing the children (…) I think she* [daughter of first partner] *stopped seeing me because of him* [her brother] *that’s what I reckon happened I might be wrong but I’m not bothered ‘cos she was quite a problem when I was in contact with her*

His current life, in a different area from that he had grown up in, and with his partner, had perhaps provided some stability and an opportunity to (literally) move away from past difficulties. Despite her lack of empathy his partner was ‘t’riffic’ and, with her input, P22M was able to get some of his LTC support needs met.

6.8.4 Participant 10F

Several participants stated that ‘nagging’ was not helpful and this often came from close ties, such as wives, in-laws or parents, which meant that it was difficult to avoid. P10F explained about her father:

> P10F *He’ll go to the hospital and doctor’s and that he’ll help me out he nags me and makes sure I eat properly when he sees me like dad’s do*
>
> Interviewer *So what do you think about him nagging?*
>
> P10F *He’s a pain in the you know what some days*
>
> Interviewer *So is that helpful to you to be nagged?*
>
> P10F *Not always it wears you down that, not all the time*
>
> Interviewer *Does it make you feel a bit bad?*
>
> P10F *Yeah gets me down at times*

P10F recognised that her father was trying to help her but she found some of the ways he did this exhausting and unhelpful leading to incongruity in her perceptions of his support. Nagging detrimentally impacted the affinity between herself and her father and ultimately did not achieve a practical purpose.

The three male participants described their wives (or partner) as not always providing the type of support they felt they required for managing their LTC. P10F too described some of the support her father provided as helpful but she found his nagging to be tiring. There is tentative evidence that in these types of circumstance, despite some aspects of utility or affinity with the other person, there can be a mis-match in terms of the support the ego expected and wanted and what the alter provided.

6.9 Building social ties: a summary

Azarian (2010) suggests that social tie building through grounds of affinity, utility and reliability are more helpful than typologies of tie direction, strength and frequency as her basis for matching provides an explicit and yet flexible foundation for social tie constitution. Importantly the basis enables matching through three different mechanisms whereas other typology descriptors match through one factor, such as type of support provided. As another example, Rogers et al (2014) define *strong* ties as those placed in the inner circle of a network diagram and *weak* ties as those in the outer circle. They note however that, '…weak tie connections were conflated with stronger ones that people were dissatisfied with.' (Rogers et al 2014 p10). Here the language implies a perhaps general understanding that certain connections, e.g. health professionals and spouses, are 'strongly tied' to self-management support because they are experts (HCPs) and available (spouses). Nevertheless, the positioning of a supporter is not just a product of the *role* of a supporter but how the ego *feels* about the supporter and their expectations of what the supporter should or could contribute. In agreement with Rogers' et al (2014) therefore, the strength of a tie cannot be assumed from the supporter's social position or role however, the binary description of either weak or strong ties does not fully illuminate social tie relationships. My supposition from Azarian's (2010) work is that the phenomenon of strong and weak ties (Granovetter 1973, Rogers et al 2014, Small & Sukhu 2016, Vassilev et al 2016) can be explained in terms of social tie matching. A strong tie could be one in which there is affinity - for example a husband or wife relationship - but there may not be utility in the tie, for example the partner may not understand that someone living with diabetes requires a specific diet and may provide inappropriate meals. A weak tie could be one in which there may be utility, for example a taxi driver who takes the person to their health-related appointments, but no requirement for affinity. Azarian's three grounds for social tie building are helpful for explaining the basis for weak and strong tie formation.

Sections 6.4 – 6.8 have presented and discussed examples of the grounds for social tie building, that is, the process whereby an ego seeks to gain a match for their support wants with the support perceived as available (Shumaker & Brownell 1984, Thoits 2011). When living with an LTC and requiring support with self-management, building social ties is a balancing act requiring careful choice of who to draw upon for support (Vassilev et al 2014). It has been possible to infer from the research findings that there is some confirmation of the proposition that a match occurs and ties are built when an ego perceives affinity, utility and/or reliability with an alter. The ego will search for affinity with an alter, that is, expect or hope for a tie with someone (or something) with whom they have something in common and who they like (Thoits 2011, Gage 2013, Grace 2020). The findings revealed that, when requiring support with managing an LTC, experientially similar others were appropriate and relevant in this respect (sections 6.5, 6.6). Utility, a practical purpose, will be sought and this could comprise emotional, instrumental, decisional or informational support for self-management (Thoits 2011, Morris et al 2015). There are indications in the findings that the club setting was of relevance in this aspect as the context provided a safe environment for the exchange of different types of support, particularly informational support (section 6.4). The third ground for tie building is the perception of reliability and there is tentative evidence that similar others were viewed as reliable; however the nature of the data does not enable confirmation and further investigation of this aspect is required.

While the ego's perceptions of the support they might receive was important for social tie building the ego was also required to find ways to negotiate support from the alters with whom they came in to contact (Thoits 2011); for example, they may have wished to ignore others that they deemed as unhelpful. Three tactics for negotiating social ties were identified from the research data and are discussed in the following section.

6.10 Negotiating social ties: three tactics

This section presents novel findings for personal social networks in that it explores ways in which participants used different tactics to either build or re-buff social ties and therefore manage their network. Presented here are three tactics which participants applied when negotiating social ties for self-management support. Participants explained ways in which they ignored or avoided some people, particularly those they deemed as 'unhelpful'. Secondly, as people living with an LTC they knew from their own experience that advice from similar others was helpful (see sections 5.6.5 and 6.6) and understood that they could be sources of information but a few participants showed reluctance to do so and providing information support or ‘giving advice’ was a nuanced process. Finally, the discussion below presents how some participants used humour to negotiate and build ties with potential supporters.

6.10.1 Ignoring unhelpful others

Participants did have tactics for managing unhelpful others, those they perhaps lacked affinity with. When asked about unhelpful others P1F explained:

> P1F *I wouldn’t speak to them, I wouldn’t tell them anything, I wouldn’t bother, if they struck me as being like that* [unhelpful] *I wouldn’t go to them for advice anyway.*

P1F seemed to make a judgement about who would, or would not, be helpful and for those she deemed as unhelpful she used a variety of tactics to avoid or ignore them. P2F also described the way she dealt with people she deemed as unhelpful or unreliable:

> P2F *…. sometimes I, if certain people give me information then…* [she shrugged and turned away]

Her body language showed how she would respond by physically turning her back and ignoring the person, perhaps attempting to demonstrate her lack of affinity with them.

P4M, as explained in Chapter 5 (section 5.6.4), rated experts as the best source of health information and he had a slightly different ‘ignoring’ tactic, explaining:

> P4M *… the advice they are trying to give is not very good and I just let it, take it in, yeah okay fine but certainly wouldn’t act on it*

It seemed that he would politely listen and then ignore the information by not acting on it. He later explained his tactics in more depth:

> P4M *I don’t discuss things with other people or whatever….. I just, umm I don’t suffer fools gladly, if that makes sense and so when you meet people or you talk to them or whatever you form an opinion and some you are just on nodding acquaintance with and others you sit down and have a chat to, you know.*
>
> Interviewer *So, you kind of make your own decisions about who you are going to listen to and who you are going to, just kind of be polite to?*
>
> P4M *Yeah, exactly, yeah, yep.*

It was important to P4M to have reliable, preferably expert sources of help. With those he deemed as ‘fools’ he was polite, that is showed some affinity, but he judged them as unreliable sources and therefore not of utility to him.

These participants described a range of tactics for ignoring the input of those they deemed as unhelpful, that is, lacking utility for self-management support. The participants resisted the building of affinity through ignoring or not talking to unhelpful others or showed polite behaviour but then ignored the advice, having deemed it as unreliable.

6.10.2 Giving advice to similar others

The benefit to self-management of acquiring information and ideas from similar others has already been noted (see sections 5.6.5 and 6.5), with several of the participants discussing the affinity and utility they gained from similar others. When asked about giving advice to others who were self-managing an LTC the participants gave responses which acknowledged that 'giving advice' was a nuanced process.

Some participants spoke about their reticence to give health advice, for example:

> P13F *If I knew yes, if I knew obviously if I didn't know then I wouldn't, I wouldn't give someone advice what I didn't know on, so I would look it up for myself think people should go to the proper people don't they* [laughs]

P13F was concerned about her level of knowledge and would only provide advice that she 'knew'. P22M was also concerned about his understanding of health information, particularly 'medical advice':

> P21M *if I understand it meself or I've been through it then yeah you know we talk about prostate cancer and that y'know "ooh what are you on and what do you do?" and this that and the other and diabetes y'know but uh only if I understand it myself, I wouldn't want to give somebody sort of medical advice if I didn't know* [chuckles]

P22M recognised that discussing experiences, 'I've been through it', and medications with similar others was helpful but drew a line at giving 'medical advice'.

P20M understood that the way in which advice was provided could be important, he explained:

> P20M … *I let them talk and I mean who am I to give them advice there's no point in me doing that is there?* (...) *I'm not one to sort of dictate what I consider they should be doing 'cos it's their life after all's said and done, though I don't object to people saying to me "oh you wanna try so and so and so and so"* (…) *who am I to tell them what they should be doing?*

P20M realised that 'dictating' and 'telling' was ultimately unhelpful. P19M also appreciated that advice-giving had its limits explaining:

> P19M [I] *direct people to where they can go then what they do with it is up to them*

P19M recognised the autonomy of others to ultimately make their own decisions and be responsible for their own actions.

A few participants had developed specific tactics for giving advice. P18M, who worked in a community club and for whom part of his role included working with others to promote their health and well-being stated:

> P18M ***I** would say go to the GP* (…) *I might recommend things that worked for me* (…) *my advice might not work for others*.

P18M ensured that any advice he gave was reliable by recommending someone see their GP, he did understand the benefit of sharing tactics that had 'worked' for him and he appreciated that his advice 'might not work for others.'

As explained in section 6.6 P6M took a technical approach to managing his diabetes and he co-ordinated a self-help group within the club. His tactic was:

> P6M *I'd always try* [to] *give, not medical advice, but just what's happened to me*

He understood the limits of his expertise and favoured an approach which enabled him to provide information while emphasising that it was his experience. The way in which participants gave advice to others appeared to be an outcome of insight in to their own situation, that they did not know everything and were not medical experts and had an appreciation that what worked for them may not work for others. The participants showed some understanding of how affinity might be built, or broken, dependent on the way they spoke to others. P20M understood that 'dictating' what people should do was not helpful, although he found it helpful himself to hear other's ideas. P6M and P18M appreciated that discussing their LTC experiences and 'what had worked' for them was a useful tactic; possibly because doing so built affinity with recipients, provided utility and could be deemed as reliable as it was delivered by a similar other.

6.10.3 Use of humour

While interviewing I noticed that participants would sometimes laugh after saying something negative or difficult. These utterances were indicated in the transcriptions by the use of (laughs) next to the statement, categorised during data analysis as 'the use of humour' and, in the data extracts shown below by the inclusion of an exclamation mark. There is some evidence for humour being important for social functions and coping (Martin & Ford 2018) and for facilitating learning (Savage et al 2017), meaning that humour could be used as a tactic for self-management of a long-term condition.

Martin et al (2003) proposed four classifications of humour styles, two of which can be understood as benign and two as injurious. The two benign forms are the use of humour to enhance self, self-enhancing humour, and humour to enhance one's relationships with others, affiliative humour. Self-enhancing humour is thought to be a means of relieving tension, asserting one's feelings of control and building courage and Martin et al (2003) suggest that an affiliative use of humour can build a social network through reducing conflict and strengthening ties. The two injurious forms of humour are defined by Martin et al (2003) as: aggressive, which is the use of humour at the expense of others; and self-defeating, being the use of humour at the expense of oneself.

Affiliative humour was used by some participants to elicit support from others, a kind of jokey way of asking for help, which resulted in making the request but either down-playing the need for help or exaggerating the need for help in a humorous way. The language used showed that, while to some extent they put themselves down, they also appreciated others trying to understand their difficult situation:

> P1F …. *sometimes I have to phone her* [daughter] *up and say, 'can you drive because it's either that or I'll kill you all!'*, [when too tired to drive]
>
> P2F *my grandchildren say, 'I'll help you up Nanny'!*
>
> P3F *I can't be suicidal with this crazy lot in my groups!*
>
> P17M *my wife thinks it's a ploy for getting out of things!* [extreme tiredness]
>
> P19M *my wife takes stuff in;* [for me] *it goes in one ear and out the other!*

These participants used humorous statements which put themselves in a negative light but also reflected the fact that managing an LTC was difficult and they required others to help and understand them. With this approach participants were perhaps attempting to make light of their own difficulties while acknowledging the support of others to do things as, 'silly me, I need others to help me'. This was potentially a way to build affinity with social ties and is supported by Martin & Ford's (2018) premise that self-deprecation can enable a demonstration of modesty which helps to ingratiate oneself with a listener. Self-deprecation in the circumstances above may be leading to laughter because it accentuates the incongruity of a situation and the self-deprecation, rather than being injurious to the ego, was used to elicit sympathy and affinity from ties. The humorous statements above reflected self-deprecation and incongruity and yet built affiliations with others so potentially the humorous communication approach strengthened ties.

The use of humour by some of the male participants came across as affiliative, that is an attempt to build affinity, *and* mildly aggressive:

> P9M *I love's to help people – they may not want it but I love to do it!*

> P18M *others help me but I like to take the credit when it goes well!*

Despite to some extent belittling others with their humour P9M and P18M were at the same time able to recognise the importance of others: 'I love's to help others' and 'others help me'. While talking about support, two other male participants explained:

> P14M … *my mate says, 'I'm glad I phoned you* [for support]*', I says, 'I'm not, what you's done is abuse me!*

> P22M *we wind each other up* [at the club] *and nobody takes any notice!*

For some men their approach to supporting each other did appear to be somewhat combative, however there was some confirmation that this approach was acceptable to other men. As previously discussed in section 6.4.1 the male participants talked about the club as being like a 'work's canteen':

> P19M *ermm the way I've described this place is it's like the works canteen without the work*

The use of humour within the men's club seemed to be important, P21M emphasised that:

> P21M *I'd recommend* [the club] *to anyone – as long as they have a sense of humour! You've got to have a very good sense of humour.*

This seemed to be because, in the 'work's canteen', as P21M explains below, it was important that people could have a laugh, a joke:

> P21M *if you've ever worked in a warehouse, right, and you go into the canteen and everybody is having a laugh and a joke and they're talking about anything that's what it's like here y'know in like the social side of it and um y'know I mean I could go down and tell 'em anything*

The club perhaps provided the men with an opportunity to use humour in a more extreme way than they would do in other contexts, but it was used to generate camaraderie rather than hostility and facilitated discussion of difficult subjects in a way that was acceptable to the men. The humour, albeit mildly aggressive at times, enabled creation of a context where it was acceptable to 'talk about anything' and thereby get support from others.

6.11 Chapter conclusion

Mapping participant's personal social networks for self-management of an LTC has, in common with other studies (Vassilev et al 2013, Vassilev et al 2016), enabled categorisation of networks according to size; size being determined by the number of supporters or resources and the frequency of seeing or using the support. Taking in to consideration the score for the network size and structure of the social network diagram it was possible to gauge whether an ego drew on a very small, small, moderate or extensive personal social network for LTC self-management. All the participants drew on support from their network to a greater or lesser extent and one important observation from the data findings is that participants did not have to be health literate to leverage social network support. The fact that participants were attending a community club also appeared significant for this finding. As Jeffries et al (2015) and Kelly et al (2019) suggest, the clubs provided a context for social interaction – and provided access to a range of social bond opportunities.

Azarian's (2010) grounds for social tie development as comprising ego's perceptions of affinity, utility and reliability with alters has been applied to the data and has been found to have value for understanding how and why egos have drawn on specific supporters. Experientially similar others were particularly helpful self-management supports for the participants, particularly if the other was a partner or relative, which was the case for P19M. He had affinity with his wife, found that her suggestions and support had utility and he deemed her a reliable source of support who '*pushed him along*' with managing his conditions.

The clubs created an atmosphere of friendship and provided the opportunity for talking with others. This enabled the participants to build affinity and gain utility, if they wished, from the emotional, instrumental and informational social capital within the club. The clubs were sources of similar others and participants were aware that they could talk about their condition at the club, enabling them to gain tips and ideas for managing.

Ego's perceptions of affinity, utility and reliability also helped to explain why resources such as pets, cars and the Internet were valued by some participants. Those who gained utility from the resource valued these resources. With pets affinity and reliability was important, participants reported enjoying the companionship and affection of pets. Reliability, or lack of it, was an important factor with cars, the unavailability of a car could seriously impact participant's ability to socialise with supporters.

The findings have provided some examples of family ties which did not meet the ego's expectations for self-management support. It is possible that, for some aspects of support, family members do not bring utility, meaning that the ego finds the support unhelpful or seeks support from other alters. In addition there is the possibility that, with family members for example, the alter is liked but some of the support they provide is not liked. In other words, there is affinity with the alter but no affinity with some aspects of the support they provide. The grounds for mis-matches, particularly when an ego might expect a match for support to be made, for example with their wife, warrants further investigation.

A novel finding is that three tactics for negotiating social ties have been identified within the data. Firstly, there is some indication that the tactic of ignoring others occurs when the ego perceives the other as unhelpful, perhaps as a result of not feeling affinity. The participants talked about ignoring others who gave unreliable or unacceptable advice. Secondly, the tactic of giving advice to similar others appeared to be important for some participants who recognised that advice from similar others was helpful for them so could be helpful if they provided it to others. Some participants were reluctant to provide advice to others. This could be because they perceived that advice about an LTC should be provided by '*the proper people*', that is HCPs, and they wanted to prevent harm. Reluctance to provide advice could also be linked to their health literacy skill ability or their own confidence (or lack) with LTC self-management. These propositions require further study. The third tactic, the use of humour, allowed participants to recognise their helplessness or difficult situation, generate an incongruity and therefore humour, and garner support from others. Men used mildly aggressive humour but this appeared to be acceptable, and perhaps even expected, in the male environment of the Men's Shed.

Empowerment is viewed in this thesis as a transformational, social process which facilitates an individual's health-related goals (Mok 2001) and it is pertinent here to consider whether the social opportunities the participant's experienced, that is the clubs, enabled empowerment. There were many examples within the data of participants gaining health-related and personal benefit from club membership. P3F, as the co-ordinator of the Crochet Club, was enabled to provide and receive instrumental support and she found that organising the club took her mind away from her health difficulties and chronic pain. For one participant, P6M, the club provided an opportunity to support similar others to manage their diabetes, which he enjoyed doing and reinforced his view of himself as something of a technical expert in managing his condition. The club provided a social context for the sharing and providing of a range of support for club members, including instrumental, emotional and informational support for self-management of LTCs. However, at times the power of the club context went beyond the social process, the club enabled transformation of participant's beliefs and perceptions. P3F's experience typifies what Mok (2001) discusses as the benefit of participating and being connected, which gives a person responsibilities and commitments to meet but also generates purpose and meaning in one's life.

The experience of P6M illustrates Mok et al's (2004) proposition that power arises from the ability to do things, rather than from exerting control over others: I observed men willingly join P6M's 'living with diabetes' group. Importantly the club situation enabled participants to view circumstances from a new perspective, that is, other's perspectives, this opened their minds to new ways of thinking and acting. The finding of a new perspective bringing empowerment was illustrated and encapsulated by a comment from P19M:

> P19M … *downstairs it's relaxed, chilled out, you got your cup of tea or coffee or whatever and topics will generally come up about all sorts of different things but if you've got something that you're not sure of you can just sort of chuck it in as a "this is happening" or "that's happening, what do you lot think?" and take on board some of the umm responses people give you, sometimes "I dunno really" or some people it might be a bit more in-depth and they'll say whatever and other people might know of other places you can look up for information about different things that you haven't thought of*
>
> Interviewer *Yep so is it having those other ideas that is helpful?*
>
> P19M *Yeah, it's like having a physical Google.*
>
> Interviewer *Yes [laughs]*
>
> P19M *It's like so you can just ask*

Chapter 7 Discussion and conclusions

7.1 Introduction

This chapter provides critical discussion and synthesis of the study findings in relation to existing literature, summarises the novel findings within this thesis, explores the study strengths and limitations and sets out potential future work. The conclusions address the overarching research question, aims and specific research questions as listed below, and evaluate the findings in terms of the potential application to healthcare professional practice. It should be noted that the two aspects of health literacy skills and personal social networks have been discussed in separate sections for ease of reading, although the aim is to also give a sense of the, sometimes inextricable, interconnections between the two aspects.

Overarching research question:

> How do health literacy skills and a social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills?

Aim 1: To identify how health literacy skills contribute to the process of long-term condition self-management for the participants.

> HL 1. What is the level of health literacy ability (e.g. functional, applied or critical) for each participant, as quantified by health literacy ability questions?
>
> HL 2. What are the barriers and facilitators to using health information for self-management when an individual's health literacy skills are limited?
>
> HL 3. If an individual's HL skills are limited, what other tactics do people use to acquire information?
>
> HL 4. How do health literacy skills contribute to empowerment for an individual?

Aim 2: To identify how a personal social network contributes to the process of long term condition self-management for the participants.

> SN 1. What is the structure and size of the social network for each participant, as measured by the concentric circle mapping?
>
> SN 2. How are social ties for long-term condition self-management built?
>
> SN 3. How are social ties for long-term condition self-management negotiated?
>
> SN 4. How does a personal social network contribute to empowerment for an individual?

7.2 Thesis novel findings

7.2.1 Self-management of a long-term condition

Self-management of a long-term condition has been positioned within this thesis as a health behaviour, in that self-management requires the undertaking of activities to prevent or detect disease, to use health services and to improve health and wellbeing (Conner & Norman 2015). The study focus has been on understanding how individuals undertake self-management but the conceptualisation of self-management as an everyday activity has enabled elucidation of the impact of different contexts, such as being at home or being at a community club, on the process. The self-management process described by participants has not just comprised the decisions and behaviours they undertook but has also included description of the contribution of social and community factors. In Chapter 1 section 1.2.1 and Chapter 2 section 2.4 it was posited that, if people live with an LTC and experience a low level of health literacy skills, and other difficult circumstances, then their personal social network will be important for enabling them to manage their condition. This section draws on a social cognition approach to health behaviours, specifically LTC self-management behaviours, to elucidate potential pathways of action for health literacy skills and personal social networks which maintain or enhance health status.

Models which describe and predict health behaviours are collectively known as social cognitive models (SCMs) and can help us understand why people behave the way they do, enable us to understand the barriers to behaviour change and, ultimately, ensure interventions promote successful behaviour change to improve health (Conner & Norman 2015). Social cognitive models attempt to explain how people make sense of their social situation, how they perceive stimuli and why they respond in particular ways. Some SCMs are critiqued for their emphasis on intention and lack of explanation of how intentions are actioned (Schwarzer 2014). As to self-manage their health people are required to perceive their environment (including their own body), make sense of what they perceive, *and* act, both motivation and volition are important. Furthermore, SCMs are generally designed to explain one specific behaviour change, whereas LTC self-management requires multiple and on-going perceptions and responses (Wyke et al 2013). Many SCMs focus on the individual and lack elucidation of the contribution of supporters and resources (Wyke et al 2013, Green et al 2015). In summary, understanding the cognitions contributing to a health behaviour change are helpful however there is potential to integrate the psychological and sociological aspects of self-management.

Wyke et al (2013) suggest that illness-response models are predicated on understanding the perceptions, decisions and actions of illness behaviours as an iterative process occurring in everyday life. Accordingly the Wyke et al (2013) integrated symptom-response model has been developed from three preceding symptom-response models and primarily aims to explain consultation and illness behaviour. Their model proposes that three components contribute to an individual's ability to interpret, evaluate and action illness activities. These include the 'embodied state', that is, the symptoms or signs that are noticed; the 'resources' available and the 'knowledge' of the individual. The three components are reciprocally impacted by the individual's social structure, culture and interaction. This model is helpful for positioning illness management (or health management) within everyday situations and as an ongoing process, while also explaining the cognitions required. When considering how people undertake self-management of an LTC there is utility to be gained from combining aspects of illness behaviour models and social cognitive models and incorporating and comparing these with the rich descriptions of LTC self-management that the participants provided.

A model of LTC self-management has been developed which aims to set out the process of self-management and the position and role of health literacy skills and a personal social network within the process. The development of the model is a work in progress but nevertheless is presented here to aid understanding of the preceding discussion sections. The model is presented in Figure 12.

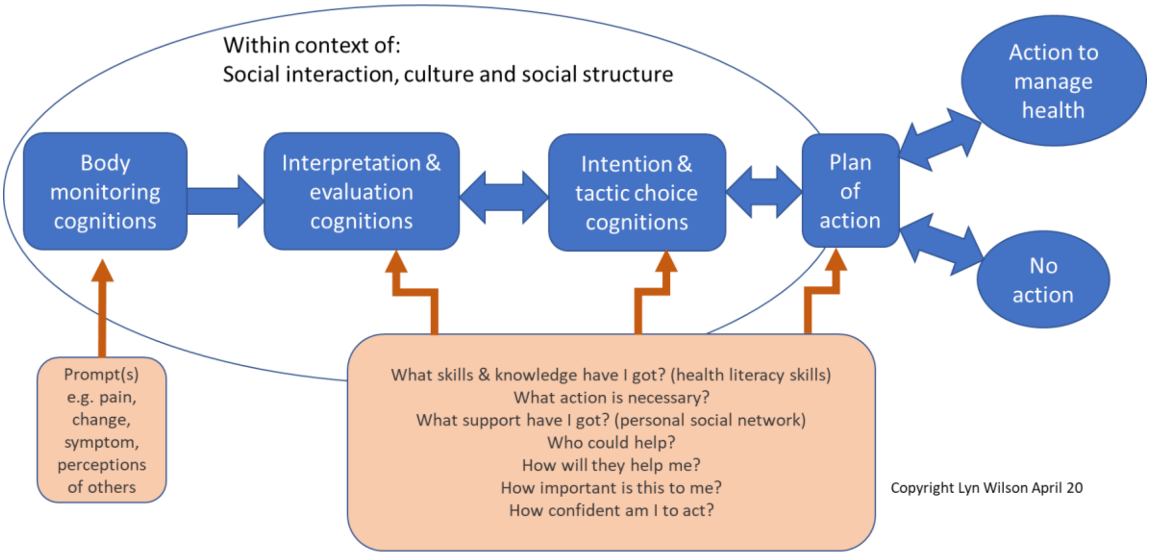

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Figure 12 Model to represent self-management of a long-term condition

The long-term condition self-management model in Figure 12 specifies four stages to cognitions for self-management: body monitoring, interpretation and evaluation, intention and tactic choice and preparing a plan of action (or inaction). The model also indicates the contribution of skills, potential resources and supporters, and motivation and recognises that self-management occurs within social structures and interaction.

Body monitoring (Wyke et al 2013, Riegel et al 2018) is the noticing of feelings, changes in health such as blood glucose levels, and symptoms of poor health, for instance pain or fatigue. In some cases the prompt could be another person, for example several participants discussed being prompted by others to take their medication. Participants were asked about their responses to prompts, including changes in their health, however these findings are not reported here. The focus for this thesis has been on the process that occurs once a prompt has been noticed, that is, the process of interpreting and evaluating the prompt, making decisions about what could be done (intention), and the selection of tactics to implement. These stages of the model are influenced by the individual's motivation for change, their level of health literacy skills, and the support available from a personal social network.

The second and third stages of the model point to a weighing-up of the prompt and a decision to undertake action or not. The weighing-up process incorporates consideration of whether the prompt is understood, which requires health knowledge and whether the person knows what to do and has the skills to act (Aaby 2020). Learning and knowledge from past experiences is likely to be important at this stage (Wyke et al 2013). A consideration of whether support for the action is available or required (Foot et al 2014, Vassilev et al 2016) is likely to occur. Finally, the individual will consider how important it is to undertake action and how confident they feel about undertaking specific actions (Miller & Rollnick 2013). The weighing-up process will lead to an assessment of the resources available, the actions required and, potentially, a plan for action. The importance of planning is drawn from current health behaviour approaches (Michie et al 2013) but is not discussed within this thesis. Ultimately a decision is made to not undertake the action or to undertake or partially undertake an action. As an example, if a person does not understand a prompt, has no support to interpret the prompt and understand the action required and is not motivated to undertake a change, then action is unlikely. Conversely, if a person does not understand a prompt but has a supporter with whom they can discuss the problem and possible action then they are more likely to understand the importance of change, have the confidence to change and be able to act. Importantly, the model aims to show that having a high level of health literacy skills (i.e. being health literate) can enable action but, in the absence of health literacy skills, a person's social network has the potential to 'fill the gap' and support understanding and, potentially, action. The model points to the major contribution of social context and supporters for enabling understanding of prompts and actions and for encouraging the building of importance to change and confidence to change. Having set out how the findings are influencing the development of a model to illustrate the cognitive pathways to self-management the following sections discuss the novel findings for the study and explore, in-depth, the role of health literacy skills and a social network within the process.

7.2.2 The role of health literacy skills

This thesis has recognised the importance of and investigated the contribution of health literacy skills to the process of long term condition self-management. The discussion in this section reiterates the thesis definition of health literacy skills, discusses examples of the three levels of health literacy skills as functional, applied and critical, and elucidates the tactics participants drew upon when living with low levels of health literacy skills. The novel aspects of defining the intermediate level of HL skills as applied (rather than interactive or communicative) and the requirement for translators of health information are presented, and the inextricability of the use of health literacy skills from social context is emphasised.

Contemporary definitions position *literacy* as a culturally situated practice that enables human learning to inform action (Hobbs 2016), hence the relevance of literacy for this thesis. Literacy can be understood as the sharing of meaning through symbols, such that people can become conversant in specific bodies of knowledge. Accordingly the term *literacy* is appended to many areas of practice; for example, authors variously discuss the existence of digital, legal, public health, emotional and health literacies. The implication then is that *being literate*, in a specific context, is the ability of a person to draw on the knowledge resources made available in the context (Barton et al 2007). Being literate in such circumstances enables benefit from opportunities to learn and, potentially, the capacity to challenge when expectations are not met; hence literacy is not just the ability to access resources but also a process enabling the opportunity to access resources. Literacy becomes political as social structures can prevent or facilitate literacy and, therefore, access to resources. It was pertinent to draw on Vygotsky (Karpov 2014), whose work encourages consideration of the role of identity, agency and social structure in literacy practice. That is, literacy occurs within social structures and shifts according to who we are and how we act and whether we have agency to act. A lack of literacy can lead to a lack of agency and vice versa. For example, where *health* literacy is the use of literacy skills in health contexts, possessing health literacy skills can enable access to health care services and health information and a lack of health literacy skills can lead to health inequalities (Nutbeam 2000). As managing a long term condition requires access to healthcare services and the ability to understand and apply health information, health literacy skills are key to self-management (Matarese et al 2018 and Figure 12).

This thesis suggest s that broader conceptualisations of *health literacy*, such as that of Sørensen et al (2012) or Osborne (2014), entail health promotion interventions that can mitigate or improve low health literacy skills. Confusion perhaps arises where the health literacy field conflate the health literacy skills of an individual with, arguably, health promotion interventions to ensure medical and health communication and health care services are health literacy friendly. I have posited *health literacy* as a process whereby *society* works to ensure populations (and ultimately individuals) become health literate *and* where health care organisations ensure access to health services is facilitated for people regardless of their health literacy skill level. The decision was made to avoid the use of the nebulous term *health literacy*, focus on individual's use of health information and use the term *health literacy skills*. Possessing health literacy skills enables a person to access and understand health information, where health information is health knowledge in a coded form and either written or spoken (Egan & Gajdamaschko 2003). Health literacy skills include the ability to: find and read health information, understand (or de-code) information, apply information to one's situation, judge the quality of information, and explain information to another person (Nutbeam 2008, Ishikawa et al 2008). Defining health literacy skills in this way facilitates an understanding of the importance of health literacy skills for LTC self-management; having health literacy skills enables a person living with an LTC to understand, apply and act on health information, to judge whether the information is trustworthy and help others to understand such information.

7.2.2.1 Health literacy skill levels

This thesis has aimed to comprehend the health literacy skill ability of the study participants, where ability level is defined as the degree to which an individual can obtain, understand and apply information required for health-related decisions and actions. The health literacy skill questions applied in interview one enabled categorisation of participants' levels of HL skills and a majority lived with a functional level of HL skills. The premise for *levels* of HL skills has been derived from Nutbeam (2008) and Ishikawa et al (2008) and there were some parallels with the skills, or difficulties, these authors posit as existing for people with low, or a functional level of, HL skills. Participants with a functional level of HL skills reported being able to read health information but also discussed not being able to understand or remember information and finding it difficult to apply information to their own situation and judge the quality of information. In line with Harbour & Grealish's (2018) review findings this study found that participants with functional HL skills were often aware of their literacy limitations and knew they should use trustworthy sources of health information. Nevertheless they found it difficult to judge what was trustworthy, positioned themselves as 'not looking' when asked where they found information and positioned HCPs as expert sources of information. However participants reported difficulties with navigating and gaining access to health care services, and relayed frustration with not being able to just ring and ask questions; or having consultations but leaving with uncertainties and a lack of confidence about what to do and when. Some participants explained away their literacy difficulties as their standpoint of 'not looking' for information and not being 'savvy', a finding also noted by Harbour & Grealish (2018). Importantly some participants recognised that others lived with the same problems and difficulties, and this narrative supported their situation and occasionally assisted them to gain helpful information and potential actions they too could undertake. The importance of others, particularly similar others, with informational support is discussed later following an analysis of some characteristics of participants living with applied and critical levels of HL skills.

A novel aspect of this work is the proposition that the intermediate level of HL skills should be termed *applied* rather than interactive or communicative. The terms interactive and communicative (Nutbeam 2008, Ishikawa et al 2008) have been argued to imply the use of oracy skills which, unlike literacy skills, are learnt through experience rather than taught (Nation 2006). Taken literally skills of *interacting* and *communicating* could be judged as essential basic skills required for a functional level of health literacy. Rather than communicating or interacting with others this thesis argues that the important skill, beyond a functional level of proficiency, is rendering the application of new information to a range of situations or changing circumstances. Furthermore, the term *applied* enables relation to Bloom's taxonomy of learning (Heick 2020) which posits intermediate levels of learning as requiring skills of application and analysis. Participants identified as living with an applied level of HL skills were confident with using a range of information sources and had tactics to deal with situations where they needed more information to support their self-management actions, P15M for example asked a pharmacist (section 5.4.3). Comparable findings were reported by Johnson et al (2010) who found that, when using pharmacists, people with low levels of HL were unlikely to ask questions whereas people with adequate levels of HL felt it was their responsibility to ask questions and clarify their medication requirements. Understanding the tactics of people with an applied level of HL skills has the potential to aid illumination of ways to support and encourage people with functional HL skills to boost their health literacy skill level and, potentially, improve their management of their LTC. For example, encouraging people to ask questions about their treatment regime is a tactic that HCPs can undertake (Harbour & Grealish 2018). Further recommendations for HCPs are discussed in section 7.3.

The study findings indicated that participants with applied HL skills had a wider range of skills than participants deemed to live with functional levels of skills, but fewer skills than participants deemed to experience critical levels of HL skills. The three participants, P8M, P16M and P17M, experiencing critical HL skills described searching for, reading and understanding information and judging the quality and reliability of information. These skills enabled them to build their knowledge and confidence to make informed choices and decisions. Importantly, they would ask questions to facilitate their understanding of medical and health information drawn from a range of sources. In this way these participants were empowered to make decisions about their health, including decisions to reject advice or treatments. As Zimmerman (1995), Nutbeam (2008) and Laverack (2016) posit, critical health literacy skills enabled a level of health knowledge such that P8M and P17M, in particular, expressed feelings of agency, awareness of the context for their health status and were ultimately able to maintain control of their health.

7.2.2.2 Using health literacy skills in context

For participants experiencing functional levels of health literacy skills not understanding information was a potential barrier to becoming informed and empowered. Additionally, participant’s ability to understand and remember information was sometimes exacerbated by their health condition (section 5.5.2). A key finding though was that some participants actively worked to mitigate a lack of knowledge through applying other tactics for obtaining and understanding information. Through attempting to clarify their tactics a novel elucidation from the findings was that participants, particularly those with a low level of HL skills, required support to de-code information; they required *translators*, that is, a mechanism by which complex health information was modified, simplified and presented to them in a way which they *could* understand. Participants did make efforts to become ‘savvy’ by drawing on translators, where translators could comprise other people: such as a partner, HCP or a similar other; or digital technologies. Samerski (2019) argues that discussions of health care usage in the context of health literacy ability should acknowledge the efforts that people undertake to become knowledgeable, particularly their efforts to collaborate with others. The study participants were recruited from community clubs, which provided interactions with others and opportunities to collaborate. The importance of being social raises the point that people who are isolated may struggle to locate translators and could benefit from referral to opportunities to meet with others and opportunities to learn how to use digital technologies. Further investigation could elucidate how people with functional HL skills can be encouraged to access and use translators, particularly in the context of LTC self-management.

One final finding reiterates the embeddedness of health literacy skills within social structures. A popular tactic - for all participants not just those with low HL skills - was drawing on informational *support*; that is, support from others to find, understand and use health information (Thoits 2011). This was sometimes facilitated for participants through being members of a community club and this aspect is discussed in more detail in the following section. The range of ways in which participants drew on informational support included: being guided by a spouse or partner, drawing on others as translators as discussed above, and comparison with similar others. All participants discussed becoming more informed about LTC self-management through drawing on, listening to and observing the experiences of similar others (section 5.6.5); a finding also noted by Gage (2013) and Grace (2020). Mok et al (2004) found that a lack of knowledge about a health condition could lead to fear and helplessness but sharing experiences with others in a similar position aided acceptance and understanding of illness. Study participants seemed to weigh up the advice and experiences of similar others, sometimes leading them to consider trying an action that had worked for others (sections 5.6.5 and 6.10.2). There is evidence that observing similar other's behaviour provides a relevant everyday context for recommendations that might be presented by health services as complex scientific or medical information (Shin & Sham 2019), and that talking with similar others enables translation of health information from scientific information to experiential knowledge (Karpov 2014). The potential for advice and support from similar others to boost knowledge and confidence for self-management actions is the premise for expert patient interventions (Francis et al 2019) however the capacity for people to gain such support through everyday interactions, particularly in social spaces, is worthy of further analysis.

The aim with this study has been not just to categorise each participant's HL skill ability but to elucidate from this tactics that people use to improve their health knowledge and mitigate the impact of low HL skills. These findings have enabled a burgeoning understanding of ways to support and encourage people, who are living with LTCs and a low level of HL skills, to gain access to information, understand and apply information to self-management. Gaining health information occurs in social contexts, accordingly the following section synthesises the finding for the role of personal social networks within LTC self-management. Section 7.2.4 presents conclusions for the overarching aim of understanding the role of HL skills *and* personal social networks to LTC self-management.

7.2.3 The role of personal social networks

The conceptualisation of a personal social network as comprising a person surrounded by supports and supporters has been applied within the study to elucidate how individuals draw on such resources to assist them with managing a long term condition (Thoits 2011). Diagramming of participant's social networks for LTC self-management support has been combined with narrative findings to understand who supports participants and to what extent; Framework analysis and theoretical abstraction has then been applied to enable elucidation of the mechanisms for social tie building and negotiation of social support. As Bellotti (2016) suggests, diagramming enabled participants to visualise and explain the contributions of alters to self-management and, during analysis, facilitated comparisons between participants.

In this study all participants drew on support for LTC self-management from a self-reported personal social network and networks ranged in size and complexity. For example, two participants with self-reported mild symptoms of arthritis drew on small networks (P11F, P18M) and two participants living with considerable disability drew on extensive networks (P3F, P5M). Diverse networks enable access to a wide range of resources and support (Vassilev et al 2016), however extensive networks may not always be easy to manage (Cattell 2001). P3Fs comments (section 6.3.5) reflected this dilemma and she discussed the balancing act (Vassilev et al 2014) of accepting and providing support to the many alters in her network. In contrast, P18M explained that he did not require much support with managing his LTC, and he recognised that, if necessary, he could draw on others for support. A concern however would be for people like P11F who, if she had not been a member of the Crochet Club, would have been quite isolated and, potentially, lonely. Vassilev et al (2016) note that people with restricted networks, that is, isolated people, may experience lower levels of health and higher levels of co-morbidity than people with diverse support networks. In follow-up research Vassilev et al (2019) found that a social network intervention which encouraged people to access community-based activities enabled the building of new relationships and gave people a wider range of support options. Cruwys et al (2019) posit the importance of social connectedness as a protective factor for health and in this study P11F described how joining the club had enabled her to manage bereavements and 'become herself' again. These findings reiterate the importance, to self-management of health, of access to community-based social opportunities.

7.2.3.1 The grounds for social tie building

The types of support social networks provide to people living with LTCs is well-researched (Bury 1991, Thoits 2011, Reeves et al 2014, Vassilev et al 2014) so the decision was made to focus on how participants built and negotiated social ties. As far as can be ascertained Azarian's (2010) basis for social tie building, which was applied in this study, has not been operationalised or used in previous studies, nevertheless Chapter 6 sets out findings which illustrate that the basis does have efficacy for explaining the grounds for social ties. Previous literature which has discussed ego's perceptions of social ties - and the aim to attain a match regarding support the ego wants and what the alter provides - includes Shumaker & Brownell (1984) and Thoits (2011). A more recent discussion of social networks and matching of response to need occurs in Aoun et al (2019) which considers bereavement support. Aoun et al (2019) note the important role of ego's perceptions of support but analyse their findings in terms of *what* is provided rather than *why* it is perceived to be helpful or not; that is, they do not consider the grounds for social tie building. This thesis posits that defining the grounds for ties enables an explanation of the dimensions for matching (or not) of ego's support wants with alter's support provision.

As critiqued in section 2.5.2 and 6.2, Azarian (2010) theorises the ego to consider perceptions of: affinity - whether the alter and/or the support provided is liked; utility – whether the support has a practical benefit; and reliability – whether the alter can be relied upon to provide the support in an acceptable way. A range of examples of social tie building, and the bases for these, have been presented in Chapter 6 and the three grounds appear sufficient to explain tie building in different circumstances and for different actions and requirements. The findings have explored social tie building with similar others, pets, cars and the Internet and found that ties are built because the support provided has utility, the ego perceives affinity with the support or supporter and perceives the alter as at least reasonably reliable. The occurrence of mis-matches of support has also been exemplified using the three grounds, and it appears that a lack of utility and/or a lack of affinity and reliability can lead to the ego perceiving the support offered as unhelpful or unwanted. This thesis posits that understanding tie building in this way enables explanation of incongruities in reported relationships. Several of the men, for example, discussed close, helpful relationships with their wives in some respects of LTC self-management and a distant or unhelpful relationship in other respects. It seemed that some of the self-management support provided or offered by their wives did not engender affinity and utility for the men (section 6.8).

Taking the *ego's* view of support wants and expectations across the three dimensions bypasses contradictions that may occur when explicating tie strength. For example, a *strong tie* (Granovetter 1973, Rogers et al 2014) could exist because the alter/ego relationship is intimate (e.g. a spouse) *or* because the support provided is very helpful. Likewise a *weak tie* can occur because the relationship is *not* intimate or close but the support provided may still be very helpful. Where the focus is on what the ego wants and their perceptions of what is (or is not) provided, understanding the precise type and source of support, the frequency of support and the relationship of alter to ego is not required, circumventing methodological difficulties with measuring tie strength. Instead, the three grounds for social tie building explicate why a specific offer of support to the ego is viewed as helpful and wanted, or not. So a 'weak' tie, where the relationship is distant but the support is helpful, is formed because there is utility, even when affinity is weak. The nature of the data and analysis is such that more work is required to develop this theory for understanding the mechanisms of social tie building but a range of examples have been identified from the data and discussed as exemplifiers below.

Participants were recruited from community clubs and the clubs provided important opportunities to 'just talk'. Kelly et al (2019) note evidence for Men's Sheds as providing opportunities for socialisation, the building of relationships and the elicitation of a sense of purpose and confidence. This study's findings help to explicate the mechanisms through which building social ties generated support and consequently confidence for self-management.

Through getting to know each other in an informal situation participants described liking (some) others at the club and this potentially enabled the building of social ties as affinity with others developed. The extent of affinity with alters could be further investigated, for example some men described a lack of closeness, in terms of relationships with others at the club, but still gained utility from the relationships. This finding resonates with Allen et al (2020) who found that using Internet support provided distant, less tangible ties, but fostered control over self-management. Potentially the club situation enabled affinity in terms of the support provided rather than affinity with the alter *per se*, although having some aspects of affinity, for example living with the same LTC, was helpful. Participants also formed relationships and gained utility from ties with others at the club. Club members helped each other out with tasks at the club and with lifts; participants gained implicit and explicit emotional support from club members too. Some participants described being able to depend on others at the club, indicating that these ties were perceived to be reliable.

The clubs were important sources of similar others with whom participants discussed having affinity and gaining utility. Thoits (2011), Gage (2013) and Grace (2020) discuss the importance of others who experience a shared stressor, such as an LTC, for enabling role modelling, sharing of experiences and solutions, and the ability to provide support which is relevant to the ego. As at least some circumstances are shared the ego can rely on the information or guidance provided, the support is likely to be of utility because the ego perceives affinity and reliability. A comparable process occurs with similar others in other social contexts, such as with family members who are similar others. Thoits (2011) discusses how family members can provide ongoing emotional sustenance to the ego and, where the family member is a similar other, also provide what Thoits (2011 p152) terms ‘active coping assistance’. Thoits (2011) positions active coping assistance as particularly helpful because, as a similar other, the alter can support in a variety of knowledgeable ways, including assisting the ego to identify tactics to cope with difficulties, emotionally and practically. Applying Azarian’s (2010) grounds for social tie building: the similar other family member demonstrates affinity through providing emotional support and empathy for the ego’s situation *and* provides instrumental support which is relevant, has utility and is, potentially, reliable. All three aspects for social tie building are met and this enables explication for the strength of ties with similar others, particularly when these are family members.

Findings to explore mismatches of social ties have been presented (section 6.8). In these situations the ego perceives, and has perhaps had previous experience, of a lack of utility and affinity, even when it might be reasonable to expect affinity due to the relationship with the alter. For example, with close family members affinity could be compromised when the support offered was unacceptable, perhaps making the ego feel nagged, judged or belittled. Mayberry et al (2014) report similar outcomes for egos when experiencing family behaviours that obstructed LTC self-management, although their participants also reported LTC-supportive family behaviours too. In circumstances where alter's behaviours are viewed as obstructive or unhelpful it is possible that affinity existed with the alter but not with the support they provided. In other circumstances the same alter may provide support which does have utility. There was some evidence that egos had tactics to avoid unhelpful or unwanted support and this is discussed below.

In conclusion, the premise of affinity building, utility and reliability as mechanisms requires further elucidation but appears to have value for explaining and predicting social tie formation and strength.

7.2.3.2 Tactics for negotiating social ties within a personal social network

The identification of tactics applied to *negotiate* social ties is novel. Three tactics of: ignoring unhelpful others, giving advice, and using humour were identified (section 6.10).

Sani (2012) recognises that not all social relationships are healthful and beneficial, and Ong et al (2011) suggest that social networks can be facilitative or inhibiting and that control of social networks is part of the 'work' of LTC self-management. This study found that, when asked about unhelpful others, participants explained how they ignored - either explicitly or implicitly - unhelpful advice or alters that they found unhelpful (section 6.10.1). Mayberry et al (2014) investigated family support for diabetes when egos also experienced low HL skills. They suggest that, when living with low HL skills, family support for diabetes management is important, however not all support offered is perceived as helpful and the authors question how obstructive family behaviours might be reduced. Findings for this study suggest that egos could be supported to understand that unhelpful or obstructive support is likely to occur and they may wish to develop tactics for ignoring unhelpful advice. Furthermore, family members could be encouraged to appreciate that an ego may, for example, ignore their advice but still want their support with other self-management tasks. Family members could be facilitated to ask questions in a more helpful way, for example asking, 'what help do you need?' rather than, 'you should do this'. From understanding the tactics people with low HL skills apply to avoid unhelpful advice it is possible to posit potential tactics for others to draw upon.

The tactic of giving advice was a nuanced process. Some participants discussed not being confident to provide advice even though they appreciated the information they gained from similar others (section 6.10.2). The reasons for this reticence could potentially be an outcome of participant's health literacy skill level or knowledge level - it appeared that participants with functional levels of HL were less likely to give advice to others. Participants with critical HL skills, particularly P8M and P17M, were happy to provide support and advice to others. In addition P6M (applied HL skills) expressed confidence with using digital technology and ran a diabetes support group at the club; he was able to harness group dynamics to support LTC self-management for himself and others. Further reasons for some participants not giving advice could include a lack of confidence with managing their own condition or personality type. The tactic of giving advice is a helpful one because a person being able to teach and explain self-management actions or information to others evidences that they themselves have knowledge and understanding (Egan & Gajdamaschko 2003). Furthermore, people living with functional HL skills may require advice-givers to support them with de-coding information for LTC self-management, and opportunities for them to gain access to advice-givers can occur in social spaces such as clubs.

It was noted that some participants applied irony and self-mockery when describing their self-management actions (section 6.10.3), suggesting that people use humour as a tactic to reinforce their support networks. Savage et al (2017) posit humour as reducing anxiety and enhancing participation; in addition to positive physiological effects humour can build relationships with others. The tactic of using humour required participants to denigrate themselves to a certain extent but doing so created an incongruity which led to humour (Martin & Ford 2018) and participants used laughter and the lightening of mood to, perhaps, build affinity with others and gain utility. Kelly et al (2019) note that Men's Sheds create an environment with similarities to male-dominated workplaces and the study participants commented on the importance of the Shed for re-creating a 'work canteen' style environment. Within this environment it was acceptable for the men to use humour in a somewhat aggressive way and this appeared to foster social connections.

In conclusion, there is potential to further interrogate and explicate the tactics people use to negotiate social ties. Understanding the ways in which people negotiate social ties for LTC self-management is important as tactics for managing one's network could be learnt by people living with LTCs and could support people, particularly those living with functional health literacy skills, to self-manage in a more knowledgeable and confident way.

7.2.4 The contribution of health literacy skills *and* a personal social network to self-management

The over-arching aim of this thesis is to understand the contribution of health literacy skills *and* personal social networks to LTC self-management when a person is living with a functional level of health literacy skills. To achieve this aim the study was designed such that all participants were living with at least one LTC. The first interview enabled understanding of participants' level of HL skills and the size and structure of their personal social network; the second interview enabled in-depth exploration of how participants self-managed and how they drew on HL skills and their personal social network. As most of the participants lived with a functional level of HL skills it has been possible to elucidate how they self-managed and some of the barriers, for them, to self-management. It was also feasible to compare their self-management tactics with the tactics of participants who lived with an applied or critical level of HL skills. The discussion above has presented the key findings for the contribution of HL skills and a personal social network to LTC self-management when considered separately; this section evaluates findings which aim to explain how people (particularly those living with functional HL skills) can become informed about self-management and, ideally, empowered to manage their health.

Empowerment has been conceptualised in this thesis as a process of transformation which can occur in social situations (Mok et al 2004). The premise for this definition is that, in social situations, people may view situations through other's eyes - and experiencing a new viewpoint can enable the acquisition of new knowledge, skills or beliefs. As LTC self-management requires health knowledge, skills to undertake health-related actions, and a belief that it is worthwhile managing one's condition (Matarese et al 2018), the conceptualisation of empowerment as transformation is of value within this thesis. Through a process of empowerment a person can gain more information about why and how they could self-manage, this contributes to feelings of importance to act (Rollnick et al 1999). Seeing how others act, viewing their success with actions and then judging that it is helpful to act in a similar way can contribute to feelings of confidence to act (Rollnick et al 1999). Empowerment processes have the potential to build motivation for self-management and contribute to people feeling they have control over their health. All the participants reported wanted some degree of control over their health condition, even while they recognised that 'full control' was not possible, a finding also acknowledged by Francis et al (2019).

The two previous sections have critiqued findings indicating that both health literacy skills and a personal social network provide important resources for managing a long-term condition; however, in the absence of a high level of HL skills the personal social network has, as Sentell et al (2017) suggests, the potential to 'fill the gap' by enabling access to resources or people who can provide informational support. In this study all participants benefitted from being members of community clubs and importantly, as will be illustrated below, the participants did not need to have a high level of HL skills to be able to leverage support from club members. Nutbeam (2008) suggests that a critical level of HL skills enables empowerment and there was some indication, from the comments and actions of participants with critical HL skills, that this was so. However two aspects remain to be explained; how participants with functional levels of HL skills might become empowered and how 'being social' leads to empowerment to manage an LTC. For these aspects participant's membership of community clubs, and the subsequent ability to 'be social', was key.

Mok et al (2004) view empowerment as the ability to do things rather than using power to have control over others; empowerment processes are a means to attaining personal power or inner strength. People living with LTCs will experience, at times, poor health which can lead to a deficit in power as their physical strength, energy and ability to act may falter (Francis et al 2019) and all participants reported times when poor health had restricted their activities. At such times support from others becomes important; the provision of knowledge, information regarding solutions and others doing things for them, can compensate for a personal lack of power (Mok et al 2004, Vassilev et al 2014). Participants included the club in their personal social network for self-management and all made comments about the contribution, implicitly and explicitly, of club members to their health; participants' emphasis of the club as an opportunity 'to talk' has been set out in section 6.4. Significantly, clubs provide a context for people to participate, build social capital through interaction with others and enable access to a range of resources (Jeffries et al 2015, Kelly et al 2019). Participating in the club provided opportunities for support from others that might otherwise not have been available. Mok (2001) theorises that from participation comes power, with the optimal aspect of power being *able* to participate. Importantly, the community clubs not only facilitated people with disability and morbidity to attend, people experiencing these circumstances were *encouraged* to attend. Where primary control is, 'believing one's actions can have a direct impact on the situation' (Mok 2001 p74) it was important that the club's purpose was to encourage things that people *could* do (woodwork or crochet for example), rather than emphasise what people could *not* do.

Mok (2001) suggests that being connected gives a person responsibilities and commitments, leading to purpose and meaning in life, and this appeared to be the experience of P3F, who co-ordinated the women's Crochet Club, and for the men who viewed the Men's Shed as a replacement for the workplace. Talking at the club was helpful and, through talking, participants gained a new perspective. Men's Sheds aim to provide informal opportunities for social and informational support (Kelly et al 2019) and this was what the men reported. Also, as was found in this study, Jeffries et al (2015) note people reporting community groups as providing camaraderie and the opportunity, but not an obligation, to discuss health matters. Casual or 'accidental' sharing of information was important for some participants. In addition, knowing a diverse range of people enables a person, when experiencing difficulties, access to a choice of solutions and supporters (Cattell 2000, Vassilev et al 2014, Sentell et al 2017). All participants gave at least one example of feeling empowered by the club environment, as the context expanded the range of resources available to them in times of need. Talking with others, or connectivity, enables people to envision a new perspective on their health problems or self-management tactics (Foss et al 2016, Cruwys et al 2019).

Bossy et al (2016) investigated LTC-specific self-management groups and found these not to be beneficial for some people as the groups created potentially unhelpful social comparisons and some group members felt labelled as someone *with* (or who *was*) the condition. LTC-specific groups can perhaps create conditions where people begin to feel that they cannot gain control; whereas the community hobby-based clubs were not overtly focused on managing health but enabled many opportunities for health discussions. Interestingly, one Bossy et al (2016 p165) participants is quoted as saying, '…*I understand that it's good for me* [joining a group] (…) *you get all of these new impulses when you talk to other people*'. Several examples for this study of participants getting 'new impulses' from being social were identified (sections 6.4, 6.5, 6.6). P6M, who had an applied level of HL skills and took a technical approach to LTC self-management, talked about 'bouncing off' ideas for diabetes management with a friend, his partner, his daughter and men at the Shed. He described the multiple perspectives as providing him with information and confidence for making the final 'serious decision-making'. For P10F (applied HL skills), pursuing a new hobby of learning to swim had enabled her to learn a skill, get fit, burn off sugar, get out [of her home], not brood *and* meet new people. She gained multiple benefits from the hobby, making it important to her and worthwhile to continue. Participants discussed their supporters as providing instrumental, emotional and informational support *and* as providing the opportunity to gain a new perspective on their own health and LTC. Participants discussed similar other's ideas as helpful (sections 6.5, 6.6), that making comparisons with others was helpful (P12F section 6.3.2) and that being with others took them out of themselves (P11F section 6.3.1). The strength of a personal social network is therefore not just as a form of capital or a resource but also as a *mechanism* by which people come to see things in a different way.

Ould Brahim (2019) critiques traditional health care views of autonomy which assume that someone should make the right choices, be independent and be competent, positing this viewpoint as particularly troublesome when people live with LTCs. As an alternative Ould Brahim (2019) emphasises the importance for autonomy to be forged *within* relationships and our social context, such that maintaining autonomy becomes an ongoing process of creating our 'self'. This allows for an acceptance that social conditions, rather than being causal to autonomy, are inextricably intertwined with 'self', and control can come from being able to shape one's life *in* a social context rather than from 'being independent'. Having undertaken the study a powerful impression for me is that the club environment provided a context for participants, regardless of their HL skill level, to be themselves *and* an opportunity, if required, for them to draw on support. P19M spoke about how the club environment enabled him to gain ideas and possible solutions for a range of problems that he, and others, might experience, including management of an LTC. He described the situation as being one in which it was possible to gain support *and* remain in control and autonomous. As his description encapsulates the important conclusion of this thesis for support in the context of empowerment, it is presented here:

> P19M: ….*if you've got a problem of* ***any*** *description whether it be on diabetes, depression, health, umm money, anything you like, there's always somebody here who knows something who can help you maybe in some way or another, give you advice, or just give you information and it's up to you then what you want to do with it so I would say the club is supportive* [his **emphasis**]

7.3 Implications for practice

Having evaluated the novel findings for this thesis it is prescient to consider the application of the findings to health care and health promotion practice. There are opportunities to inform HCPs as to preferred practice for working with people living with LTCs, which include comprehending their role as teachers of the medical, scientific and complex aspects of LTC self-management, and as sign-posters of reliable information. For health promotion practice there is the recommendation that health literacy is defined clearly within interventions and that the importance, for health, of 'being social' is emphasised.

This thesis has posited that people living with an LTC and experiencing low health literacy skills may lack control over their health, particularly if they find it difficult to understand their health condition and the actions required (Easton et al 2010). Not only does this result in poorer health (Berkman et al 2011), it is exacerbated by socioeconomic situations; the link between incidence of LTCs and, for example, financial difficulties and low levels of education has previously been discussed (section 2.4). An important aim of health promotion is therefore to reduce health inequalities and one way for HCPs to achieve this is to encourage and support self-management of LTCs. This thesis has argued that calls for action to raise health literacy levels (WHO 2013) can be confusing for HCPs who primarily work with individuals so the focus of the study has been on understanding the everyday process of LTC self-management, with a view to illuminating how HCPs can encourage the process. This study has shown that HCPs working in a way to mitigate low health literacy *skills* and to encourage the use of a personal social network has the potential to contribute to improving people's ability to self-manage and, therefore, to reducing health inequalities. With the support of HCPs patients can be encouraged to make more and better use of health information, friends and family and other resources such as clubs, social opportunities and the Internet. Using the strategies discussed below people living with an LTC can be enabled to take control of managing their condition.

In my role as a facilitator of learning for HCPs I would advise and support HCPs to follow good practice and evidence for effective methods for communicating health information, for which there is much evidence (Rollnick et al 1999, Shaw et al 2009, Gaglio et al 2012). A specific recommendation emerging from this study is that HCPs should position themselves as a *teacher* when discussing self-management of an LTC. What is meant by this is that they should consider their role as to ‘translate’ what can be complex, scientific information, in to a form that is understood by patients. Ideally understanding could then be checked by using a teach-back process. Finbråten et al (2020) found that patients with access to nurse-led appointments, which facilitated time for explanations and questions, had higher levels of HL skills than those who lacked access to nurse support. Effective consultations will require resources including: a range of information to refer patients to, interactive teaching materials, and enough time to explain, check understanding and question patients about their confidence and knowledge for self-managing in their everyday environment.

Participant’s relationships with HCPs were not a prime focus of this study however HCPs were listed when participants discussed self-management personal social networks and practice nurses were mentioned as being particularly helpful for facilitating LTC self-management support and advice. In support of this Harbour & Grealish (2018) posit nurses as playing a pivotal role as a source of information particularly when patients are meeting different HCPs and need to manage conflicting or confusing advice. A key recommendation from this study is that asking questions about people’s network of supporters will enable HCPs, and the patient, to understand the barriers and facilitators for social support. Ould Brahim’s (2019) conclusion that asking about social context, including discussing helpful and unhelpful relationships and how to manage these, can be reiterated as an important role for HCPs. Network diagramming is a straight-forward method that could be implemented into HCP practice and facilitate such discussions. Importantly diagramming enables people to view their network from a new perspective and, as reiterated in section 7.2.4, a new perspective can lead to improved knowledge, skills and beliefs about LTC self-management and encourage people to gain control over their health (Mok et al 2004). HCPs would be required to recognise, however, that empowerment can lead people to make (informed) decisions not to comply with HCPs advice, to reject treatment options and to gain control by accepting, or ‘living with’, the condition (section 4.3.4, Mok 2001, Francis et al 2019).

Potentially, one way to boost people's knowledge and access to social support is to recommend or sign-post patients to a community club (Kelly et al 2019, Vassilev et al 2019). Interventions such as GENIE will be important for encouraging people, who may be somewhat reluctant, to engage with social opportunities (Vassilev et al 2019). The study findings indicate that a condition-specific club is not a necessity and some people may reject that idea anyway (Bossy et al 2016). In addition, Hughes et al (2020) found that facilitators for specific group programmes for self-management missed opportunities to encourage the type of informal shared learning which the study participants reported experiencing within their community groups. As explained in the previous section incidental rather than planned opportunities to discuss health enabled participants to maintain autonomy and control. Furthermore, LTC-specific groups may be time-limited or run on an occasional basis. There is evidence to suggest (Moore & Carpiano 2020) that clubs which run on a sustained basis - in terms of frequency and longevity - better enable relationships to build over time. The study participants did not always need support from the club members but took comfort from knowing that support was there if and when they required it. The club being available over a period of time was important not just for relationship-building but for ensuring that support was there when people needed it.

The use of digital technology as a source of information and as a potential translator of information could be encouraged. All patients will benefit from being signposted by HCPs to reliable websites, apps or other sources (Chen et al 2018), particularly as HCPs are viewed as trusted sources of health information. For those who do not wish to or are unable to access technology reliable sources such as the Diabetes UK magazine can be recommended (Arcury et al 2020). Some participants had been encouraged to sign up to receive the Diabetes UK magazine and they found it helpful; it was difficult to understand why other participants living with diabetes had not been encouraged to access this magazine. Participants reported that digital and non-digital sources of the magazine helped them to understand what similar others do to manage their health, the resource was there for reference when it was needed and participants read it, asked others to help them understand it if necessary and could take their time with this process. Participants, particularly those with functional HL skills, asked for information to be relayed in simple terms however, as Chapman et al (2019) conclude, there is still some way to go to ensure that health information is readable, visual, accessible *and* reliable and accurate.

Regarding my own profession of public health the thorny problem of defining health literacy remains (Liu et al 2020), however this thesis has posited that there is utility in distinguishing health literacy as a *process* from health literacy *skills* as a characteristic of an individual. Understanding health literacy as a *process* encompasses communities being enabled to access and make best use of health care services and encouraged to improve their health *and* actions to ensure the accessibility of health care services and health information. That is, actions with parallels to a health promotion process. Health literacy then becomes distinct from efforts to understand *individual's* levels of health literacy *skills* and health education interventions to raise levels of health literacy skills. The clarification of health literacy as a process and health literacy skills as an individual characteristic has the potential to aid the design of health promotion interventions. For example, interventions to 'improve health literacy' could be judged through comprehending whether the aim is: to raise health literacy skills in individuals; or a population-based approach to enabling access or improving education levels. For health care professionals it then becomes clear that their responsibility is to work with individuals in such a way that health literacy *skills ability* is recognised and informs HCPs' consultation approach.

The final consequence of this thesis for health promotion practice is to reiterate the contribution of 'being social' to the process of empowerment for health (Mok 2001, Green et al 2015, Laverack 2016, Kelly et al 2019, Vassilev et al 2019). This thesis has given weight to the importance, for people living with LTCs, of being social, and the potential, through contexts such as community clubs, for becoming empowered to self-manage their health (Jeffries et al 2015, Harbour & Grealish 2018). Furthermore, referral to interventions to increase people's social support and social contact has the potential to reduce loneliness and social isolation and is perhaps easier for HCPs to undertake than efforts to improve health literacy skill levels through education. This study's findings point to community clubs as being opportunities for *all* participants, regardless of health literacy skill level, to become more informed and, sometimes, more motivated to self-manage their LTC.

7.4 Study strengths and limitations

7.4.1 Study strengths

The value of qualitative inquiry is that it enables in-depth understanding of individual's situations (Flick 2002). Acknowledging that LTC self-management is perceived by people as a part of their everyday life and all that entails (Foss et al 2016) and employing detailed qualitative data to explore how people self-manage has enabled a comprehension of self-management as a way to create health within settings in which people live, love, work and play (WHO 1986). This has broadened the discussion of self-management such that encouragement of self-management is not just the role of HCPs but something that people living with an LTC view as being part of their whole life. The findings have emphasised that people draw on opportunities for support or advice from their whole life experience. While recognising that some people may have limited resources and choices, ultimately people can make their own choice as to whether to take control or responsibility for their health (Laverack 2016). However the findings highlight that public health and health care practitioners can be urged to assume people will want to do *something* and take some control. In such circumstances our role is enabling clients to gain information, support and control by working collaboratively, being flexible, being alert to and responding to people's wants and needs and encouraging active involvement.

In this thesis it was important that findings and explanations were relevant not just for the participants but also applicable for others living with LTCs and of value to HCPs working with people living with LTCs. Hence a pragmatic design-based approach to the study was implemented and purposive selection of people living with LTCs and, potentially, living with low HL skills was undertaken. To ensure dependability (see section 3.10.2.2): the methods have been set out in detail; the relation of methods to the research questions has been reflexively considered; and findings have been authentically presented. Finally, to enable credibility through peer review (section 3.10.2.1) detail has been provided regarding: the participants (e.g. age, LTCs lived with); the analysis process; the theoretical framework used to abstract findings; and examples of data to support findings.

Phase one was a planned and thought-through aspect of the study design whereby the data collection tools and interview process was undertaken with a small number of participants (five). The phase was planned to coincide with the requirements of the doctoral upgrade stage. In addition the 'gap' between phase one and two enabled the review of emerging findings and provided the opportunity to reflect on and adjust the data collection tools – based on findings and feedback from the first five participants. It was important to undertake this review of methods as participants could potentially be marginalised as result of living with an LTC and/or a low level of education, the intent being to check that the questions asked were acceptable and understandable (Yeo et al 2014).

The decision to undertake two interviews with each participant was a pragmatic and research-question driven judgement. Being a novice interviewer I wished to have the opportunity to speak twice with participants, enabling me to gain further depth of understanding of situations that they may mention only briefly in a first interview. This design aspect of triangulation also ensured the rigour and robustness of the data collection (Morse 2017). The first, structured interview was: an opportunity for participants to understand what I would be asking them about; gave participants time to reflect on their thoughts about self-management between interviews; enabled me to consider how to probe and build on their responses to interview one; and facilitated comparison of responses in interview one and interview two. I was encouraged by the fact that all participants returned for their second interview, indicating that interview one was acceptable to them. Potentially the offer of a shop voucher and donation to the club, on completion of the second interview, was an incentive to return.

The study design and the research findings are such that it has been possible to elucidate how HL skills and a personal social network contribute to self-management of a long-term condition, that is, the aim of the thesis has been addressed. It has been revealed that people living with low HL skills will attempt to draw on others to support them with understanding information. Furthermore, there are indications that clubs are convenient and important contexts for sharing information and providing support for LTC self-management and that viewing LTC actions through understanding how *others* manage can bring a new perspective and build empowerment.

7.4.2 Study limitations

The cross-sectional study design constrains the ability to draw causal conclusions. This design also impacts the ability to explain temporal features.

Potentially more could have been done to ensure pre-testing of the health literacy skills tool and the interview questions. However, the decision to undertake data collection in two phases did provide an opportunity for reflection on the data collection process and, therefore, a check of the efficacy of the interview process. As discussed in section 3.10.2.3 efforts have been made to strive for authenticity through maintaining participant's perspectives as central to the study.

The health literacy skills data collection tool applied in interview one has face validity but may not have external validity as the tool was developed specifically for this study. This reduces the capacity to compare the results for this study with other studies using different health literacy skill tools.

For the personal social network aspect of interview two questions were asked which probed the types of support drawn on by participants. At the analysis stage it became clear that building and negotiating social ties were key findings, therefore these aspects would benefit from future investigation which questions participants specifically about these mechanisms.

During the analysis stage it was noted that at times during the interview I missed opportunities to probe responses. The ability to ask probing questions will improve with experience of undertaking interviews although, to be better prepared, I could have considered the different reasons why probing was required. Yeo et al (2014) suggest that probing can enable amplification and explanation of responses or elicitation of values and beliefs, all of which can contribute to depth of understanding for participant and researcher.

Member checking of the main findings was not undertaken with the participants for reasons of time and expedience; there was not enough time to undertake return visits to the clubs and the main findings were not elicited fully until toward the end of the study time. As discussed in 3.10.2 a lack of member checking can detrimentally impact credibility and authenticity. However, findings were implicitly member checked as the interviewing progressed and when club members asked about the study aim and findings. In addition, findings will be member checked through the future work set out in section 7.5.

People who were living with an LTC but *not* self-managing their condition were possibly under-represented. This conclusion has been reached as an outcome of observing participants talking about other people they knew or who attended the club and who were living with an LTC and were unwell and were reported by participants as not following HCP guidance.

All participants were white British, aged 49 – 70 years of age and attending community clubs therefore findings may not be generalisable to other populations.

7.4.3 Reflection on study strengths and limitations

One of the appeals to me of the pragmatic paradigm was that pragmatism recognises the contribution of experiential and practice-based knowledge in the research process. Having worked and taught in the field of health promotion and health behaviour change for twenty years my substantive knowledge is considerable and it has been important for me to incorporate substantive understanding within this thesis. Fortunately pragmatism ‘allows’ the mixing of everyday common-sense inquiry and scientific inquiry, i.e. the substantive and the scientific, although I recognise that at times the different approaches may conflict. Pragmatism also allows for creativity in terms of the ability to move between problems and solutions, enabling me to draw on my strengths of interpretation, abstraction and an ability to explain meanings in straight-forward ways. The applied nature of this work is important and ultimately requires me to ‘translate’ my findings in to forms which are understandable and which enable others to understand the potential application to their practice. I also recognise that interpretation, meaning-making and application to practice is an ongoing process; what makes sense and illustrates something clearly for me may not do so for others.

The comment that, ‘every stage of the research process relies on our negotiating complex social situations’ (Harrison et al 2001 p323) resonated with me, particularly when reflecting on the process of finding and recruiting participants. As Harrison et al (2001) posit, we bring our 'selves' to research, and some 'selves' made me an 'insider' in the club environments and some made me an 'outsider'. As an outsider who does not live with an LTC I had to convey my genuine interest in wanting to understand how people managed an LTC, while managing my own goal to complete a doctorate, which also made me an outsider. At the Crochet Club being a woman and of a similar age to the club co-ordinator was potentially beneficial. The ways in which I was not similar, that is being an academic, a researcher, and not being there to join the club, perhaps enabled me to keep some distance from the women and encouraged them to open up to me. At the Men's Shed I was a more obvious outsider, I had to find ways to build rapport with club members and this was one reason why visiting the clubs in person was so important. For all participants I hope I brought my skills of being a good listener and showing empathy and am optimistic that I have presented what they offered me in a human, accurate and empowering way.

Harrison et al (2001) consider that reciprocity between researcher and the researched is necessary to gain depth of data. Participants knew that I was interviewing them for doctoral research and it is important to consider what they might have gained from participating. Beyond the obvious incentive of a voucher for them and a donation for the club, I observed participants having the opportunity to 'tell their story' and a few talked about the possibility of this being helpful for others. Ultimately it was altruistic of them to participate, and, for me, reflected the support they gave each other at club. I formed the impression from my observations that people would give support to others, not because they wanted support from others, but because if they (later) needed support the others would provide it. This has prompted me to consider reciprocity as a future theme for exploration.

A further question for me is whether my work can make a difference for the participants, and others living with long-term conditions. Academic study sometimes felt as if it was miles away from participants' lives – not to mean that they are helpless – but I questioned how writing about 'translators', for example, could be helpful. Harrison et al (2001) suggestions are helpful here. They urge researchers to tell it how 'it' (in this study, encouragement for self-management) *could* be. For example, ideally health care professionals would be encouraged to recognise what people *do* to manage their LTC, not what they do not do or will not do. It is therefore important that I aim to publish and present my findings and use my new knowledge to inform my practice as an educator of health care professionals. An ideal test of pragmatic validity is that research becomes validated by its role in practice (Kincheloe 2012) – only when the work is published and used in mine and others' teaching will I come to know its value. Taking a pragmatic, health promoting approach has enabled me to investigate self-management in the context of everyday life and the detailed qualitative findings have emphasised that viewing LTC management as a day-to-day process has revealed important implications for health professional and public health practice.

7.5 Future research activity

The following future actions are planned:

- Continued analysis of the data to develop a self-management cognitions model.
- To prepare for publication a discussion of the theoretical and empirical basis for the use of the term *applied*, rather than interactive or communicative, level of HL skills.
- To further test the health literacy skill questions.
- Explore further the postulated basis for social tie building.
- Further exploration of the ways in which people negotiate and manage social ties, including the role of reciprocity.
- Disseminate and share findings with others: including people living with LTCs and health care professionals, permitting development of the findings and their application, and enabling elicitation of the authenticity and pragmatic validity of the findings.

7.6 Concluding reflection

Having, literally, got to the conclusion of this thesis I, rather frustratingly, find I have carried out the planned research and made discoveries but am now in the position of having more questions to answer. It seems appropriate here to reflect on Dewey's philosophy that inquiry is never settled. The warranted assertion standpoint from Dewey (Dixon 2019) suggests that the usefulness of knowing something is then the value of its applicability to future inquiries, which helps me to understand why questions remain. It is important that I maintain momentum and publish from this work and plan follow-on research.

A difficulty throughout this work has been grappling with the hugely broad topics that I selected to investigate, however I also feel satisfaction with the fact that I have been able to design and undertake a study which elucidated the contributions of health literacy skills and a personal social network to the process of self-managing a long-term condition. I know there is more to uncover and discover from the data and I am looking forward to that challenge. I am also looking forward to working with others to publish work and to develop future research. My recommendations, therefore, point toward future areas of research and inquiry to pursue. Undertaking a doctorate is somewhat of a lonely pursuit, I am now ready to work with others to discuss, critique and develop conclusions and application for my findings. Finally, the irony of writing a doctoral thesis about the importance of 'the social' for health and well-being, during a time of lockdown due to the Covid-19 pandemic, has not been lost on me. I do hope that the participants found ways to maintain their health and keep in contact with family, friends and the club members.

7.7 Thesis conclusion

The study aim to identify how health literacy skills contribute to the process of self-managing an LTC has revealed the utility, for health care professional practice, of focusing on the health literacy skill levels of individuals. *Health literacy* has been viewed as a population-wide process, within which health care professionals play an important role through working with individual patients. This thesis has defined three levels of health literacy skills as functional, applied and critical, where an applied level of skills is postulated to be a level of skills which enables application of health information to one's situation. Participants living with functional health literacy skills discussed wanting to trust information and recognising that health information should be reliable and accurate but they also reported struggles with judging the quality of information. Health care professionals are recommended to work with patients living with long-term conditions to support them to locate, read, understand and apply reliable health information sources. All participants made use of 'translators', that is, people - such as health care professionals, or resources - such as the Internet, who could de-code health information and provide information in such a way that the ego could understand the information.

Diagramming of participant's personal social networks and integration and analysis of qualitative interview data facilitated application of three grounds for social tie building. The grounds for participants searching for affinity, utility and reliability from social ties was of value for explicating why supporters, and supports they provided, were viewed and accessed in particular ways. The findings also revealed that participants applied tactics for negotiating social ties. The tactics of ignoring unhelpful supporters, giving advice to others, and the use of humour to broker social ties, have been presented.

When considering the over-arching aim of understanding how health literacy skills and a social network contribute to self-management when a person is living with a long term condition and a low level of health literacy skills this thesis has found that - for participants living with a low level of health literacy skills - their personal social network was fundamental in providing support for self-management, particularly informational support. The network was a source of translators and the process of being part of a social group also enabled empowerment, where empowerment is viewed as a process of personal transformation enabling control over one's management of health. The community clubs provided the participants with the opportunity to socialise with others and viewing their own situation through the eyes of others brought a new perspective to their difficulties and offered them potential solutions. Others enabled them to view situations in a re-framed and newly interpreted way. Some participants were able to acquire knowledge from others, experiment with skills and actions that others suggested or modelled and ultimately learn new ways of acting. In a situation of self-managing one's health, knowledge, skills and changes in beliefs can contribute to motivation and learning for behaviour change, ultimately contributing to capacity for action.

Overall I was struck by how participants all had their preferred, unique ways of managing their conditions. Although they lived with difficulties which sometimes made managing their conditions hard work they all worked to gain some degree of control over their health; for some this entailed letting go of a perception that their health could be improved. The term *self-management tactics* is apposite to emphasise that people with capacity to self-manage a long-term condition will aim to act in ways which provide them with choices *and* empower them to achieve *their* health-related goals. Having recognised that people living with long-term conditions experience health inequalities - and taken a health-promoting stance toward self-management - this thesis has emphasised the role of health care professionals and public health practitioners in working with people to enable them access to health information and to encourage them to draw on, and manage, their personal social networks. Importantly, interventions to support self-management, at the social and community level and with individuals, have the potential to address the public health priority to reduce health inequalities and improve the health and well-being of people living with long-term conditions.

Appendix A Participant Information Sheet

Study Title: How do people manage a long term condition?

Researcher: Lyn Wilson **Ethics number**: 23842

I am Lyn Wilson; I am doing a study to find out more about how people with diabetes or arthritis look after themselves. By helping with this study you will help me to understand how people with diabetes and arthritis could be supported to look after their health. We know that a lot of health information is very complicated for a lot of people. I am interested in talking to people who find health information difficult to read.

This sheet will help you to decide whether you wish to take part in this study. After reading this information, or having this information read out to you, if you are happy to be interviewed you will be asked to sign a consent form.

This study is being done by me, Lyn Wilson. I am a lecturer in public health at the University of Southampton and this study is part of work for my doctorate (PhD). My work is supervised by three professors.

Why have I been chosen?

You have been asked to take part in this study because:

- you have either diabetes or arthritis
- you find health information difficult to read
- you are aged between 30 and 70

What will happen if I take part?

I will meet with you to talk about how you manage your diabetes or arthritis, how you use written information and how other people support you. I will NOT be asking medical questions about your condition.

We will have two meetings in a private room in a public building such as a library or community centre. At the first meeting I will ask some questions about how you manage your diabetes or arthritis. This will take between 20 to 30 minutes and your answers will be recorded and written down by me.

Between one day and a week later I will meet with you for 30 – 40 minutes to discuss the answers you gave in the first meeting and to find out more about how you manage your condition. This meeting will be recorded.

If you would like to know what the research finds out you can ask to be sent a copy of the research results.

What will happen with the information I give to Lyn?

The information you give will be typed up and stored on a secure password protected computer. Your name and all other information which could identify you will be **removed**. Information kept on my computer is protected by a password. Only I, Lyn, will know which information was provided by which person.

The information you give will be reported in a University document written by me and may also be published in academic journals. Your name and details will NOT be included.

Will my taking part be confidential?

Yes, your personal details will be kept safe and any information which could identify you will NOT be published or shared with other people. This includes things like your name and address. I will be working to the Data Protection Act and the University of Southampton policy on keeping information.

Are there benefits to taking part?

As a thank you for your time you will be given a £20 shopping voucher and £10 will be donated to your club/association.

There may be some benefit for you from talking about how you manage your condition. You will be contributing toward a better understanding of how people manage arthritis or diabetes.

Are there any risks to taking part?

There is a small risk that you could become upset when you talk about how you manage your condition. I will do my best to ask questions in a kind way and if you do need support I can give you telephone numbers for helpful services.

What happens if I change my mind about taking part?

If you change your mind let me know, you can ask to leave the study at any time.

What happens if something goes wrong?

If you are worried or would like to make a complaint then you can contact the Research Governance Office and they will investigate.

[RGO contact details, supervisor’s email address and required Data Protection statements followed]

Appendix B Consent form

Study title: How do people manage a long term condition?

Researcher name: Lyn Wilson
Ethics reference: 23842

Please initial if you agree with the statements:

Statement	Initial here
I have read, or had read to me, the information sheet (April 2017 version 1)	
I understand the information sheet	
I have had the opportunity to ask questions about the study	
I agree to take part in this research project	
I agree for my data to be used for the purpose of this study and associated publications	
I understand that I can withdraw from this study at any time without my legal rights being affected	
I agree to be interviewed	
I agree to the interview being recorded	

Data Protection
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study and associated publications. All files containing any personal data will be made anonymous.

Name of participant (print name) ....

Signature of participant...

Date interview 1...

Date interview 2 ....

Appendix C Sources of help and support

Your GP

Your Diabetes/Practice Nurse

Your local pharmacist

My research is finding that one of the best things you can do for your health is to be in contact with other people. Don't be afraid to ask family and friends for help when you need it. Talking to other people with the same long-term condition can also be helpful as you can share information and ways to manage your condition.

When meeting with health care professionals my tips are;

Ask questions

Ask for something to be explained if you don't understand it the first time

Help the nurse/GP to understand how your medication/treatment/diet/activity level fits in, or does not fit in, with your everyday life. This will help them to support you to better manage your long-term condition.

Reliable websites:

Arthritisresearchuk.org

Arthritiscare.org.uk

Diabetes.org.uk

Diabetes Research & Wellness Foundation, www.drwf.org.uk

Appendix D Health literacy tool development

Table A Justification of the health literacy tool requirements for this study

Study requirement of HL skill tool	Justification
Must encompass health literacy enacted as a skill for an individual (NOT, for example: motivation, ability to communicate with or access HCPs or willingness to undertake healthy behaviours) NOT numeracy	Important aim of study, see section 2.4
Tool encompasses use of health literacy skills within context of everyday life, not just health care settings	Important aim of study, see sections 1.3 and 2.2
Application of health literacy skills generally, not to a specific LTC, and to multi-morbidity	To enable application to self-managing diabetes or arthritis (or both)
Suitable for UK audience/adults (written in English and appropriate for adults)	Study recruiting UK based adults
Focus on determining health literacy skill level for an individual	Important aim of study, see section 2.4
Records self-report of skills enabling classification in to functional, applied (communicative or interactive), critical level of skills	Important aim of study, see section 2.4.2
Uses a reasonable number of measures & can be completed in less than five minutes	Too short - unlikely to enable valid judgement of level of skills Too long - could be burdensome for participants (Bowling 2002)
Statements or questions easy to read and/or easy for me to read out to participants	Aimed to recruit people who found reading health information difficult/had left school with no qualifications, see section 3.4
Statements or questions have one part only and are easy to understand	Good practice for survey questions, improves accuracy and validity. Question should be a test of person's ability not a test of whether they understand what the question means. (Bowling 2002)
Available to use (no charge for use and no restrictions on use)	Cost and practicality

Table B AAHLS questions - critique and application to study HL tool

HL skill level	Question	Critique and comment	Adapted? Statement which is similar and level of skill
Functional	How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?	Context of ‘help you’ may not be understood. Adapted as context of requiring help indicates functional skills	‘I ask other people to explain health information to me’ functional
Functional	When you need help, can you easily get hold of someone to assist you?	Context of ‘help’ may not be understood, for e.g. help to do what?	‘Work with others to understand health information’ Applied
Functional	Do you need help to fill in official documents?	May not be viewed as relevant – writing rather than reading information	Not used
Communicative	When you talk to a doctor or nurse, do you give them all the information they need to help you?	Potentially leading ‘Of course I do’ Not clear what skill this is testing	Not used
Communicative	When you talk to a doctor or nurse, do you ask the questions you need to ask?	Potentially leading or confusing – ‘I don’t know what questions I need to ask’	Not used but asking questions is key so might be used/adapted in future
Communicative	When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?	Examines motivation rather than skill?	‘I ask other people to explain the information to me’ functional level
Critical	Are you someone who likes to find out lots of different information about your health?	Adapted as relevant to critical level of skills	‘I compare info from different sources and select the most useful’ Critical
Critical	How often do you think carefully about whether health information makes sense in your particular situation?	Adapted as relevant to critical level of skills	‘I can judge whether the info is relevant to my LTC’ Critical
Critical	How often do you try to work out whether information about your health can be trusted?	Isn’t *trust* sought by everyone? Adapted	‘Decide how reliable the info might be’ ‘Judge the quality of the info I find’ critical
Critical	Are you the sort of person who might question your doctor or nurse’s advice based on your own research?	Potentially leading, focus on visits to GP not everyday self-management	Not used

Table C FCCHL/HLS-14 questions - critique and application to study HL tool

HL skill level	Statement	Critique and comment	Adapted? Statement which is similar and level of skill
Functional	Find characters that I cannot read	Chinese translation, not totally applicable to English	'I find lots of words difficult to read' functional
Functional	Feel that the print is too small for me to read	Could be for eyesight reasons	'Read information about my LTC' functional
Functional	Feel that the content is too difficult for me to understand	Testing content of info rather than skill? Negative.	'I can read the words but do not always know what the words mean' functional
Functional	Feel that it takes a long time to read them	Confusion over 'read what?'	
Functional	Need someone to help me read them	Potentially rather vague	'I ask other people to explain the info to me' functional
Communicative	Collect information from various sources	Too similar to final statement? (at critical level)	'I compare info from different sources and select the most useful' Critical
Communicative	Extract the information I want	Extraction/application appropriate for this skill level	'Use info to help me manage my LTC' applied
Communicative	Understand the obtained information	Understanding will vary according to difficulty of info rather than skill level	'I will only act on the info if it is relevant to me' applied
Communicative	Communicate my opinion about my illness	Potentially confusing – 'my diagnosis'?	
Communicative	Apply the obtained information to my daily life	Application of info appropriate for this skill level	'I take in the information and try to act on it' applied
Critical	Consider whether the information is applicable to me	Judged as an applied level skill (see e.g.s above)	
Critical	Consider whether the information is credible	Relevant for this skill level but ? understanding of 'credible'	'Decide how reliable the info might be' critical
Critical	Check whether the information is valid and reliable	Relevant for this skill level	'Judge the quality of the info I find' critical
Critical	Collect information to make my healthcare decisions	Relevant for this skill level but more than just 'collect'	'I compare info from different sources and select the most useful' Critical

Appendix E Health literacy questions

Part A: These statements are asking you to think about what happens when you look for or use information to help you manage your long term condition (LTC).

Likert scale: never, sometimes, often, always.

I am able to….

1. Find relevant information about my LTC (functional)
2. Read information about my LTC (functional)
3. Remember information about my LTC (functional)
4. Use information to help me manage my LTC (applied)
5. Share health-related information with others (applied)
6. Decide how appropriate the health information is for me (applied)

Phase 2 added: 'Work with others (friends or family) to understand health information' (applied)

7. Use written information to answer my questions about my LTC (applied)
8. Help other people to understand health information (critical) in phase 2 changed to 'Take the lead with helping other people to understand health information'
9. Decide how reliable the health information might be (critical)
10. Judge the quality of the health information that I find (critical)

Part B (not changed in phase 2): These statements are asking you to think about how you use medical or health information that is given to you by a health professional, for example a GP, nurse or pharmacist.

When I read medical or health information that I am given;

Likert scale: never, sometimes, often, always.

1. I find lots of the words difficult to read (functional)
2. I ask other people to explain the information to me (functional)
3. I can read the words but do not always know what the words mean (functional)
4. I take in the information and try to act on it (applied)
5. I will share the information with others (applied)
6. I will only act on the information if it is relevant to me (applied)
7. I can judge whether the information is relevant to my LTC (critical)
8. I recommend information to others (critical)
9. I compare information from different sources and select the most useful information (critical)

Appendix F Review of social support measures

Name of Scale	**Authors & date**	**Brief description & pros of scale**	**Cons – in relation to this study**
Berlin Social Support Scale	Schwarzer & Schulz (2013)	Perceived emotional support, instrumental support, need for support and support seeking scales (not all published scales need to be used together).	Original form (2000) designed for coping with cancer surgery. Query acceptability to study participants – who are not in hospital setting/unwell
Duke Social Support Index (DSSI)	Koenig et al (1993)	Used with elderly and frail people, 45, 23 and 11 item tools.	Not freely available for use. Developed for use in USA.
Inventory of Socially Supportive Behaviors (ISSB)	Barrera et al (1981) cited in Haber et al (2007)	ISSB tool available online 40 questions, rate support received. Measures amount of support received (not type).	Developed with adolescents. USA focus in original. Query relevance of some questions for people living with LTC (e.g. gave you money $).
Multidimensional Scale of Perceived Social Support (MSPSS)	Zimet et al 1988	Focus on source of support, family, friends, significant other. 12 items Validated and used in many studies/surveys	General feel of support available, not specific to managing health. Focus on source of support overlaps with SN diagram. Type of support not elicited.
Oslo social support scale	Brevik & Dalgard (1996)	3 questions asking about number of close confidants, sense of concern from other people and relationship with neighbours	Too short, questions one and two too general. Q1 overlaps with SN diagram, Q2 – comprehension of ‘sense of concern’ in terms of LTC?
Sarason’s Social Support Questionnaire	Sarason, Levine, Basham & Sarason (1983)	Qs ask – who can help you when …. (for e.g. you are really upset) …? List people then rate satisfaction with overall support you have.	Query relevance of questions for people living with LTCs (originally developed with student aged group) Listing of supporters too similar to process required for social network diagram
Social Support Measures	Krause et al (1995)	Received support (3 items inc tangible support), emotional support (4 items), informational support (4 items e.g. sharing ideas), satisfaction with support (3 items), negative social interaction (e.g. criticism and demands by others 3 items)	Original questions now dated, USA focus, general questions about support received. Only parts of measure are relevant.

Appendix G Social support questions

Phase One: social support questions – participant version

When managing your long term condition how often do you…..

		Never	**Sometimes**	**Often**	**Always**
1	…. get the emotional support you need from other people?				
2	…. get the help you need from other people?				
3	….. get the resources you need from other people?				
4	….. get the advice you need from other people?				

Phase two social support questions – participant version

When managing your long term condition how often do you…..

		Almost Never	Sometimes	Often	Always
1	…. get the emotional support you need from other people?				
2	…. get support with doing things that you cannot do alone?				
3	….. get the information you need from other people?				
4	….. get the advice you need from other people?				
5	…..get support with making decisions about your health?				
6	…..find that the support you receive is helpful?				

Participant code …………………………..

Appendix H Interview guidance phase one

Phase ONE approach

Participant demographic information

Age

Gender

Long term condition(s) and how long lived with each

Qualifications: do you have any O levels? (or GCSEs – if under 40) If yes - higher qualifications?

Any other features to note? E.g. wear glasses, hearing aid, LTC impacted ability to read?

Interview 2 (semi-structured) Questions

How/when do you know to manage your LTC? (Embodied state: from Wyke et al 2013)

- What has to happen for you to start thinking about making changes/taking action?
- Prompt – could be; internal stimuli/external stimuli/changes in knowledge/physical symptom
- Why do you act or not act?
- Do they describe an explanatory model/causation?

Where does your knowledge of symptoms and how to act come from? (Knowledge: from Wyke et al 2013)

- Previous experience
- Feedback from others
- Information – health prof/read/TV/media

Take me through the most recent time when you had physical symptoms on which you acted (interpretation/evaluation/action) (Typical day strategy from Miller & Rollnick 2013, interpretation etc from Wyke et al 2013 and Lorig & Holman 2003)

- Ask about importance and confidence to act (when appropriate)
- Identity
- Timeline (duration) expected
- Consequences (expected outcomes)
- Cause
- Controllability
- Action taken
  - Not much change
  - Manage at home
  - Access health service(s)
- ‘If then’ strategies used?
- How did you know action successful or not? Their judgement of outcome
- Main emotion (fear, avoidance, worried, not worried, upset)
- Was anything else going on at the same time which influenced you?

If not already clear from first meeting: possible questions which reinforce/provide check for those already asked in first meeting.

Who supports you to manage your LTC? (Resources and social structure/interaction)

- Instrumental support (e.g. helping out, doing things)
- Information support
- Emotional support – listening, understanding
- Appraisal support – help with decision-making (Types of social support from Berkman et al 2000 and Heaney & Israel 2008)
- Is the support reciprocated? (do you provide them with support?)
- Is the support usually or always positive/helpful?
- Is there anyone who is in your social network (explain term if necessary) but not very supportive/is unhelpful?

Who is in your network of support?

- Frequency of contact (how often do you see them?)
- What type of contact? (see list above)
- How long have you known them?

How do you find and use health information? (Resources/health literacy)

- Do you know where to find relevant information?
- What sources do you use? (doctor, nurse, friends, family, web, helpline, books, TV)
- Which sources do you find easiest to understand?
- Do you think about the quality of the info? (eg how reliable it is)
- Do you ask others to help you find or use info?
- When you have found/are given info do you find it easy or difficult to act on the information?

Questions above probe health literacy level, checking out whether HL is basic, applied or critical (see questionnaire).

Final overall questions about motivation to self-manage (Miller & Rollnick 2013)

- How much control do you feel you have in managing your LTC?
- Where is your motivation level for self-managing? (Importance for self-managing, confidence for self-managing?)
- Does confidence vary? If so, when?
- When do you find it most difficult to manage?
- When do you find it easiest to manage?

Appendix I Interview guidance phase two

Phase TWO approach

Interview One – using structured data collection tools

Go through aim of research, check participant has read information sheet, check any questions or concerns. Go through consent form and check that participant is happy to take part and sign.

Participant record information

Age

Gender

Long term condition(s) and how long lived with each (self-report)

Qualifications: do you have any O levels? (or GCSEs – if under 40) If yes - higher qualifications?

Any other features to note? E.g. wear glasses, hearing aid, LTC impacted ability to read?

Start recording and go through:

Health literacy questions tool (see participant version)

Compile diagram of social network using 3 concentric ring approach. Indicate for each actor the frequency of contact, daily, at least weekly, monthly and less frequent than monthly.

Social network questions (see participant version)

Turn off recorder

Check participant OK and thank for time. Arrange date and time for second interview.

Interview two – semi-structured interview

Re-cap aim and check no questions or concerns and happy to proceed.

Start recording, select from questions below as appropriate:

Health literacy skills

Do you use written information to help you manage your LTC?

If yes, where do you get the information from?

If no, what are your reasons for not using written information?

What other sources of health information do you use?

EGs TV, friends, support group, family, web info, health professionals, others

What are the barriers, for you, to using health information?

What are the things that help you to use information when managing your LTC?

Social network for LTC management

Refer to visual diagram of social network compiled during interview 1

Check network diagram check that everyone is on there and in correct position and that frequency of contact (how often do you see them?) is noted.

How do the people in your network support you to manage your LTC? (Resources and social structure/interaction). Possible categories to probe:

- Instrumental support (e.g. helping out, doing things)
- Information support
- Emotional support – listening, understanding
- Appraisal support – help with decision-making
- Is the support reciprocated? (do you provide them with support?)
- Do you give advice to others?
- Do others give you advice?
- Is the support usually or always positive/helpful?
- Is there anyone who is in your network but not very supportive/is unhelpful?

How/when do you know to manage your LTC?

- What has to happen for you to start thinking about making changes/taking action?
- Why do you act or not act?

Where does your knowledge of symptoms and how to act come from?

If prompt required to gain more information use:

Take me through the most recent time when you had physical symptoms on which you acted (prompt for interpretation/evaluation/action)

Final overall questions about motivation to self-manage

- How much control do you feel you have in managing your LTC?
- How important is it to you to manage your LTC?
- How confident are you about managing your LTC?
- Does confidence vary? If so, when?
- When do you find it most difficult to manage?
- When do you find it easiest to manage?

Turn off recorder

Check participant OK and thank for time. Offer voucher.

Appendix J Transcriber Anonymity Agreement

Title of study: Self-management of long-term conditions: can a tactical use of health literacy and social networks make a difference for individuals with low literacy?

University of Southampton ERGO 23842

Researcher Lyn Wilson

Transcriber

As a transcriber of this research I understand that I will be hearing recordings of anonymised interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that they would remain anonymous. I understand I have a responsibility to honour this anonymity.

I agree not to share these recording with anyone except the Researcher (Lyn Wilson).

I agree to keep all research information in any format (e.g. audio-recordings and word documents) secure while it is in my possession.

I agree to return the research information in any format (e.g. word documents) to the Researcher when I have completed the transcription.

I agree to erase or destroy all research information which is any format that is not returnable to the Researcher (e.g. stored on computer) when asked to do so by the Researcher.

Signed researcher: signed electronically Lyn Wilson as date Date: 2.7.18

Signed transcriber: email acknowledgement received July 2018 Date:

Glossary of Terms

Empowerment	a process of personal transformation enabling control over one's management of health
Health information	information which is useful for managing health, can include written or verbal information such as facts, treatments and management actions
Health literacy	a process whereby society works to ensure populations become health literate
Health literacy skills	skills of finding and reading health information, understanding (or de-coding) information, applying information to one's situation, judging the quality of information, and explaining information to another person
HL skill ability	the degree to which an individual can obtain, understand and apply information required for health-related decisions and actions
Long-term condition	a condition that impacts on a person's health and lasts at least a year (National Institute for Health and Care Excellence 2016)
Motivation	a person's judgement of the importance for making a change and their confidence to make a change
Personal social network	a theoretical construct which explains, and accounts for, the social relationships that an individual experiences
Self-management	a dynamic lived process (Kendall et al 2011) through which a person undertakes actions to promote their health, manage illness and manage life with a long-term condition (Audulv et al 2012)
Social capital	the benefit accrued from working with others within a community
Social support	the provision of resources, by alters, which is perceived by an ego as to improve the ego's health and well-being
Tactics	the art and skill of employing available means to accomplish an end (Merriam-Webster 2018)

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