Exploring the Maintenance of Social Connection for Adults Living with Complex Medical Conditions in New Zealand: A Qualitative Study

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Abstract

Background: Complex medical conditions (CMCs) are persistent and ongoing health conditions that substantially impact an individual's life and require treatments and services from a variety of healthcare specialists. One area likely to be impacted for this health population is the social dimension of their lives. An understanding of how social connection is maintained by individuals living with CMCs may be used to guide support initiatives. This study sought to answer the research question, "How is social connection maintained by individuals living with complex medical conditions?"

Participants / Method: In 2018 face-to-face interviews were conducted with 30 participants who lived with CMCs. Reflexive thematic analysis was used in the current study to analyse the data from 12 of these interviews. Participants ranged in age from 24 to 60 years of age and had lived with their conditions for an average of 15 years.

Findings: Six themes were derived from data analysis that gave insight as to how adults living with complex medical conditions maintained social connection: *Social connection is maintained despite health challenges*; *Social interaction is constrained; Social connection is enhanced by prioritising needs; Technology and connection to the outside; CMCs are linked to experiences of social isolation and loneliness; and, connecting through shared experience positively influences social connection.*

Conclusion: For those living with CMCs regular connection was made with close friends and family despite health challenges. Individuals made efforts to maintain social connection because it was considered important. Physical and emotional condition related factors constrained social interaction. Social connectedness was facilitated by prioritising needs and planning and preparing for social events. Technology significantly enhanced social connection. Individuals living with CMCs experienced social isolation and loneliness but had a variety of strategies to manage these experiences. Owning a dog positively impacted experiences of isolation and loneliness. Connecting through shared experience encouraged reciprocal engagement including informational and emotional support.

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Attestation of Authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning."

Signed: Date: 27 February 2023

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Ethics approval was obtained on 26 March 2018 from the Auckland University of Technology Ethics Committee (AUTEC) reference number 18/86 (Appendix A) with an amendment obtained on 3 August 2021 to allow deidentified data to be utilised for the current research project (Appendix A). An extension was granted on 4 October 2022 until 26 March 2023 to complete the project (Appendix A).

Introduction

Good health is considered multidimensional and dependent on an individual's ability to perform everyday activities and is influenced by an individual's happiness, quality of life, and emotional and social wellbeing (McDowell & Newell, 1996). This view involves responding not just to medical needs but also social, cultural and economic factors that influence health (National Health Committee [NHC], 2005). Globally, there has been a shift in recent years to focus more holistically on the needs of individuals who live with chronic illness, disease, and disability (NHC, 2005).

Chronic conditions describe persistent or reoccurring long-term conditions that last three months or more and that have a significant impact on a person's life and limit daily activities (Anderson 2010; Anderson & Horvath 2004; U.S. Department of Health and Human Services, 2010, Van der Lee et al., 2007). Chronic conditions can include a wide range of physical and mental health conditions such as arthritis, depression, heart disease, cancer, diabetes, and neurological conditions (NHC, 2005; Theis & Furner, 2011). In New Zealand approximately 14 per cent of the population have a long-term condition and approximately a third of these cases have multiple conditions (Ministry of Health [MOH], 2022).

Multimorbidity refers to two or more chronic conditions that require complex and ongoing care (World Health Organisation [WHO], 2016). Individuals with a chronic condition frequently live with more than one condition (NHC, 2005; Violan et al., 2014) and the number of people with multiple chronic conditions is continuing to rise (Uijen & van de Lisdonk, 2008). Multiple chronic conditions are a global health issue with one in three older adults living with multimorbidity (Marengoni et al., 2011). With multiple chronic health conditions difficulties tend to grow exponentially, treatments and visits to the doctor increase, mobility is limited, fatigue and pain increase, and employment becomes difficult or impossible (WHO & World Bank, 2011).

Individuals living with severe chronic conditions and multimorbidity are likely to experience functional limitation and disability (Chrvala & Sharfstein, 1999; MOH, 2014). "Disability is the umbrella term for impairments, activity limitations and participation

restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" (WHO & World Bank, 2011, p. 4). Living with severe chronic health conditions and disability is associated with significant challenges and healthcare demands (Iezzoni, 2010).

Complex Medical Conditions

Reference to *complex medical conditions* (CMCs) is rarely seen in the health literature. Studies of serious long-term health conditions largely refer to chronic health conditions or multimorbidity. Yet, neither of these health terms sufficiently describes the severity, or multifaceted care requirements, of more serious and complex medical conditions (Chrvala & Sharfstein, 1999).

As well as substantial ongoing care, these complex conditions require intermittent interventions to address illness and disability (Chrvala & Sharfstein, 1999). Comprehensive services are needed to proactively support functional ability, mental health, social needs, and wellbeing (Chrvala & Sharfstein, 1999). Specialist services can include: inpatient and outpatient care; nutritional support; mental and behavioural health care; occupational, physical and speech therapy; rehabilitation services; home care; transport assistance; and potentially care in nursing homes or skilled nursing facilities (Chrvala & Sharfstein, 1999).

To assist in the definition of CMCs, the current study draws on a research based framework designed to assist with care for children with medical complexity, see Figure 1 (Cohen et al., 2011). This framework identifies four domains that conceptually represent care requirements. *Needs* describes the significant burden on family who manage healthcare needs and includes financial burden. *Chronic condition(s)* refers to one or more, diagnosed or unknown, severe and chronic condition that is associated with high morbidity and mortality. *Functional limitations* relate to the ability to function and perform daily activities. Limitations are typically severe and may require assistance

from technological devices. Lastly, *health care use* describes the high utilisation of health care services in comparison with other medical conditions.

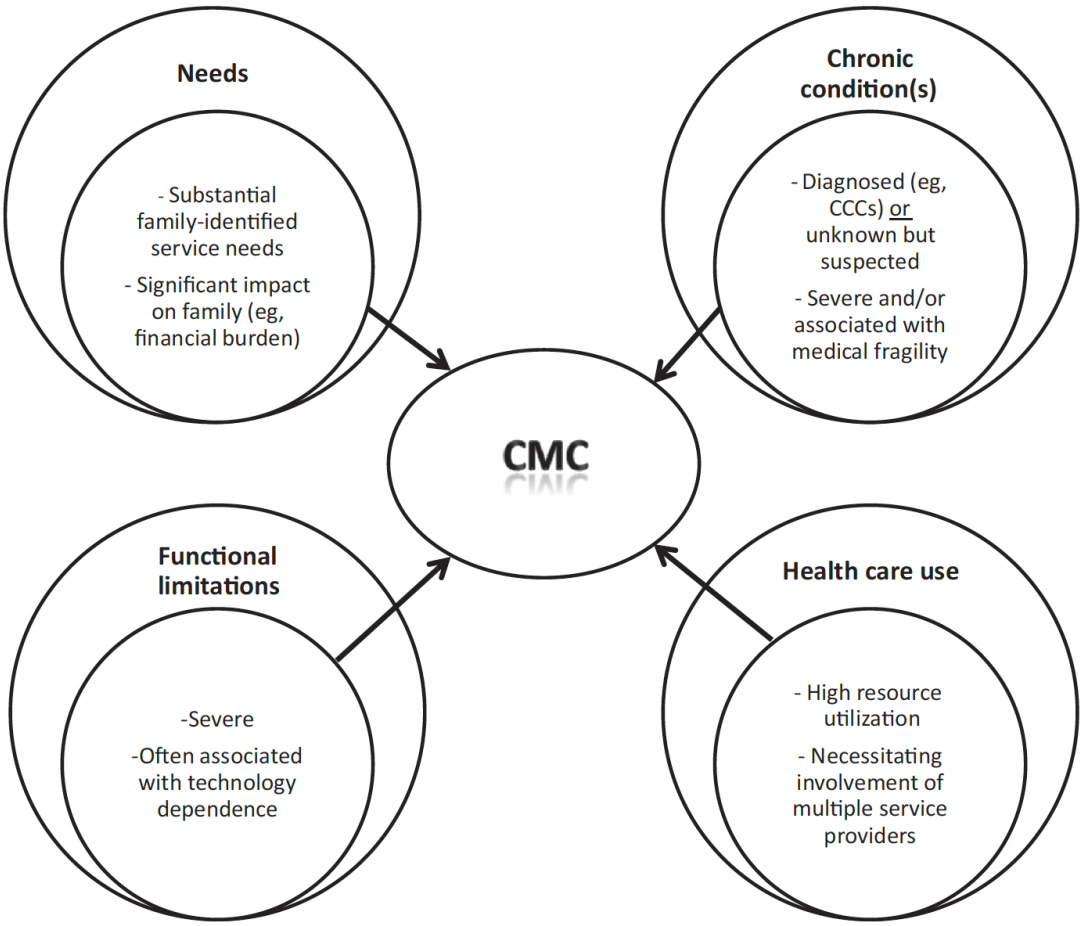


Figure 1. "Definitional framework for children with medical complexity" (Cohen et al., 2011).

While this model was designed for use with children who live with medical complexity it can be adapted for adults. Chrvala and Sharfstein (1999) have highlighted similar criteria for adults with serious and complex medical conditions.

Living with CMCs

The complex nature of CMCs mean that individuals are often balancing the effects of multiple health issues (Chrvala & Sharfstein, 1999; NHC, 2005). For example, individuals living with neurological disorders may experience severe pain or muscle

weakness and they may also be affected by vision and cognitive difficulties (New Zealand Neurological Foundation, 2022).

Studies of chronic conditions and multimorbidity help demonstrate how daily activities including connecting socially are likely to be impacted for individuals living with complex health conditions. Long-term health conditions can be associated with bodily impairments, chronic pain, fatigue, decreased mobility, and functional limitations that affect daily living and limit independence (Griffith et al., 2017; Holley, 2007; Miller, 1985). For individuals living with chronic health conditions, physical symptoms related to their condition can limit the ability to leave the house (Wilkinson et al., 2019). Transportation can become more difficult due to proximity to public transport, mobility issues, vision issues, or the need to use a wheelchair, resulting in individuals becoming more dependent and more isolated (Holley, 2007, Wilkinson et al., 2019). For those individuals that become more homebound this can lead to reduced social interaction and diminished social networks (Holley, 2007).

Individuals living with chronic conditions may also experience a loss of social roles and reduced social networks as they give up employment or social activities (Carr et al., 2018; Holley, 2007; NHC, 2005; Miller 1985). For example, Wilkinson et al. (2019) explain that social opportunities are impacted due to stopping work or needing to stop certain sports and hobbies. For some individuals living with congenital conditions they may never have had social roles through sport or employment and may have always lived with a smaller social network.

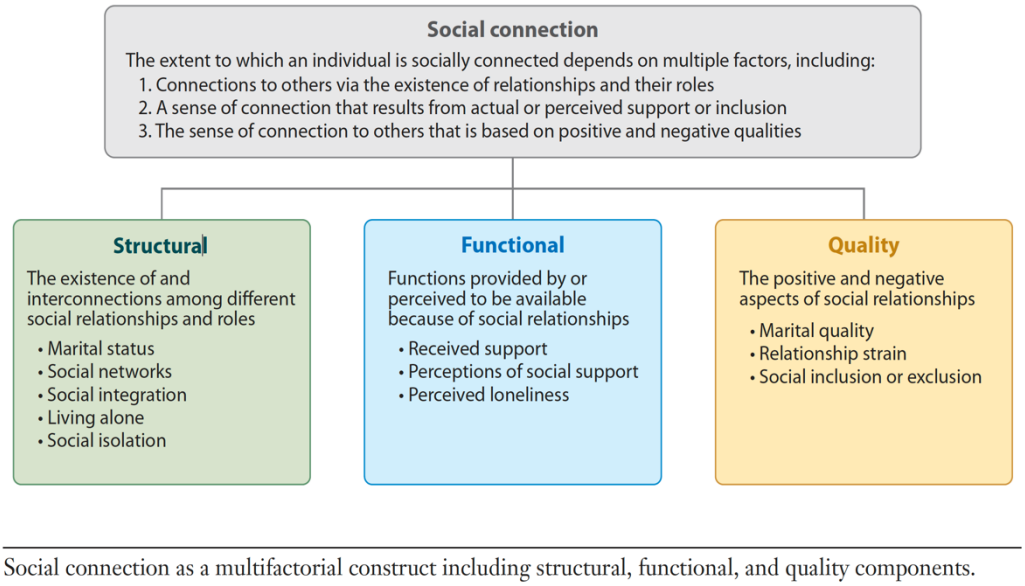
A reduced income due to changes in employment, or health expenses, can also mean that social activities become more of a luxury than previously experienced and may lead to less socialising (Holley, 2007). In their study of individuals with long-term health conditions Wilkinson et al. (2019) found that some individuals limited social occasions or stopped participating in leisure activities due to financial constraints.

The Importance of Social Connection

Humans are social beings. Social relationships play an important part in our everyday lives including a desire to create positive, enduring and meaningful relationships (Baumeister & Leary, 1995). Motivation to form social relationships is thought to have an evolutionary basis as survival was greatly enhanced when humans formed connections with others in order to protect offspring, share resources, and defend against predators (Baumeister & Leary, 1995; Hawkley & Cacioppo 2010).

There is a wealth of literature across multiple scientific disciplines investigating the impact of social relationships on health (Holt-Lunstad, 2015). It has been well established that the social dimension of our lives has a significant impact on our physical, mental, and cognitive health (Haslam et al., 2015; Holt-Lunstad, 2021; Kawachi & Berkman, 2001). In recognition of the importance of social relationships for health The World Health Organisation (WHO) now includes “social support” under The Determinants of Health (Solar & Irwin, 2010).

In broad terms, *Social Connection* can be considered the subjective sense of having meaningful, reciprocal or emotional relationships with others (Seppala et al, 2013; Wilkinson et al., 2019). Social connection refers to the existence of relationships, the role of these, including actual or perceived support, and that are influenced by positive and negative qualities (Holt-Lunstad, 2015) . The health literature supports a multi-factorial view of social connection incorporating three components: *relationship structure*, *function*, and *quality,* see figure 2 (Holt-Lunstad, 2018). Structural aspects describe our connection to others including size and diversity of social networks, frequency of contact, social group membership, and living arrangements such as married or alone (Holt-Lunstad, 2018). The functional component refers to actual or perceived functions found within social networks that meet our needs such as social support (Holt-Lunstad, 2018). Quality refers to the positive and negative influences on our relationships such as relationship satisfaction, strain, inclusion or exclusion (Holt-Lunstad, 2018).



Social connection as a multifactorial construct including structural, functional, and quality components.

Figure 2: Social connection as a multifactorial construct (Holt-Lunstad, 2018)

Early research on the relationships between social connection and health found reduced social networks and fewer social ties predicted mortality (Berkman & Glass, 2000). Social networks are described as a web of social ties that provide the structure for the functioning of relationships and their interconnections (Ashida & Heaney, 2008; Haslam et al., 2015). Most studies of structural influences on social connection have used social network analysis to explore social networks and investigate the objective characteristics of relationships such as size and diversity of networks, type of connections, and frequency of contact (Cacioppo & Cacioppo, 2014).

Research on functional components of social connection have largely focussed on social support (Berkman & Glass, 2000). House (1981) proposed four main components of social support including *emotional support, instrumental support, informational support,* and *appraisal support*. Emotional support includes providing love, empathy, trust and caring whereas instrumental support relates to assisting others with aid or help with tangible needs such as cooking and cleaning (Berkman & Glass 2000; Heaney & Israel, 2009). Informational support describes the giving of information, suggestions or advice whereas appraisal support relates to providing feedback and affirmation that is

helpful in decision making (Heaney & Israel, 2009). Frequency of contact with network members is linked with higher levels of social support (Ashida & Heaney, 2008).

However, the exchange of social support is not the only functional characteristic of social connection as social relationships provide companionship and meaningful engagement through social and emotional connection (Ashida & Heaney, 2008; Berkman 1984; Berkman & Glass, 2000; Rook 1999). Interacting with network members, family and friends, neighbours, and the community, provides a social cohesion and interdependence that gives meaning to social relationships influencing perceptions of being socially connected (Ashida & Heaney, 2008; Berkman & Glass, 2000). *Social Connectedness* describes "the sense of belonging and subjective psychological bond that people feel in relation to individuals and groups of others" (Haslam et al., 2015, p.1).

Social connectedness developed from belongingness theory (Baumeister & Leary, 1995; Lee & Robbins, 1995) posits individuals are motivated to create and sustain rewarding social connections to foster a sense of belonging. Being socially connected and socially and emotionally engaged can positively influence wellbeing aside from social support exchange (Ashida & Heaney, 2008). Research indicates that density of network as well as living in close proximity to network members is linked to higher perceived social connectedness (Ashida & Heaney, 2008). Appraisal of social relationships in regards to social connectedness can result in feelings of loneliness and need for greater connection (Ashida & Heaney, 2008).

Research highlights the importance of social relationships for individuals living with serious and chronic illness and disease. For example, individuals living with Human Immunodeficiency Virus (HIV) and Hepatitis C Virus have described living with their disease as a lonely life but they also spoke of key significant relationships in their lives that provided critical social support (Farrell & Comiskey, 2014). For older adults living with Arthritis, engaging in social activities strengthened family bonds and helped individuals cope with Arthritis symptoms (Stevens-Ratchford & Cebulak, 2005). Similarly, for older age adults living with Diabetes and multiple chronic illnesses, living in

a positive social environment, with good social support, and opportunities to engage, was linked with less depression (Yeung et al., 2022). Also, individuals living with Cystic Fibrosis report social connectedness is related to improved physical and mental health as family and friends provide support through treatments, encourage exercise, and are available to talk through problems and give advice (Harrigan et al., 2022).

The New Zealand Ministry of Social Development (MOH, 2018) commissioned research to determine how social connectedness can be better supported. Recommendations for future research included exploring how social connectedness is related to wellbeing in a New Zealand context, gaining insight as to how social connectedness is experienced for "at-risk" groups, and developing understanding as to the social ties that matter and in what context (MOH, 2018). The goals of the current study are aligned with these recommendations. Exploring how individuals living with CMCs experience and maintain the social dimension of their lives enables greater understanding of the aspects that help or hinder social connectedness and can guide policy and health initiatives that advocate for the health and wellbeing of this population.

Social Isolation and Loneliness

It is argued that strengthening social connection may act as a protective factor against the effects of social isolation and loneliness (Holt-Lunstad, 2021). Social isolation and loneliness are often discussed in the health literature together; however, they are considered related but distinct concepts (Cacioppo et al., 2011; Perissinotto et al., 2019). *Loneliness* can be defined as a painful and distressing subjective experience that is based on an individual's perception of their social networks and relationships as lacking in quantity or quality (Cacioppo et al., 2011; Peplau & Perlman, 1982; West et al., 1986). *Social Isolation* can be defined as an objective state related to social interactions and networks of a certain type and frequency that can be lacking (Cacioppo et al., 2011). More isolated individuals may be at increased risk for loneliness (Holt-Lunstad et al., 2010). Yet socially isolated individuals are not necessarily lonely and conversely

individuals with large social networks may still be lonely (Holt-Lunstad et al., 2015; LeRoy et al., 2017; Perissinotto et al., 2019).

Recent reviews and meta-analyses have highlighted social isolation and loneliness as an urgent health issue due the negative impact on health outcomes (Hawkley & Cacioppo, 2010; Holt-Lunstad, 2017; 2021; Perissinotto et al., 2019). Social isolation and loneliness can impact individuals at any age and the number of socially isolated and lonely individuals in the general population appears to be increasing (Hawkley & Cacioppo, 2010; Holt-Lunstad et al., 2015; Perissinotto et al., 2019).

Social isolation and loneliness are significant risk factors for morbidity and mortality (Holt-Lunstad, 2021), depressive symptoms (Cacioppo et al., 2006), suicide (Hawkley & Cacioppo 2010), cardiovascular health issues (Valtorta et al., 2016), cognitive decline (Shankar et al., 2013), as well as altered immunity (Pressman et al., 2005). In fact, meta-analytic research has found social isolation, loneliness, and living alone are comparable, if not greater, risk factors for mortality than obesity, air pollution, and being physically inactive (Holt-Lunstad, 2010).

Hawkins-Elder et al. (2018) analysed results from a recent New Zealand Values and Attitudes Survey and found that individuals that had the poorest ratings of health and the lowest perceived social support had the highest rates of loneliness. The majority of research investigating vulnerable health populations at risk for social isolation and loneliness has predominantly focussed on older adults (Lasgaard et al., 2016). This research consistently demonstrates a link between poor health and increased rates of isolation and loneliness. For example, data from a national survey of older-age Danish adults found poor self-rated health, limited physical ability and multimorbidity were associated with greater loneliness (Jessen et al., 2018). Also, a study of older adults in New Zealand, found those with visual impairment had significantly less social support available and felt more isolated and lonely than those without impairment (Wright-St Clair et al., 2017). Overall, studies including older adults have found general disability, greater dependence, mobility difficulties, and hearing and vision impairments are associated with higher rates of loneliness (Cohen-Mansfield & Eisner, 2020; Jones et al.,

1985; Savikko et al., 2005; Tijhuis et al.,1999; Wright-St Clair et al., 2017). Other important factors include transport issues, lack of contact with friends, and less social network support (Cohen-Mansfield et al., 2009; Drennan et al., 2008).

Chronically ill individuals in New Zealand are one of the health populations more likely to report significant loneliness (Smith, 2015). Research shows individuals with serious health conditions can feel excluded from social activities due in part to physical limitations and pain but also due to a lack of mental energy (Bay et al., 2020). Also, many symptoms of serious health conditions such as cognitive or hearing difficulties can be invisible to others leading to increased feelings of isolation and marginalisation during social interaction (Cohen-Mansfield & Eisner, 2020; Holley, 2007; Umeh et al., 2017). Moreover, Bay et al. (2020) found that individuals living with a significant health conditions can fear future loneliness whereby they anticipate the need to stop work, or stop social activities, leading to increased isolation.

In addition, individuals may choose to withdraw socially from fear of being treated differently often leading to greater isolation (Biordi & Nicolson, 2013; Farrell & Comiskey, 2014; Umeh et al., 2017). These experiences may be linked to 'anticipated stigma' which describes when an individual believes they will experience prejudice, stereotyping, and discrimination in their future interactions with others (Earnshaw et al., 2012). Individuals may not want to reveal their condition to others to avoid judgement and withdraw from interaction instead leading to further isolation (Biordi & Nicolson, 2013). Research indicates for individuals living with chronic illness, anticipated stigma was associated with less perceived social support and less perceived social support was linked to lower quality of life (Earnshaw et al., 2012). These findings highlight the need to explore how living with CMCs may impact an individual's ability to maintain social connection.

Research Question: How is social connection maintained by individuals living with complex medical conditions?

Purpose of this Study

The current study is part of a larger study funded by a bequest from the late Dr Jeanette Crossley. Dr Crossley directed her Trustees to apply certain funds to understand the causes of and solutions for loneliness and social isolation in New Zealand society, especially for those living with complex medical issues.

Previous research exploring the relationship between poor health and social connection has been limited to mainly older adults (Lasgaard et al., 2016) whereas the current study aims to add to the health literature by exploring social connection maintenance for those living with CMCs across a wider range of ages. In addition, studies investigating the impact of health on social relationships has been primarily quantitative in design demonstrating a gap in the literature (Wilkinson et al., 2019). The current study includes a qualitative research design. Research from a personal perspective can provide greater insight as to what aspects facilitate or limit social connectedness and gain new understandings that quantitative research may not capture (Cohen-Mansfield & Eisner, 2020).

CMCs that are severe and demand substantial ongoing care across a range of services are likely to impact an individual's ability to remain socially connected due to physical, mental, emotional, and financial factors (Bay et al., 2020; Chrvala & Sharfstein, 1999; Griffith et al., 2017; Holley, 2007). Maintaining social connection is important as it has been shown to support vulnerable health populations with physical and mental health and wellbeing (Harrigan et al., 2022; Rybarczyk et al., 2012; Stevens-Ratchford & Cebulak, 2005; Yeung et al., 2022). There is a need to explore how those living with CMCs experience and maintain the social dimension of their lives in order to better understand how to adequately support this population.

Lastly, an important goal of this research is to provide practical benefit. Insights gained from this research can support those that advocate for enhanced quality of life, health and wellbeing for individuals living with CMCs. For example, this research can be used to inform future policy and procedures that aim to enhance social connectedness for vulnerable health populations as outlined by MOH (2018). Also, providing an

increased understanding of how CMCs impact social connectedness including experiences of social isolation and loneliness can be used by health professionals to guide care, treatment, and intervention to support wellbeing (Perissinotto et al., 2019; Wilkinson et al., 2019).

Methodology

This chapter provides the rationale for the methodology used to conduct this study and includes detailed information on the methods involved.

Theoretical Perspectives and Epistemological Position

Research design and methods are ideally guided by a research framework to direct the most suitable approach for addressing the research question and be clear about research objectives (Willig, 2008). It is important researchers describe the theoretical and epistemological assumptions underpinning their research methodology as that in turn guides the framing of the research question, the process, the methods used, and impacts the overall research outcome (Braun & Clarke, 2006; Grant & Giddings, 2002).

Abstract beliefs and feelings about how the world can be understood and studied are influenced by the principles of ontology and epistemology (Denzin & Lincoln, 2000). Ontology refers to our assumptions about the nature of reality and what kind of being a human being is (Denzin & Lincoln, 2000). The current research takes a relativist stance which rejects the notion that there is a singular reality and posits that there is diversity in interpretation (Willig, 2008). This research attempts to understand the multiple perspectives and meanings attributed to the experiences of participants.

Epistemology describes what we consider knowledge and defines the relationship between the researcher and what can be known (Denzin & Lincoln, 2000). The current study was influenced by an interpretivist view of knowledge. An interpretivist perspective strives to understand what meaning people attach to life and understand human experience through the eyes of the individual (Grant & Giddings, 2002; Nicholls, 2009a).

Interpretivist research requires the researcher to listen to descriptions of experiences told by individuals and then interpret the significance of those descriptions to provide new insights (Grant & Giddings, 2002). Interpretivist research has become increasingly popular in health care to gain knowledge by studying illness as a lived

experience (Nicholls, 2009a). This style of knowledge acquisition fits well with this study which aims to explore the experience of social connection for people living with CMCs including the meaning they attribute to those experiences.

Qualitative Design

There are many strengths to a qualitative design relevant to this study. Qualitative research is ideal for exploring phenomena in a natural way and sense of the lived experience of others within the social and cultural systems that they live (Denzin & Lincoln, 2000; Nicholls, 2009a). Understanding health and illness from the narratives of those involved can facilitate a sense of self for those experiencing illness and deepen understanding of how illness can impact wellbeing (Boylstein & Hayes, 2012; Nicholls, 2009a).

Qualitative research can provide enhance learning within healthcare as it brings different goals, methods and analysis in order to understand the complexity of health (Nicholls, 2009a). Qualitative research focuses more on the quality of experience in contrast to cause and effect relationships therefore rather than defining variables prior to commencing their work researchers are concerned with the meanings attributed to events (Willig, 2008). Importantly, this style of research allows people to describe their experiences in their own words and therefore can improve the power balance between researcher and participant and is particularly useful for giving disadvantaged or vulnerable populations a voice (Webber-Ritchey et al., 2021).

Method

Wrapson and Patel (2019) amended the framework for children with medical complexity based on the work by Cohen et al. (2011) and van der Lee et al. (2007) to include criteria for adults with medical complexity as outlined by Chrvala & Sharfstein (1999). For example, the needs domain was expanded to include impact on intimate relationships as well as disruption to daily activities such as paid employment. This model was used in the current study to assist in definition and criteria for CMCs.

Participants needed to meet 1 criteria from each domain to be eligible to participate (see Figure 3).

Based on the work by Chrvala & Sharfstein (1999), outlining serious and complex medical conditions in adults, the following definition of a CMC was used: *A complex medical condition (CMC) is persistent and ongoing, substantially impacts on your life, and requires treatments and services from a variety of healthcare specialists (excluding your GP).* For example, an individual may see a rheumatologist and a cardiologist in relation to an ongoing medical condition that has a substantial impact on their life. Or an individual may see a specialist because they have other medical conditions or health risks that are related to their primary medical condition. For example, an individual with Diabetes may see an endocrinologist but may also see an eye specialist because of the possibility of eye problems.

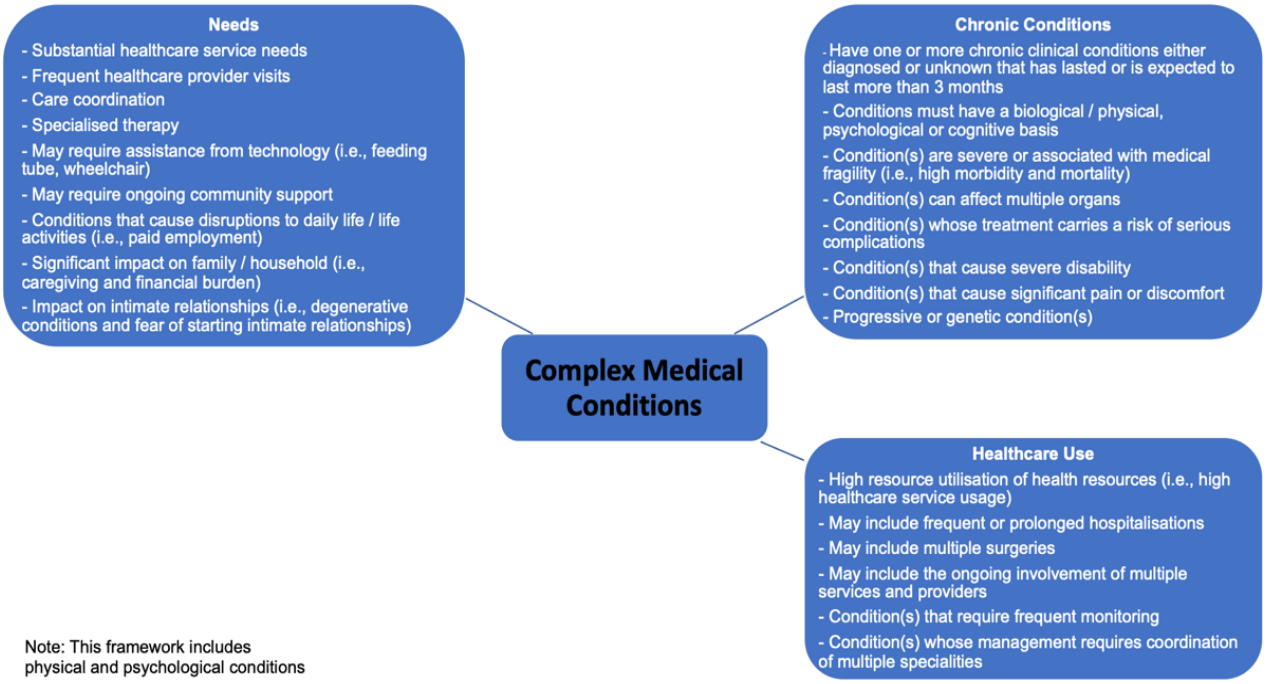


Figure 3: Framework to describe CMCs in adults, as adapted by Wrapson and Patel (2019) from the definitions and criteria established by Chrvala and Sharfstein (1999) Cohen et al. (2011) and van der Lee et al. (2007).

Participants and Recruitment

Qualitative interviews were undertaken as part of a larger project conducted by Dr Wrapson, Primary Investigator, at the National Institute for Public Health and Mental Health Research, Faculty of Health and Environmental Sciences, AUT. Recruitment and interviews were conducted in 2018 by a Research Fellow employed on the project. Participants were recruited using purposeful sampling. This style of sampling is widely used within qualitative research as individuals who may share a common experience, and who are open to talking about their experiences, can provide information rich data on the phenomena under study (Braun & Clarke, 2013; Nicholls, 2009b).

A request to participate in the overall project was advertised in local community newspapers. In addition New Zealand organisations that provide support and advocacy to adults living with CMCs advertised on behalf of the research team in support group newsletters and on social media (see Appendix B). Participants needed to be between 18-65 years of age and living in Auckland. Those who were interested in taking part were then asked to contact the investigators via phone or email to get more information on the project and answer any questions. This study focussed on maintaining social connection with network members outside of the home.

A participant information sheet (PIS) was forwarded to interested individuals (see Appendix B). Potential participants were informed that they were invited to take part in a study that aimed to gain insight into their experience of living with CMCs and in particular the impact on social connection. For those that expressed an interest to participate, an interview time was confidentially arranged.

Data collection. Informed consent was obtained before the interview began (see Appendix B). A brief demographic questionnaire was also given prior to the interview to be used for describing the research sample (see Appendix B). A 7-day journal was given to participants to complete prior to the interview but the analyses of these do not form part of the work comprised in this dissertation.

Face-to-face semi-structured interviews were undertaken in a private meeting room at AUT or in the participant's home, dependent on their preference. Interviews lasted between 60-90 minutes. The Research Fellow began the interview by building rapport

which is important for building trust when sharing personal information (Morrow, 2005) and often critical when working with Māori participants to develop a trusting environment for personal disclosure (Mooney, 2012).

Semi-structured interviews are the most common tool used by qualitative researchers (Willig, 2008). Face-to-face semi-structured interviews were chosen as the most appropriate method of data collection for this study as this allowed the participants to describe their experiences in their own words and to converse in a more natural manner (Braun & Clarke, 2013). This method is ideal when interviewing on complex or emotionally sensitive material (Kallio et al., 2016). Semi-structured interviews are often used in healthcare to help guide participants as they share personal experiences (Gill et al., 2008). Additionally, this style allows the interviewer to diverge and ask spontaneous and unplanned questions leading to more full and rich responses (Braun & Clarke, 2013).

An interview question guide was used to assist with the interview (see Appendix B). An example question is “Do you have any friends that you see on a regular basis?”. Questions were designed to be open ended to encourage broader responses (Hill, 2014). For each interview the questions typically followed the same format as per the guide. However, the semi-structured format meant that the researcher could explore areas more in-depth that were important to individuals (Kallio et al., 2016). This type of interviewing style is more respectful and collaborative (Grant & Giddings, 2002). The interviews were audiotaped and then transcribed verbatim by a professional transcriber who had signed a confidentiality agreement.

Sample. To keep this dissertation within an acceptable scope, this report is based on the first 12 interviews from the 30 total participants. A general rule of thumb for a small research project such as an Honours dissertation is that 6 – 10 interviews should be sufficient (Braun & Clarke, 2013). Perhaps a better question is whether the sample size is large enough to allow diversity without being so large that there is risk of compromising detailed accounts from participants (Sandelowski, 1995).

Saturation has typically been used to judge adequate sample size within thematic analysis however the concept does not fit well with the values and assumptions of reflexive thematic analysis which requires researchers to make decisions about sample size

depending on the quality and richness of their data during the research process (Braun & Clarke, 2022). More important, is that the sample size is large enough to produce patterns of meaning across the dataset related to the research question (Terry et al., 2017). In other words, sampling in qualitative research relies on quality rather than quantity to gain an in-depth understanding of a phenomena (Nicholls, 2009a; Terry et al., 2017).

This idea is consistent with the concept *Information Power* that Braun and Clarke (2021; 2022) have suggested may be a more useful and pragmatic way to determine adequate sample size than saturation. *Information Power* suggests the more a dataset holds relevant information, and a rich description of the phenomena under study, the less participants are needed (Malterud et al., 2016).

Therefore, throughout analysis adequate sample size was continually monitored as the research process progressed. In consultation with the Primary Supervisor, following analysis of the first 12 participants, the researchers were confident the sample represented a rich description of the phenomena under study.

Participants included in this study were mostly female. Ages (range 20 – 60 years) were fairly evenly spread across the sample. Only one participant lived alone and eleven lived with others. Most participants identified as New Zealand European. Half of the sample were unemployed and half worked either full-time or part-time. Half of the participants identified as single whereas half of the sample had a partner or were married. There were a range of CMCs across the sample. Table 1 lists the descriptive details of the 12 participants included in the current study as well as the total sample of 30 participants to be used as a comparison as to the spread of characteristics.

Table 1. Demographic details for study sample (n=12) and total sample (n=30).

Details	**Total Sample n=30 (%)**	**Study Sample n=12 (%)**
Gender:		
Male	6 (20)	2 (17)
Female	24 (80)	10 (83)
Relationship Status:		
Single	16 (53)	6 (50)
Partnered	14 (47)	6 (50)
Living alone versus not alone:		
Living alone	6 (20)	1 (8)
Not alone	24 (80)	11 (92)
Age:	Mean 41	Mean 43
20 to 30 years of age	6 (20)	2 (17)
31 to 40 years of age	8 (27)	4 (33)
41 to 50 years of age	8 (27)	3 (25)
51 to 60 years of age	8 (27)	3 (25)
Ethnicity:		
New Zealand European	22 (73)	9 (76)
Māori	2 (7)	1 (8)
Māori / NZ European	1 (3)	0
Samoan	1 (3)	1 (8)
Irish	1(3)	1 (8)
British	2(7)	0
British / NZ	1(3)	0
Employment status:		
Full-time	4 (13)	2 (17)
Part-time	8 (27)	4 (33)
Not working	17 (57)	6 (50)
Student	1(3)	0

Examples of CMCs included in the sample: Facioscapulohumeral Muscular Dystrophy, Myotonic Dystrophy, Lupus, Rheumatoid Arthritis, Acute Reactive Arthritis, Epilepsy, Leukodystrophy, Mitochondrial Myopathy

Data Analysis

Thematic analysis was used to analyse the deidentified data transcripts. Thematic analysis (TA) is a widely used data analysis method that can be used to systematically interpret patterns of shared and collective meaning, themes, or ideas in qualitative datasets (Braun & Clarke, 2013). The researcher has the task of utilising TA in order to identify commonalities or patterns in shared meanings in the dataset in relation to the research question and subject under exploration (Braun & Clarke, 2013). Rather than a single qualitative analytic approach, TA can be thought of as an umbrella term for a number of broad approaches that manage data analysis differently in regard to coding and theme identification and development (Braun et al., 2019).

Reflexive Thematic Analysis (RTA) was the particular approach chosen to analyse this dataset. This type of analysis was first described in a landmark paper by Braun and Clarke (2006) who promoted the method as an accessible and theoretically flexible approach to qualitative data analysis but one that required a “recipe” for practice that was theoretically and methodologically sound. RTA acknowledges the active and subjective role of the researcher throughout data analysis and highlights the importance of reflecting on researcher assumptions and practices that shape the analysis process (Braun & Clarke, 2022). This method is aligned with the qualitative design and interpretive epistemological position of the current study that seeks to explore and interpret the shared meaning of lived experience in order to provide a “coherent and compelling interpretation of the data, grounded in the data” (Braun et al, 2019, p. 848).

Braun and Clarke (2006) suggest a 6-phase process for RTA that is not intended to be linear but iterative, reflexive and recursive. The first phase includes familiarisation of the data and includes immersing yourself in the data in order to be familiar with all aspects of the data as you search for patterns of meaning (Braun & Clarke, 2006). Each interview was read and reread a number of times. Each time notes were taken, sections highlighted, and thoughts were written in the columns of the printed interviews. Ideas for potential codes were noted as well as any subjective

points of reflection as the researcher. Secondly, initial codes were generated that were connected to either a semantic or latent feature of the data that appeared meaningful (Braun & Clarke, 2006). Notes and highlighted sections of text were used to generate initial codes on small post-it notes on the pages related to the meaningful segments of data. The dataset was worked through several times in order to ensure full and equal attention had been given to all data segments and with the aim to generate as many potential themes as possible (Braun & Clarke, 2006). Initial codes were then entered in to NVivo 20 software in order to collate and further refine codes. Codes were evaluated in relation to the research question and phenomenon under study and were either merged or discarded. Context was maintained by including notes in the comment function or by ensuring extra segments of data were included in the coded selection (Braun & Clarke, 2006).

Once all the data had been coded and collated into a list of codes, the third phase of data analysis began which focused on searching for themes (Braun & Clarke, 2006). Through coding and familiarisation a deeper understanding of the dataset encouraged the formation of themes by identifying shared experience and meaning across the codes (Terry et al., 2017). The research question was used to guide the clustering of codes grouped together to form initial themes (Terry et al., 2017). The clusters were then analysed and those determined to have an underlying concept that grouped the codes together in a meaningful way became a potential theme (Terry et al., 2017). Thematic maps were used to assist this process which identified potential main themes and connected subthemes (Braun & Clarke, 2006). Phase 4 involved reviewing themes as part of a quality control process and this was done in consultation with the Primary Investigator (Terry et al., 2017). Themes were reviewed in order to ensure that the collated data segments under each theme grouped together appropriately to support that theme (Braun & Clarke, 2006) and that the overall themes were meaningfully supported by the entire dataset and were a valid thematic interpretation (Braun & Clarke, 2006). Also, reviews were undertaken to ensure that themes were not only distinct from each other but that they meaningfully related to

each other (Terry et al., 2017). Once there was confidence in the final thematic map, phase 5 began which included defining and naming final themes to present for analysis. This included the final hierarchy of themes and subthemes and final assessment of the themes in relation to how well they answered the research question (Braun & Clarke, 2006). This led to the final and sixth stage which included producing this report. This report aims to support analysis by choosing key examples of extracts to support themes and then compiling this analysis as part of a convincing narrative demonstrating how the interpretations are connected to the research question (Braun & Clarke, 2006).

Ethical Considerations

Ethics approval was obtained on 26 March 2018 by the Auckland University of Technology Ethics Committee (AUTEC) reference number 18/86 (Appendix A). On 3 August 2021 I was approved to analyse deidentified transcripts in order to carry out the current project. An extension was granted on 4 October 2022 until 26 March 2023 to complete the project.

Ethical principles as outlined in the "Code of Ethics For Psychologists Working in Aotearoa / New Zealand" were used to guide this research process (New Zealand Psychological Society, [NZPS], 2002). Steps were taken to ensure all ethical principles were evaluated and adhered to.

The PIS outlined the research process for individuals. The PIS included information on the research purpose and explained that participation was voluntary and that individuals could remove themselves at any time without detriment. Consideration of potential risks and benefits of the research were outlined in the PIS. Participants were given a $30 petrol or supermarket voucher as a token of appreciation at the end of interviews. Participants were also offered a summary report at completion of the study. Additionally, contact details for the research investigators were included if participants had any concerns at any time.

Prior to the interview commencing the participants were again given time to refer to the PIS and have questions answered. Informed consent form was obtained prior to the interview to ensure participants were fully informed before proceeding. The consent form

restated that participation was voluntary, the right to withdraw at any time without consequence, the right to remove personal data prior to reporting, the need to audio tape and transcribe the interviews, and the option to receive research findings.

Participants were assured that all identifying information would be kept strictly private and confidential. Only the research investigators had access to the names and codes. Only the deidentified data was used for analysis. Any transcripts that were potentially identifiable due to the rare nature of the condition were removed from analysis to protect participant confidentiality.

Only the primary research investigators had access to original confidential participant material including all consent forms, audio tapes, and transcripts. These materials were stored securely onsite at AUT. Only the investigators could access private and confidential digital data that was saved on a password protected and secure AUT server. All research material was to be held for six years before being destroyed in a confidential manner.

This study involved a healthcare population and as such this study had a number of responsibilities to ensure ethical care for a vulnerable population. Efforts were made to meet with individuals in a private space either at the university or at the individuals home if more comfortable. In addition, the length of time and expenditure of energy of participants was constantly monitored throughout the interviews. This study also aims to provide practical and meaningful benefit to those affected by CMCs.

Cultural Obligations.

All research in New Zealand must uphold the principles and values of partnership, participation, and protection that are recognised by *Te Tiriti o Waitangi* (NZPS, 2002).

There were a number of steps taken to ensure these values and principles were maintained throughout the research process. Te Ara Tika outlines the ‘Māori Ethical Framework’ for ethical research practices which includes the principles of “whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity) (Hudson et al., 2010). Whakapapa was respected through whakawhanaungatanga which describes the process of establishing of

relationships and acknowledges the importance of rapport building (Mooney, 2012). Research was conducted in a consultative manner providing information and a transparent research process. Tika was respected by following best practice guidelines and using a qualitative research design and interview data collection methods which allowed the participants to share their experiences through their own voice. Also, it was ensured participants had control over personal content and the option to remove data at any point in the research process prior to reporting. In addition, researchers considered the impact of the research for Māori to ensure appropriate and ensure no harm. Manaakitanga guided research in a culturally sensitive manner, with aroha, care, and respectful treatment, ensuring informed consent and the right to privacy. Mana was honoured by acknowledging individuals right to choose to participate, to be informed of risks, and to share in the benefit of the findings of the research.

Research Rigour & Trustworthiness

When conducting qualitative research it is essential to take steps to ensure trustworthiness and research rigour to enable confidence in the quality of the overall research process and integrity of findings (Connelly, 2016).

Trustworthiness for this qualitative study was addressed according to a number widely accepted criteria including credibility, dependability, confirmability, transferability and authenticity (Guba & Lincoln, 1994; Lincoln & Guba 1985).

Credibility refers to the confidence or internal validity of the research findings (Connelly, 2016). This was achieved by conducting the research according to best practice guidelines for qualitative studies using thematic analysis and similar to other qualitative studies. Care was taken to maintain participants' voices by transcribing interviews verbatim and all transcripts were reviewed by the Primary Investigator to ensure accuracy. Analysis for the current study included in-depth engagement with the interview transcripts, analytic journaling, reflexive journaling to manage bias, and returning a number of times to evaluate coding to ensure themes most appropriately

represented the data. To assist with interpretation mapping of patterns across the dataset was also done a number of times (Braun & Clarke, 2022). Vivid quotes were included in the findings to validate interpretations.

In order to facilitate dependability and transparency as suggested by Braun and Clarke (2021) researcher positioning, research steps, definitions and decisions, including final sample size, are clearly explained throughout this project in order to create an audit trail. In addition, the Consolidated Criteria for Reporting Qualitative Research (COREQ) was also used to further assist in transparency of reporting (Tong et al., 2007).

Confirmability refers to findings that are consistent and repeatable similar to objectivity (Connelly, 2016). Detailed notes were kept of all decisions throughout the research process and analysis of data. These notes and decisions were kept to discuss at meetings with the Primary Investigator in order to try and prevent research bias.

Transferability refers to the ability for readers to assess the findings as relevant and applicable to their situation or generalisability (Cope, 2014). This study has limited transferability to the general population. However, with sufficient information on the context and participants in the research this study is potentially transferable to individuals living with CMCs and other health populations that can relate to the findings (Cope, 2014).

Authenticity describes the capability of the researcher to portray participant experiences as a faithful representation of their expressed thoughts, emotions and feelings (Cope, 2014). In this study, this was enabled by providing participant quotes that support the interpretation. This also describes efforts made to ensure the research process was fair and collaborative, included informed consent, sharing of information, caring for participants, trust, and transparency of process (Amin et al., 2020)

Reflexivity

Reflexivity is considered the gold standard for ensuring quality and rigor in qualitative research (Teh & Lek, 2018). Reflexive research requires constant reflection, evaluation, and questioning of how our subjective responses may influence the research process and analysis through researcher bias (Finlay, 1998). Reflexivity is "acknowledging the central position of the researcher in the construction of knowledge", (Banister et al., 1994, p. 151). As research takes places within a social context it is affected by both emotions and behaviour making it essential to explore the dynamics between researcher and participants to ensure trustworthiness of findings (Finlay, 1998).

A social identity map was used as a tool to assist reflexive analysis (Jacobson & Mustafa, 2019). This tool allows for reflection on positionality by considering how one's identity can influence the research process to better understand the power relations involved to minimise researcher bias (Jacobson & Mustafa, 2019). Trustworthy research requires that researchers be explicit about how their perspectives and social identity may shape the research (Jacobson & Mustafa, 2019).

For example, the current study included individuals living with CMCs therefore I was an outsider in regards to my health status and understanding of what life is like living with a CMC. Yet, I was aware of being similar in age to the average age of participants, also female as was the majority, and I am a parent like many of the participants. Therefore there were some social identity similarities. This meant at times I had to focus on material that was new to fully comprehend the meaning as well as not be distracted by experiences that I could relate to.

As a psychology student who is interested in mental health I tried to make sure I gave equal weight to all data during coding as opposed to being drawn only to areas I am passionate about such as loneliness and wellbeing. I am also a social person and so I was conscious of trying not to make assumptions of social interaction based on my own values and behaviours. I also come from what I consider a large family of seven

and so I was aware I would be interpreting participant family interactions though my own lens of what family meant to me and how I understood family to operate.

In addition, I endeavoured to have complete immersion in the transcripts so that I felt I knew the participants as well as possible so that interpretations and findings were an authentic representation. At times material in transcripts related to painful experiences and I could feel myself becoming emotional. I was aware of sharing these personal experiences in a respectful and sensitive manner. While I wanted to ensure I gave voice to important emotional content I needed to give data equal weight within the pattern of meaning of social connection across the entire dataset.

I was acutely aware that I was analysing data for a vulnerable health population who had trusted me with their personal experiences in order to produce meaningful insights. I wanted to fairly represent experiences during coding and analysis without changing meaning and twisting responses to suit the research question. I was also aware of not wanting to discard themes along the way due to invested effort and needing to refocus again on prioritising themes that best fit the data.

Findings

At the beginning of the interview, participants were asked how living with their conditions had impacted their everyday lives including personal tasks, household chores, and employment. This information provided context for their responses to the remaining interview questions. Names were assigned to participants for ease of reading and to personalise the quotes.

Almost all participants described tasks that had become more challenging as their condition progressed. A variety of day-to-day tasks such as dressing, showering, cleaning, driving, lifting heavy items, and reaching high above shoulders for laundry, were now significantly more difficult, took more time, or involved pain:

"And for me to open all the bottles and the containers is really hard…I can't stand up and put my underpants on now. Well I can if I stand beside the bed and sort of rest my leg on the bed so balance is a problem…I have trouble waking up. I have a special sleeping machine because I stop breathing." Sally, 56 years old

"Well the main everyday constant symptom is fatigue. So small tasks are doable but I can't do as many of them… for example I can shower myself but it takes longer and afterwards I have to stop and have a rest…The more you push it the more you suffer the next day…If you get yourself to a point where you're exhausted then you do start to need assistance to do things…Cooking is quite hard because not only is it physical it's also a memory to remember that you've left something on the stove … we call it brain fog." Aroha, 34 years old

"In terms of household chores such as cleaning and shopping… I do them and still with a bit of effort and pain… Takes me longer to recover after I've finished." Mike, 38 years old

Individuals discussed how living with CMCs had impacted employment. Some participants had given up employment or reduced their hours due to their health status. Individuals referred to the physical nature of their previous employment as one of the main reasons they stopped work. Some participants had found that by reducing hours, incorporating more job variety, or reskilling via study, they could continue working:

"I've had to, I put down early retirement because um I was working in (city) as a I'm a kindergarten teacher um and then this just flared up out of nowhere and I thought it would get better and it didn't so I came home and I thought an operation like last time was going to fix it and they said no. I'd have an operation but they said the rheumatoid in my back is causing a lot of damage and working gonna make it worse so they said my working days are over." Nancy, 60 years old

"Yeah starting to become more difficult as the fibromyalgia and the lupus progress... I'm finding its becoming a lot harder these days really showering and

cooking and that sort of, it's really quite exhausting so yeah quite a lot. I'm only working part time now. Um I can't hold down a full time job any more. Um studying as well so that I can start my own business so I can work from home." Vanessa, 40 years old

In response to the research question *"How is social connection maintained by individuals living with Complex Medical Conditions?"* 6 themes and 4 subthemes were developed from the interview data (see Table 2).

Table 2. Themes and subthemes

Themes	Subtheme
1. Social connection is maintained despite health challenges	
2. Social interaction is constrained	Maintaining social connection is important
3. Social connection is enhanced by prioritising needs	Maintaining connection is a balancing act needing planning and preparation
4. Technology and connection to the outside	
5. CMCs are linked to experiences of social isolation and loneliness	Strategies for reducing social isolation and loneliness The positive impact of owning a dog
6. Connecting through shared experience positively influences social connection	

Theme 1: Social Connection is Maintained Despite Health Challenges

Outside of the home individuals connected frequently with close family and friends via visits, phone calls, text messages, and messaging apps. Participants also spoke of socialising with close family and friends face-to-face anywhere from weekly to monthly. Closer proximity enabled easier and more frequent contact. In-person contact was typically linked with a specific purpose, for example, a "catch-up" over a coffee, or a meal, or special celebration such as birthdays and holiday events. Visits were often related to young children, for example, to connect with wider family or to organise playdates. In-person connection was also frequently linked to social support from close family members:

"(Talking about two friends) I see Lisa more than I do Sally so I see her couple of times a week probably and Sally at least twice a month… We usually just go to a movie if we go out or a meal. No more partying (laughing)." Vanessa

"So we did the brickman the lego thing on the weekend with them… they like to get out and kind of do stuff with their kids as well. And our daughter and their boys get on quite well so we do stuff with them a lot." Claire, 38 years old

"Um his mother. His grandmother. Um my sister. And my ex sister-in-law. (Researcher: So do they all live quite close by those four people?) "Yeah. Within half an hour. They pick him up from school take him away for a little while and play with him. If I'm feeling tired or if I need to go out and do some rehab or do need to do something. Every week it's only probably one person a week." Mike

Participants spoke of maintaining close friendships with people they knew from high school and previous and current employment. They also spoke of making new friends while living with their conditions via friends of friends, or their significant other, through their health service networks, through study, and their children's school:

"yeah I have no problem making new friends. Um through other friends, through my physiologist, just I've always met people through people." Mike

"(Researcher: how long have you been friends with her?) Since I first started working when I was twenty one. Yeah after teachers college my first job I worked in Mangere." Sally

Individuals regular friendship networks were typically small in number. Participants indicated they didn't mind smaller networks necessarily if it meant they could rely on their friends to be there for them and have more regular support and genuine interaction rather than "haphazard" friends:

" Probably been friends about two or three years and she's just one of those thoughtful people that if she heard that I was sick she wouldn't need to hear she would know. If she hadn't heard from me during the day she would send a message…That's what the illness does you work out who is willing to come across town to visit you because they haven't seen you for two weeks because you can't get out of bed." Aroha

"My husband's got a really big network of support or people that we have around us but it's just I value I suppose the people that are gonna be there day in day out those regular interactions more so than the ones that are haphazardly there." Claire

Individuals also spoke of social networks within the community that helped participants' maintain social connectedness. These activities included attending church, exercise classes, youth groups, and volunteering:

"Yes, sorry to say I do a lot of volunteer work. I just had the last month I joined up with IHC as a volunteer so I've got a buddy now a buddy that I you know volunteer to you know". Matt, 47 years old

"I had one was a games night and one was a girls club and those are with the youth group and those are people that I interact with on a daily basis. I have two life skills courses. I have one on Tuesday which is a fit for life and that's for other people so I interact with [name]. And then there's another one on Thursday which is just a life skills one. I interact with [name] and five other people. But I do dancing as well. But I do dancing as well. Which I love I'm doing it tonight. It's just contemporary dance. That's also special needs and I have quite a few um people there that I know and it's so much fun." Taylor, 27 years old

Theme 2: Social Interaction is Constrained

Most participants described how their condition had constrained social connection opportunities and therefore reduced overall social interaction. Physical ability and symptoms such as pain, fatigue, hearing and speech difficulties, or effects from medicine, often made it challenging for individuals to interact socially. Participants expressed frustration, because it wasn't that they didn't want to participate but more that they couldn't. They also shared emotional reasons as to why interaction was difficult, such as feeling like a burden, or not being fully present, or feeling like social activities were "pointless":

"I feel like maybe a slight burden to people because I'm um even though everyone tells me I'm not but you know I sort of feel like when I go somewhere I sort of slow people down. There's a lot of places where I can't go … because I can't access it or … steep and stairs or uneven … because I've got one of my legs is really really weak." Nancy

"I missed out on my niece's sixth birthday a couple of weeks ago because I was, I'd just come back from Palmy and I was really sore… Um my ability to be able to just go out and do stuff … um isn't there all the time like for example I can't go out on the town with my girlfriends and stay out till one or two in the morning. Like I just physically couldn't do it. Um I am tired all the time so even going to a movie I fall asleep at movies all the time. Um so that being present I suppose is harder." Claire

Um I don't drink any more so when there are functions at the bar or at work or around drinking and going for a barbeque are pointless to me. Um because I take medication at night that knocks me out I've got to be home by a certain time. It took a while a bit for me just to also learn to say to him just go. We can't both go out. There's no point us both staying home." Aroha

Giving up employment due to their condition was discussed by participants as impacting their social networks. Participants explained how being unemployed had reduced their ability to meet new friends. They also spoke of the difficulty maintaining friendships as they could only interact with friends outside of work hours:

"Um I guess um not working so I don't have those working relationships that I used to have. So that's probably the biggest um like because I'm not working during

the day I tend to be on my own quite a bit … so everybody's working so I've sort of can only catch up with people um weekends or mainly weekends except for my roommate flat mate." Nancy

"(Researcher: Ok um what about making new friends?) Well because I'm not working or I mean that's where you make friends working… Yeah I mean my friends are all old friends." Sally

Saying no to social events had reduced social interaction and was perceived by some participants to have reduced their social networks as some network members stopped making effort to connect.

"Yes (friends) I do see them a lot less… Um they're always ringing you know ringing up to see if I wanna go … they have a work do… but you know it's always associated with you know drinking." Matt

"Yeah and you just you know once you've sort of cancelled a few times or changed plans people don't invite you anymore." Wendy, 40 years old

Maintaining Social Connection is Important

Even though maintaining social connectedness could be difficult due to their condition, and interaction was limited, it was considered important and prioritised by participants. Individuals made efforts to make new connections and friendships. They emphasised the need to be proactive and make continued effort to engage socially despite health related challenges:

"Keep social networks keep up with your friends. Push yourself. You have to push because it makes you very lazy this condition… I mean we can all sit down and die can't you." Sally

"I think it's good just to do what you can and get out and about and mix with other people definitely. Um as much as you can. You've gotta make a point of doing, or make a point of organising get-togethers don't you. It's up to you, you can't wait for other people to do it, you've gotta do it." Lynn, 59 years old

"That's why I've joined this Arthritis support group tomorrow to try and meet some more people. I've been looking at things in the neighbourhood. There's a … I love reading and I saw at the local library once a month they have a book club – so I'm trying to find ways." Nancy

Theme 3: Social Connection is Enhanced by Prioritising Needs

This theme represents how social occasions were positively influenced by meeting the needs of participants both physically and emotionally. Prioritising needs meant social occasions could be more frequent, easier, and more enjoyable.

Participants were thoughtful about choosing venues closer to home, venues with easier access and with comfortable seating, as well as choosing a particular type of activity:

"(meeting friends and family)…could be a café with a like a Plant Barn with playground inside – so he can play while I sit down." Mike

"Like I said we go we might go and have a coffee or something um or we go you know to the driving range or stuff like that yeah… because I don't really I don't drink as much anymore." Matt

(Researcher: less active gatherings or less active activities are better for you?)
"I don't get sore from them… much better for my mental health. So I find that it's much more relaxing and I find I get myself into a better head space which helps me deal with flare ups and all those types of things far better. So when I do have one it's just like it's just a part of life rather than a bang this awfulness that you're consistently dealing with." Claire

Participants also spoke of family and friends accommodating needs, for example, by providing transport, being considerate of physical comfort and access issues, as well as understanding how participants may be impacted emotionally and physically. Individuals expressed significant appreciation for friends and family that anticipated and cared for their needs:

"Um so I do socialise with friends but they are very accommodating and they often come to me. And are happy just to chill watch Netflix or something. Um yeah they're really good at that so I'm kind of still feel included in things. But they are aware that I might not have a good day and we might have to just change what we're doing a little bit. Yeah." Vanessa

"My son in (city). He was gonna come over and shout me to the rugby in June and I was worried about how I would get in the stands but he did some research and found out there's some accessible places to sit." Nancy

"So spending time with him (younger brother) is a lot easier than quite a few other people just because he anticipates what I need." Aroha

Conversely, participants shared accounts of how social interaction was impacted by those friends who didn't understand their needs which led to less social interaction within those social networks:

"Part of them saying your new needs are too hard work for us and me just saying like I'm just too tired or I don't drink or I don't do things that they like anymore … so I've felt like I've stopped trying with them because I found that they've stopped trying with me … they don't see that I desperately want to come out but things are just it's just too much hard work for them. Easier to invite somebody who doesn't have restrictions." Aroha

"Friends um the ones at school didn't understand it. I had one good one who it was cool having a condition that she couldn't pronounce. Um a few didn't understand which meant to them I was weird and different so they didn't really like it much." Taylor

Maintaining Connection is a Balancing Act Needing Planning and Preparation

This subtheme highlights how socialising was a balancing act needing planning and preparation in order to prioritise health needs. Participants talked about "listening to their bodies", and socialising when they had enough energy, physically and mentally, and a chance to rest afterwards. They indicated that a cost-benefit analysis was almost required before social events in order to evaluate the level of difficulty against the perceived value of the interaction:

"Depends on how comfortable I am with driving and standing around for an hour and a half and then driving home.. yeah so it does sort of slow things up ... Just gotta prepare well in advance. So have nothing on for the week if I'm gonna do something big like that. You prepare for it for the whole week so you rest up. Make sure I'm not doing anything like mowing lawns or washing the car or anything silly like that - that's like adds pain in." Mike

"The day before and the day after we'll try and plan nothing. So it's all about planning and making sure that you don't overwhelm yourself … You realise you're overtired but then you panic because there's all these other things you've got to do. And so you would start saying to people I can't come to something." Aroha

Theme 4: Technology and Connection to the Outside

All participants spoke to the role of technology in enhancing and maintaining social connection and networks. One participant described texting and messaging as their means to "communicate with the outside". Participants used a wide range of communication methods including phone calls, text messages, social media, messenger tools, and video apps. Predominantly, texting and messaging apps were used. Participants discussed how the wide variety of options available to them meant they could engage more easily and more frequently by tailoring communication to their specific needs. They explained it was especially helpful to connect with others while remaining in the comfort of their own home sitting or resting, when it was difficult to leave the house, or when in bed if feeling unwell:

"He uses voice messages but I use I text because I think my speech is more difficult to understand." Sally

"(Researcher: So with the Skype you're pretty much lip reading?) Yeah and different people obviously different tones of voice and some are just easy to pick up and some aren't so and they're used to me saying can you speak a bit slower you know and I need an iPad so I couldn't look on the computer would be too far so an iPad I can hold it right up in my face and I can be in bed while I do it so there's no physical exertion." Aroha

"(Researcher: So in terms of the social interactions um things like texting and Facebook are easier?) Yeah because there's not a physical … I guess having to maintain a conversation I'm, some days I find it really hard to um find words and it's quite hard to continue a conversation. I lose track all the time… and so I find it quite hard and it is tiring." Wendy

Technology not only helped maintain social networks but also increased social interaction. Technology created opportunities for new relationships via the online community, therefore expanding social networks. For example, some participants had made friendships though a variety of online forums. In addition, many participants had chosen to connect with support groups online related to their conditions. Still, participants noted that while these online connections provided meaningful interactions, they did not always consider these online connections to be "real" friendships:

"Yes that's pretty much my lifeline to everyone. Is Facebook. If I didn't have the internet like if we didn't have an internet connection I don't think I'd have any social interaction...I have more people who I call online friends now. Like people I've never met in my life but I talk to once a week but you do realise that they're not a real, not that they're not a real friend but they're someone you're just chatting to .. That's my outlet and I but I'm very aware that they aren't real friends and not so many you physically depend on." Aroha

"(Researcher: have you found Facebook Messenger to be quite helpful for you?) Definitely. Otherwise I wouldn't really have interactions with people at all… Yeah. It's probably not healthy but at least I'm interacting with them… Probably messages more than anything… I've joined a couple of online groups where people have the same illness as I do and I find that quite helpful and because you do share the same you know side effects and what they are having. And it is easier to get close to them but it is still online. It's not real. I've never met them in person." Wendy

Theme 5: CMCs are Linked to Experiences of Social Isolation and Loneliness

Most participants shared experiences of social isolation and loneliness associated with living with CMCs. For example, they related periods of being more housebound, being without transport, or being alone while others were at work. For some participants isolation was discussed interchangeably with loneliness, while some participants identified periods of isolation versus experiences of loneliness:

"I guess like you said (loneliness) it's triggered by like when you know your friends, you don't hear from your friends um much …" Matt

"We sold our cars and we bought one car between us which allowed us to update and anyway but when I first but when mum would then go to work she was still working a lot… I felt really trapped and really lonely. Because mum was working every day and I was at home alone… I was alright until I lost my car when I lost my car that's when I started to feel really lonely." Sally

Experiences of feeling lonely were often related to a sense of "missing out" on social activities:

"Ah at times especially at nights. Yeah yeah especially those social things on Saturdays and Sundays." Mike

"On Facebook you know you see these wonderful things and you're jealous bit, it's different when you know that those things are out of your reach. Going to a club you know, seeing everyone else having fun can be quite hard… and you're at home like on Saturday … I'd like to be able to just go out." Aroha

For some participants adapting to a major life change such as unemployment led to feelings of loss that contributed to greater feelings of isolation or loneliness:

"It was almost like that I was wondering whether I would ever work again and I'm a passionate teacher. I loved what I did. So that was like a sense of loss and I so I used to spend a lot of time in my room and not want to interact with everybody so yeah it was yeah sort of an isolation. So I don't have those working relationships that I used to have. So that's probably the biggest um like because I'm not working during the day I tend to be on my own quite a bit." Nancy

"Yes and I really miss it you know… you know it's very hard, that's probably one of the things that kind of inspires me because they're still out there working their arses off and you know making something for themselves and it does depress me sometimes that I can't you know... just go outside and just do gardening and stuff like that. Make out that I am working." Matt

Some participants spoke of feeling as if their symptoms, such as hearing difficulties or pain, were "invisible" making it harder for people to understand how social interaction was challenging. These participants worked hard to fit in to the "normal group" and not let on they were having difficulty which further increased feelings of isolation in those moments. Individuals didn't want to have to explain that their condition was impacting their ability to participate; instead they often withdrew from social activities because of these negative experiences. It was sometimes easier to

simply opt out. However, opting out of social activities typically made individuals feel even more invisible and isolated.

"Yeah even if I go out at the mall I feel very lonely because I can't hear what people are saying… Or everyone laughs at a joke or we play a board game. I can't do that so I have to be like I'll just be on your team and you can play for me sort of thing … and then you feel like I might as well not be here if no-one's talking to me and people don't care whether you're there or not … I get depressed because no-one's talking to me and I'd love to meet new people. I find it more depressing to be lonely in a group and I think it's probably why I don't go out ..." Aroha

"At times you can feel like you're in this, you're not part of the normal group. Um because I can't do certain things. … But it can be isolating just because you're different and incapable of some things. We had an extended whanau basketball game and my husband loves basketball and kind of all the people that were there were playing and blah blah blah and basketball was not my thing at all. I had sore hands and just literally someone passing the ball to me um would cause me so much pain like in I was just like the only person there that kind of wasn't playing. So I felt isolated in that, in that situation because I didn't want everyone to know that I'm not participating because of my diagnosis. I don't advertise what I have to everybody that kind of comes along. So it felt isolating because it was like no-one gets because no-one knew. I would've loved to have played. It's just painful." Claire

Not all participants had personal accounts of social isolation or loneliness related to their conditions. Participants spoke of personal attitudes and personality traits that they felt made it more unlikely they needed as much social company as others. In addition, they indicated they had enough social interaction from their duties as a parent, from family in the home, or from their work, so they did not have the chance to feel isolated or lonely:

"Luckily I like my own company. Quite happy just to chill and do my own thing and I'm fine with the kids, you know they're always busy doing something so it's running around with their schedule and um between that working and studying and maintaining the house, no there's not really time to be lonely." Wendy

"Like I'm happy to be alone. So I don't need the social interaction to feel that you know valued or you know participating in life or whatever. I'm quite happy to sit at home and read a book. I like being alone. Um every year for mothers' day I've always requested for everyone to just vacate the house. Like I like just being alone and with my own thoughts so I don't ever get lonely." Claire

Strategies for Reducing Social Isolation and Loneliness

A number of strategies were adopted by participants for counteracting feelings of isolation and loneliness. These strategies could be categorised as *distraction* or *seeking social connection*. Distraction was a common strategy. For example, doing

jobs around the house, going for a walk, or scrolling through social media apps. Proactively seeking social connection was a second key strategy. Participants reported reaching out to friends and family as well as their community when feeling isolated or lonely. These small and often casual interactions within their communities, like going to the gym, or the mall, were meaningful to them and were considered to have a positive impact.

"Like I plan a rest and make sure I do something light. Um maybe there might be something on TV or just something where I'm actually focussed on. Just try and relax. Just try and be mindful and do some stretching. Um and just make sure I have spoken to people. Ring up certain people um … sometimes even just going to the gym, sometimes I don't do my workouts, I just go to be social yeah yeah - So I go with the intention sometimes I just like the interactions everyone's positive and stuff like that." Mike

Well I just sort of decided to … things weren't gonna come to me. If I just sit in the house on my own things are not gonna manifest for me very well. And I could see it as a slippery slope um so I just started getting out um where I live. They've got a nice little shopping centre and I just started going down there sometimes and having a cup of tea and there's quite a lot of probably people slightly older than me that would go down there for social. Sometimes I just sit there and strike up a conversation and as I say I started researching ways of finding groups or clubs or organisations that I can become involved in." Nancy

"When I'm feeling lonely I motivate myself to you know either ring up someone to talk to you know. It's very important or you know go in my car and go for a drive somewhere and um to where it's busy you know to where there's people. Um I pretty much like I said I just I self-motivate myself you know. I just oh do the dishes or do something. You know do something active that's gonna make me not think about being lonely you know." Matt

The Positive Impact of Owning a Dog

Five participants lived with a dog and spoke of interacting with their dog when they needed company. Pets were seen as being good listeners and good for "a cuddle" when lonely. All participants that owned a dog talked about the value of being responsible for their dog pushing them be active. Exercising the dog also had the added benefit that this often led to increased social interaction opportunities. Furthermore, some individuals talked of forming friendships with other pet owners they had met in online group chats regarding their pets:

"I wish someone was here to talk to me and then that's when I might go outside and talk to my dog… he's got one of those faces that looks like he's actually listening. Like we used to always take turns um walking the dog but now since I've been home with my study I do it every day and it's quite good because it's getting out in the fresh

air. I know a lot of people who go to the park so if I get there at the right time we walk together and we'll have a chat while our dogs all run around altogether." Mary, 24 years old

"When I'm lonely I grab my dog and then you know she'll lick me or she'll just you know jump up and you know so - it kind of yeah it kind of treats that loneliness you know. She's always there." Matt

(Researcher: "So sorry how did you meet them again?) "I met them on a Facebook group. I joined a Chihuahua, we've all got Chihuahuas, um a Facebook page … and we just hit it off … we were taking them out, meeting for walks um with the dogs." Vanessa

Theme 6: Connecting Through Shared Experience Positively Influences Social Connection

This theme refers to the motivation to interact with others due to the shared experience of living with CMCs. Some participants also had friends or family who shared the condition. Participants also connected with others via support groups either face-to-face or online which increased their social networks. Nine participants belonged, or had belonged, to a support group. Participants discussed emotional and informational support they received from others. Connecting with others who shared their condition allowed individuals to share their experiences with others who could understand what they were going through. Individuals felt less alone and found others stories motivating and inspiring. Support groups were considered to be especially helpful for those newly diagnosed because they provided a forum for participants to share information, tips, and strategies. Support groups were considered to be a valuable part of participants' social networks:

"Just letting you know that you're not alone. Everyone's going through something. Um and a lot of people are just making the most of it, what they've got. And yeah. I get inspiration from that. Mike

"I'm into the forum groups there's five of us and we tend to share stories and that's quite so I think finding people that have similar … How do I describe it … that would have similar experiences to what I would have. You know we kind of share ideas and that kind of thing." Lily, 43 years old

"One of the mothers at school, she has it as well so her and I talk on Messenger. She's the same as me generally – face to face is difficult. Um so her and I will talk to each other and support each other you know if one of us is having a really bad time we offer to help each other with the kids and what have you. And her kids are going through what mine are going through you know. Because of course there's so much guilt for not being able to do things with them that you want to and um the physical pain

as well it hurts me when they jump on me and cuddle me and stuff so it's really hard on them. So it's good to have someone else who knows what that guilt is like." Wendy

"Um they understand me, I have friends, they um they support me and I don't think I'd be as happy as I was as I am now if I didn't have those things. And um (group) is just a place to go where you're in an environment with people who are like you." Taylor

Connecting socially through shared experience was not for everyone. Some individuals felt their symptoms weren't serious enough to justify going along to a support group. These participants explained that because their symptoms were mainly invisible that others might not think they belonged. Some felt that sharing a condition wasn't necessarily a meaningful reason to connect. In addition, they did not want to "look into a mirror" and be reminded of what lay ahead for them. Whereas for others it was the makeup of the group related to age and stage that put them off connecting through shared experience:

"No I don't because they might look at me and they go what's wrong with you? There's nothing wrong with you. Like you know I said I've gone to counselling I've done things like that but I think mostly my support group would be you know friends, my partner and I guess the grandkids is pretty much people that always support me…." P2

"I don't go because I don't really want to sit and grumble about my condition and be with people with other people that have got half of them worse… I don't have a closeness to them because they've got a condition like me. Why would that mean I have a closeness to them… I mean some things in common but lots of them are in wheelchairs and you know I don't really, it might be a mirror I don't really want to look at." P3

"Um yeah so it's hard to find people that are like you know kind of parents and like got young children and how they manage …maybe when I'm old because there seems to be a lot for older people. It would be nice when I get old it will be like where were you when I was thirty." P6

Discussion

This study was conducted to gain an understanding of how social connection is experienced and maintained by people living with CMCs. Twelve participants shared rich descriptions of how they maintain the social dimension of their lives. This enabled insight into factors that facilitate or impede social connectedness as well as factors that exacerbate or alleviate experiences of social isolation and loneliness.

Six themes and 4 subthemes were developed from this study. The first theme social connection is maintained despite health challenges identified that individuals living with CMCs maintained close relationships with friends, family, and their wider networks despite significant health challenges. This involved regular weekly communication with close friends and family via variety of messaging methods and phone calls.

Regular face-to-face interaction was often maintained by family members providing social support, for example, receiving instrumental support such as transport, assistance with grocery shopping, or minding children. High levels of received instrumental support have also been found in studies with chronically ill individuals and typically support is higher when functional incapacitation is greater (Penninx et al., 1999). This is important as social support is a significant predictor of coping with chronic illness and disability (Rybarczyk et al., 2012; White et al., 1992). Additionally, frequent supportive behaviours from family and friends are associated with enhanced wellbeing (Winefield et al., 1992). Higher perceived social support is also associated with greater social connectedness (Ashida & Heaney, 2008).

Consistent with ‘Belongingness Theory’ individuals with CMCs were motivated to maintain interpersonal relationships and were driven toward sustaining belongingness (Baumeister & Leary, 1995). Individuals maintained their social networks mostly by getting together with close friends and family anywhere from weekly to monthly to “catch up over coffee or a meal”. A national stratified survey conducted in the United Kingdom by Dunbar (2017) reported similar findings amongst the general population. Dunbar found individuals had a meal with a family member or good friend

approximately once a month. This suggests individuals in the current study were typically able to maintain these types of social activities as much as the general population despite health status. In the Dunbar study having a meal together was reported as a valuable way to maintain or create new friendships and increased individuals' feelings of closeness to those involved. These findings support the notion that social connectedness is not only maintained through social support but also through meaningful engagement (Berkman & Glass, 2000; Rook, 1999). Connecting for a "catch up over a coffee or meal" appears to be an effective way to maintain social connectedness for people living with CMCs.

Social connection was also maintained by celebrating special occasions such as birthdays or a holiday events. Research has found that social interactions centred on celebrations are associated with greater perceived social support (Brick et al., 2023). Perceived social support can be defined as an overall assessment or subjective belief that network members are available and supportive in a range of ways (Berkman & Glass, 2000; Sarason et al., 1990). Therefore, individuals living with CMCs who maintain connection in this way are likely to perceive their networks as supportive. These findings are important as the stress-buffering benefits of social support are most likely found when perception of support and assistance is available (Wethington & Kessler, 1986).

For those living with CMCs, closer proximity to friends and family consistently featured as enabling more connection and assisted with maintaining social networks and increasing connectedness. Research also describes geographic proximity and ease of access to network members as important structural factors influencing social networks and connectedness (Ashida & Heaney, 2008; Berkman, 1984).

Close friends were often long-term friends made through past schooling or employment. Participants found value in smaller networks consisting of friends that could be relied on for more regular and genuine interaction. Research has also found smaller networks, that are geographically close, with high density, high intensity relationships are associated with the most benefit when support is needed (Heaney &

Israel, 2009). This study supports that view that quality of relationships is more important than quantity (Pinquart & Sorensen, 2001; Ryan & Willits, 2007).

Maintaining community interaction positively influenced social connectedness for those living with CMCs. Participants connected with wider social networks through a variety of community groups, support groups, church, and volunteer opportunities. Individuals also spoke of looking for new friendship connections within their local neighbourhood and community. Wilkinson et al. (2019) also found individuals with long-term health conditions maintained social connection through clubs, community centres, and volunteer work. Research indicates that connecting with the wider community is associated with positive impacts on wellbeing for those living with chronic conditions (Reeves et al., 2014). Community interaction for those living with CMCs appears to not only increase social networks and interactions but positively influence perceptions of social connectedness and potentially wellbeing.

Theme 2 social interaction is constrained highlights how social connection is limited by living with CMCs. Aligned with studies on chronic illness and multimorbidity, this study found that living with CMCs impacted the ability to maintain social relationships due to a loss of social roles (Carr et al., 2018; Holley, 2007; Miller, 1985; Wilkinson et al., 2019). Needing to stop work, sports, and other social activities due to participants' conditions was linked to reduced social networks and less social interaction in the current study. Also, finding time with friends outside of work hours was challenging. Additionally, work was identified as the usual place to make new friends which was unavailable for some.

Both physical symptoms and emotional factors impacted maintenance of social connection. Participants' physical symptoms in the current study included mobility issues, hearing and speech difficulties, severe fatigue, and pain. Emotional factors such as feeling like a burden and being unable to be fully present impacted social interaction. These findings are consistent with other studies of chronic conditions that have found physical and mental symptoms limit social connection (Bay et al., 2020; Holley, 2007; Miller, 1985, Wilkinson et al., 2019).

Having to say no to social activities impacted relationships and social networks. Friends would stop calling and over time individuals felt estranged from some friendships. These findings are consistent with other studies of severe health conditions such as chronic fatigue syndrome (Schweitzer et al., 1995). Social networks reduced in size and with limited social engagement individuals reported difficulty maintaining friendships. These findings emphasise how living with CMCs can affect structural aspects of social connection (such as network size) that can influence availability of functional aspects (such as social support) as well as negatively impact the quality of connection (through relationship strain) (Holt-Lunstad, 2018).

Despite significant health challenges individuals in this study emphasized the importance of maintaining social relationships. Research indicates resilience plays a central role in motivating action especially with health populations (Rybarczyk et al., 2012). Resilience describes the ability to resist, recover, and rebound when faced with a challenge (Rybarczyk et al., 2012). For those living with CMCs, more resilient individuals appeared to recognise that their health status had created challenges for social connection and subsequently developed coping strategies (Rybarczyk et al., 2012). Social connectedness was prioritised, and individuals stressed the need to be proactive about maintaining social networks rather than allow the condition to make them “lazy”.

Theme 3 encapsulates how social connection is enhanced by prioritising needs. Maintaining social connection was dependant on prioritising health needs. Social occasions occurred more frequently and were more enjoyable by tailoring the social interaction to individual needs. Prioritising needs meant that social events were less physically and mentally demanding. Additionally, social ties were strengthened when friends and family were more considerate of needs. Prioritising needs by network members often involved instrumental and emotional support. For example, providing transport to events or emotional support by being flexible with plans and understanding of condition related symptoms. Also, consistent with similar research, social networks were negatively affected when family and friends didn’t make the effort to keep in

contact or try to understand how the illness impacted the individual (Schweitzer et al., 1995).

Alongside prioritising needs, planning and preparation for social events was critical. For example, being well rested meant individuals could attend social activities without negative consequences such as pain the next day. Sometimes this meant saying no to certain activities, to enable others to go ahead, reducing overall social interaction. Maintaining social connection was a constant balancing act. Planning and preparation is often discussed on websites that provide support for CMCs (Complex Chronic Illness Support, n.d.). The value of planning and preparation for social connection is further validated by this study.

Theme 4 describes technology and connection to the outside. Technological advances combined with lower costs have increased the availability and ability to own a range of technological devices that can be used to maintain social relationships (Balki et al., 2022). For individuals living with CMCs technology was critical for social interaction and positively influenced maintenance of social connection. Individuals could tailor technology to condition related symptoms to maintain social interaction. Studies of older adults with poor health have also found that technology significantly contributed to the ease of interacting and maintaining connection with friends and family (Balki et al., 2022). Many individuals chose to connect with the online community to simply interact with others, to join support groups, or make new connections. Engaging with online communities increased overall interaction, social networks, and provided social support. Morris et al., (2014) also found internet-based health sites, support groups, and chat groups positively influenced social connectedness.

Nevertheless, some individuals indicated that these relationships were not “real” friendships. It is possible that online interactions do not always foster the same meaningful attachment that face-to-face connection provides. Other studies have found that technology while useful for maintaining connection may have limited impact for developing new friendships (Balki et al., 2022). Understanding the role of friendship

within social connection may provide an explanation for these findings. Shared activities are important for friendships at the beginning as it gives individuals an opportunity to interact and learn more about each other (Sias and Bartoo, 2007). Therefore, it may be easier to develop meaningful friendships in-person through shared activities. Research has shown participating in shared activities can strengthen social connectedness (Cohen-Mansfield & Eisner, 2020).

Close friendships are also based on a liking, trust, self-disclosure, and intimacy (Sias & Bartoo, 2007). If individuals are typically interacting in online support groups, then self-disclosure may be mostly based on sharing condition specific information. In friendship, self-disclosure includes the sharing of personal information such as background, values, and attitudes enabling individuals to find similarity and as more disclosure occurs so does trust and friendship (Sias & Bartoo, 2007). As people develop a greater affinity the relationship develops from being an acquaintance to being a friend (Sias & Bartoo, 2007). Without sufficient personal disclosure online friendships may feel more superficial. These findings suggest that technology is critical for maintaining social connection and significantly increasing social interaction, networks, and social support. Yet, face-to-face interaction may be more helpful for developing close friendships. Research also indicates the online community has contradictory effects on social connectedness which needs further exploration (Ryan et al., 2017)

Theme 5 recognises that CMCs are linked to experiences of social isolation and loneliness. Increased feelings of isolation and loneliness were often associated with changes made due to living with CMCs that had reduced social networks through stopping work or less social events. Individuals talked about being isolated when they were without transport and were “trapped” at home. Not hearing from friends and missing out on social occasions were also influencing factors especially in the evenings or weekends. Studies of loneliness and poor health for individuals with chronic illness highlight similar contributing factors such as stopping work, less contact with friends,

mobility, and transport issues (Bay et al., 2020; Cohen-Mansfield et al., 2009; Drennan et al., 2008; Jones et al., 1985; Jessen et al., 2018; Tijhuis et al., 1999).

Additionally, 'Invisible' symptoms, such as pain or hearing difficulties, made it difficult to interact for those living with CMCs. In other studies participants have reported their hearing difficulties have made them feel embarrassed leading to reduced interaction (Cohen-Mansfield & Eisner, 2020). Invisible symptoms were linked to increased feelings of isolation and loneliness during moments of interaction. These experiences of isolation and loneliness were intensified in group situations. Individuals felt lonely that they couldn't participate with others, lonely that they were alone with their symptoms, and lonely that no one seemed to notice they were missing from the conversation. Studies of chronic illness and multimorbidity share similar findings that invisible symptoms such as cognitive impairments or concealed physical symptoms can increase feelings of isolation and loneliness (Holley, 2007; Umeh et al., 2017).

These experiences of isolation and loneliness can also be explained by the term perceived loneliness. Perceived loneliness refers to a subjective feeling of social isolation (Lim & Gleeson, 2014). Additionally, these experiences can also be explained by 'Discrepancy Theory' that views loneliness as a state that evolves from a cognitive evaluation of the difference between desired and actual level of quality or frequency of social interaction (Cohen-Mansfield & Eisner, 2020).

Feeling "different" from "the normal group" was also isolating and contributed to feelings of exclusion and loneliness. Studies of chronic illness have also linked fear of feeling different and anticipated stigma with reduced social interaction (Earnshaw et al., 2012; Farrell & Comiskey 2014; Umeh et al., 2017). Rather than disclose their condition individuals often opted out of social occasions and instead choose self-imposed isolation. This behaviour protected those living with CMCs from the negative feelings of exclusion, isolation, and loneliness in the moment. However, opting out typically reduced overall social interaction and further exacerbated these feelings. Lim and Gleeson (2014) explain that lonely individuals can be caught in a vicious cycle of loneliness by using these self-protective behaviours that lead to further isolation.

Still, not everyone experienced isolation and loneliness relating to their health status. This has been described as 'personal agency' in opting to be alone (Cohen-Mansfield & Eisner, 2020). Spending time alone was often appreciated and sought out. Also, some participants indicated they were busy with work, children, or other demands and didn't have time to feel lonely. Similar to other studies, these findings demonstrate how for those living with CMCs, experiences of social isolation and loneliness are influenced by individual differences, context, and personal preference for solitude (Buecker et al., 2020; Burger, 1995; Cohen-Mansfield & Eisner, 2020).

Participants had developed methods for managing isolation and loneliness. The main strategies identified in this study were categorised according to distraction and seeking social connection. These findings are consistent with other studies of loneliness that have also highlighted the positive impact distraction has on feelings of isolation and loneliness (Cohen-Mansfield & Eisner, 2020). Individuals contacted friends and family and others in the community to help with isolation and loneliness. Even small interactions were helpful such as going to the gym or going to the local mall. Research suggests that loneliness may trigger a sensitivity to social threats which propels individuals to seek out social relationships (Cacioppo & Cacioppo, 2014).

Participants with hearing or speech impairments relied mostly on online communities together with close friends and family for social interaction, mostly opting out of engaging in-person, and becoming more housebound. Research suggests that individuals may experience greater isolation with smaller and self-contained networks (Wenger et al., 1996). However, technology allowed more housebound individuals and those with impairments to interact and create new connections online. In a review of interventions with older age adults, use of technology was linked to reduced loneliness and enhanced social network connections and social connectedness (Balki et al., 2022). Therefore, online interaction may be a particularly useful tool for mitigating isolation and loneliness for those living with CMCs that find face-to-face interactions and leaving the house more challenging.

Owning a dog significantly reduced feelings of isolation and loneliness for those living with CMCs. Studies with adults with chronic pain have also found that dogs were a caring companion, gave emotional support, and provided a distraction from pain (Carr et al., 2018). Individuals found the responsibility of owning a dog was positive and having to walk the dog increased social interaction in the community. Likewise, Carr et al. (2018) also found dogs were helpful for giving owners something to focus on, motivating owners to walk the dog, and increased social interaction. Research now suggests that animals can fulfil the role of a friend and provide social support when feeling lonely by boosting mood and lowering stress as well as increasing opportunities of social interaction (McConnell et al., 2017).

Theme 6 describes how connecting through shared experience positively influences social connectedness. Interacting with others with a similar condition increased social networks for those living with CMCs and provided valuable social support. Connecting through shared experience enabled a platform to share personal challenges and provide and receive emotional support. Value in these relationships was attributed to spending time with others who were similar, who understood what living with CMCs was like, and to feeling less alone. Individuals felt inspired by others' experiences and appreciated their willingness to help and positive attitudes. Similarly, in a study of adolescents with cancer the participants also expressed value in sharing experience with others who "just know" as well as benefiting from giving or receiving inspiration (Cassano et al., 2008). Connection via shared experience also enabled informational support. Individuals both gave and received advice ranging from everyday tips for difficult tasks to advice on different medications, services, and healthcare experiences. Connecting through shared experience fostered connectedness through reciprocal social support and meaningful engagement (Berkman & Glass, 2000).

However, connecting with others through shared experience was not for everyone. Some individuals preferred to receive support from their close family and friends. Sharing a condition didn't necessarily provide a "closeness" with strangers that

justified an interaction. Additionally, interacting with others who could act as a future mirror was uncomfortable for some. Likewise, interacting with others with more severe symptoms could be “distressing and tasking”. For some it was difficult to hear from individuals who “could do more”. Lastly, not all support groups in the community were close enough to home or had the right makeup of age and stage.

In conclusion, this research adds to the health literature by providing new understanding as to how social connection is maintained for individuals living with CMCs. This study identified key elements that enabled maintenance of social connection. Technology was vital in facilitating connectedness both in maintenance and development of social interaction and social networks. Also, regularly engaging with friends and family who were understanding and considerate of needs positively influenced social connectedness. Also, interacting with close family members was associated with instrumental support.

Maintaining connection is important to individuals living with CMCs and efforts were made with family, friends, and in the community. These efforts included both in-person groups and face-to-face interaction and online support groups and forums. Online groups were helpful for increasing interaction and providing informational support. In-person support groups were particularly beneficial for enabling both emotional and informational social support.

Both physical and emotional factors were found to limit social connection opportunities. Accordingly, social events took significant planning and preparation and ultimately meant choosing between social activities. This led to reduced social interaction and impacted networks. Reduced social interaction was associated with experiences of social isolation and loneliness. Perceived isolation and anticipated stigma influenced social interaction and increased feelings of loneliness. Mitigating these feelings with distraction and increasing social interaction helped with these experiences.

This study adds to the literature by providing insight as to both contributing factors and helpful strategies for maintaining social connection for individuals living with

CMCs. The findings of this research can assist healthcare providers to partner with individuals living with CMCs to maintain social connectedness (Perissinotto et al., 2019; Wilkinson et al., 2019). These conversations may help identify barriers to connection in order to tailor appropriate support. By empowering individuals to increase social interaction and connectedness this may help prevent experiences of social isolation and loneliness (Cohen-Mansfield & Eisner, 2020).

Lastly, this study suggests the need for screening for social isolation and loneliness for this health population to guide care (Perissinotto et al., 2019). This research also demonstrates a need to create further public awareness and understanding of health conditions such as CMCs to reduce experiences of perceived isolation and anticipated stigma. Maintaining social connection is likely to remain significantly challenging, especially for those with more severe conditions and who are more housebound, and therefore greater assistance and intervention may be required to adequately support the wellbeing of these individuals.

Strengths and Limitations

This research includes strengths in both design and practicality of findings. As most of the health literature regarding health populations and social connection is quantitative this study fills a gap in the literature through qualitative analysis (Wilkinson et al., 2019). Qualitative research can enable deeper insights of a phenomenon that quantitative analysis may not capture (Finlay, 1998). In addition, most studies on poor health and loneliness have included older age adults whereas this study incorporates a wider range of ages. The findings from this sample may provide benefit to healthcare service providers, public health agencies, charities, and individuals living with CMCs regarding helpful ways to maintain social connection as well as strategies for reducing feelings of isolation and loneliness.

In addition, the trustworthiness of these findings were strengthened by using best practice methods to enhance quality of findings. These steps included immersion with the data, checks with the Primary Investigator, repetitive checks of codes and themes,

and transparency of research steps. Researcher bias is always an issue to manage in qualitative research (Finlay, 1998); however, significant effort was made to reduce the impact of researcher bias on the research process through reflexivity. Due to ethical requirements this dissertation research did not include observational notes or reflexive journaling from the interview process which was conducted by the Research Fellow employed on the larger study.

There are a number of limitations related to the sample. Firstly, a smaller sample of 12 was used out of the entire dataset of 30 participants. While acceptable for in-depth analysis of a phenomenon if the data is rich, it may limit the transferability of findings. For example, the sample was predominantly female and New Zealand European. Checks were made prior to analysis to compare characteristics of participants across the two samples. Most demographics were very similar although the smaller study sample had slightly more participants who were working and the larger data set had slightly more participants living alone.

It is possible that individuals that volunteered for this study are more proactive in general which may also influence their attitudes and behaviours towards maintaining social connection. Also, this study did not identify socio-economic or mental health issues that may be important factors influencing maintenance of social connection as well as experiences of isolation and loneliness.

Participants also tended to use the constructs of social isolation and loneliness interchangeably and therefore it was difficult to interpret or report on these constructs independently. Cultural factors may have also influenced the findings of this research (Stephens et al, 2011). For example, a collectivist lens views interconnectedness of social networks as central to identity whereas an individualistic lens may be influenced by more independent ideals (Nickerson, 2021). These views may differentially influence perspectives and behaviours related to social connection.

Implications and Future Research

Healthcare providers are in an ideal position to support individuals in maintaining social connection (Mossabir et al., 2015). This can be through informational support such as disseminating flyers, pamphlets, charity website details, or resources to connect within communities. Information can also be shared explaining how social connection supports wellbeing. This may start a discourse about what barriers there are to maintaining connection for individuals to identify how to best tailor support. For example, for some individuals it may mean being assessed for hearing aids (Perissinotto 2019), or assisting with transport to community activities. Research has identified the potential role for a facilitator to manage these processes on behalf of healthcare providers by connecting individuals with appropriate resources (Mossabir et al., 2019). Health populations have also identified a need for more guidance of available resources (Cohen-Mansfield & Eisner, 2020; NHC, 2007).

Health-care practitioners could also screen for experiences of isolation and loneliness and then partner with individuals to guide care. Based on the premise of providing hope, practitioners could work with individuals to design a plan aimed at enhancing social connectedness. Hope is one of the psychological constructs that underpin resilience (Rybarczyk et al., 2012). When individuals who are living with CMCs face reduced social networks, hope may encourage adaptive coping (Rybarczyk et al., 2012). Hope is defined as a "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathways (planning to meet goals)" (Snyder et al., 1991, p. 287). Individuals in this study highlighted the need and demonstrated the motivation to make increased social connectedness a goal and take steps to achieve this goal. Cultivating hope could help isolated individuals envision a more socially connected future and is potentially an important focus for interventions (Hanna, 2002).

Developing connections through the community may mitigate the loss of social roles and reduced social networks. Community group initiatives could be designed that use face-to-face settings within the community as well as online or video call initiatives

to accommodate the needs of individuals that are more housebound. Group activities that include an educational component or social support component have been shown to be beneficial (Cohen-Mansfield & Eisner, 2020). Given that individuals with CMCs seek interaction in the community to reduce feelings of isolation and loneliness these kinds of initiatives may provide extra benefit for lonely or isolated individuals. Future research is required to determine if community initiatives to facilitate social connectedness are effective for those living with CMCs.

Ensuring condition specific support groups are readily available within communities would be positive given the benefit they provide to some individuals. Coordinating these groups to be matched on age and stage would be advantageous where possible. However, support groups are not for everyone. Therefore, additional community groups could be created as outlined above or based on other community programmes such as Framework Trust (n.d.) that is a charity supporting mental health and intellectual disability with group based shared activities. The benefit of these programmes is that they bring people together to connect through similarity and shared experience but also through shared activities that can strengthen social connectedness.

A challenge for future research is to provide effective interventions for those individuals who are more housebound and who find face-to-face interaction difficult. Technology based interventions may facilitate social connectedness for those individuals for who technology is a “lifeline”. This may mean creating a variety of online group forums designed to connect individuals potentially via online foundation sources or public health websites. These forums could provide frequent interaction through chat support groups and online clubs that come together for online shared activities but with an opportunity for group interaction periodically to strengthen connections in-person. Future research is required to explore effective methods to connect individuals that are more homebound but in a meaningful way that strengthens connectedness.

Individuals also spoke of the positive impact of one-on-one interaction with a close friend. Especially those who made more effort and were more understanding.

These experiences were less isolating and associated with more positive experiences. A potential strategy for individuals living with CMCs that experience isolating moments, particularly in group situations, or when more homebound, is to focus on confidant relationships to boost overall positive social experiences (Lim & Gleeson, 2014). Future research could explore the benefits of confidant relationships for those living with CMCs and how the support from these relationships impacts social connection in comparison to other network members.

The role of online connections for supporting social connectedness needs further exploration. In the current study the use of online forums and support groups increased social interaction and social networks and provided a distraction when lonely. However, friendships were not always considered “real”. These findings indicate that there may be differences in strength of connections when formed online as opposed to in-person. Future research is required to continue to explore the influences of online networks on social connection.

Lastly, there are many ways that culture may influence an individual’s ability to maintain social connection. Future research can explore relevant cultural factors that influence meaning and experiences of social connection for individuals living with CMCs. Culturally relevant factors may impact size and diversity of social networks, social support availability, and perspectives on what is meaningful engagement and connectedness, including experiences of isolation and loneliness. Certainly, to ensure that any individually tailored or community intervention is successful demands culturally relevant aspects to be considered and incorporated.

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Appendix A - Ethics Approval

AUTEC Secretariat
Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

26 March 2018
Wendy Wrapson
Faculty of Health and Environmental Sciences

Dear Wendy

Re Ethics Application:**18/86 What are the experiences of loneliness and social isolation in those with complex medical issues in New Zealand**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 26 March 2021.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee
Cc: asmita.patel@aut.ac.nz; Alice Theadom; Richard Siegert

Auckland University of Technology Ethics Committee (AUTEC)
Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

3 August 2021
Wendy Wrapson
Faculty of Health and Environmental Sciences

Dear Wendy

Re: Ethics Application:**18/86 What are the experiences of loneliness and social isolation in those with complex medical issues in New Zealand**

Thank you for sending through the signature for the amendment to your ethics application.
Your amendment for access to de-identified copies of transcripts has been approved.
Standard Conditions of Approval.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.
Please quote the application number and title on all future correspondence related to this project.
For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)
The AUTEC Secretariat
Auckland University of Technology Ethics Committee
Cc: asmita.patel@aut.ac.nz; alice.theadom@aut.ac.nz; Richard Siegert

Auckland University of Technology Ethics Committee (AUTEC)
Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
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4 October 2022
Wendy Wrapson
Faculty of Health and Environmental Sciences

Dear Wendy

Re: Ethics Application: **18/86 What are the experiences of loneliness and social isolation in those with complex medical issues in New Zealand**

Thank you for your request for approval of amendments to your ethics application.
A one year extension (till 26 March 2023) has been approved.

Standard Conditions of Approval.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
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Please quote the application number and title on all future correspondence related to this project.
For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)
The AUTEC Secretariat
Auckland University of Technology Ethics Committee
Cc: asmita.patel@aut.ac.nz; alice.theadom@aut.ac.nz; Richard Siegert

Appendix B - Research Tools

Invitation to Participate in Research Study

Do you have [*name of medical condition]*?
If so and you:

- live in Auckland;
- are aged 18 – 65 years

and your treatment involves seeing multiple specialists (either currently or in the past), researchers at Auckland University of Technology would love to conduct a face-to-face interview with you*. This can either be held in your home or at a venue of your choice.
A $30 gift voucher will be provided in appreciation of your time.
* We may not be able to interview everyone who volunteers.

Please contact:
Dr Asmita Patel
Email: asmita.patel@aut.ac.nz
Tel: 09 921 9999 ext 7661
Text: 021 034 9644

Participant Information Sheet

Date Information Sheet Produced:
March 2018

Project Title
Living with a complex medical condition

An Invitation

Kia ora, my name is Wendy Wrapson. I am a researcher at Auckland University of Technology (AUT) and I am conducting a study to learn more about the experiences of people with a complex medical condition and, in particular, how they maintain their social connections and social relationships, and the type and extent of social support received.

We are defining a 'complex medical condition' as one that is persistent and ongoing, substantially impacts on a person's life, and requires treatments and services from a variety of healthcare specialists.

If you have a complex medical condition, I would like to invite you to take part in this research. **Participation involves taking part in a face-to-face audio-taped interview with a researcher lasting 60 – 90 minutes.**

What is the purpose of this research?

Health problems can significantly impact on a person's daily life. Not only do they sometimes cause physical limitations but they can also result in reduced social participation, including contact with family and friends. There is increased recognition that reduced social participation can itself have a negative impact on health and wellbeing. Therefore, the aim of the present study is to identify the types of physical and social limitations experienced by individuals with complex medical issues with the aim of better understanding the impact this has on their social interactions. This study is funded by the Estate of Dr Jeanette Crossley, who herself had a complex medical condition.

How was I identified and why am I being invited to participate in this research?

You have been identified as a potential participant for this research because you have responded to an advertisement in a support group newsletter, local newspaper or social media. Alternatively, you may have taken part in a previous AUT study and subsequently agreed to be contacted about other relevant research opportunities.

How do I agree to participate in this research?

If you are happy to participate in this research, please contact Asmita Patel by phone (09 921 9999 extn 7661), text (021 034 9644) or email (asmita.patel@aut.ac.nz). She will explain the study in more detail and answer any questions you may have.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been analysed, removal of your data may not be possible.

What will happen in this research?

If you agree to take part in this research, you will undertake one individual face-to-face interview with a researcher. You will be asked to complete a short questionnaire about yourself, and will then be asked questions about your medical condition and how it affects you day to day life, including your social life and interactions with other people. We are also interested in finding out if you experience loneliness or feel isolated as a result of your medical condition. The interview will be audio-taped and later transcribed.

Prior to the day of the interview, we will ask you to complete daily entries in a journal about your social interactions over a 7 day period, which we will use as the basis for some of our discussion during the interview.

Before commencement of the interview, you will need to sign a Consent Form which states that you know what the study is about and that you have agreed to take part in the study.

What are the discomforts and risks?

There is no discomfort or risks associated with this research. If you do not wish to answer a particular question for any reason, you do not have to.

What are the benefits?

By taking part in this research, you will be providing information about an under-researched area. Very little is known about how individuals with complex medical conditions maintain their social networks. Our study findings may be used to inform interventions, strategies and solutions that are designed to reduce loneliness and social isolation in those with complex medical issues. Our findings will also be made available to participants and relevant health-related support groups and advocacy organisations.

In appreciation of your time, you will receive a $30 supermarket or fuel voucher on completion of the interview.

What compensation is available for injury or negligence?

In the unlikely event of a physical injury as a result of your participation in this study, rehabilitation and compensation for injury by accident may be available from the Accident Compensation Corporation, providing the incident details satisfy the requirements of the law and the Corporation's regulations.

How will my privacy be protected?

The information that you provide during this study will not be stored with your name or other identifying details. All participants will receive an ID code upon joining the study. The information or data that you provide will be stored with this ID code only. The research team will be the only people who can match the codes to names.

No individuals will be identifiable in any journal articles, conference presentations or reports from this research.

What are the costs of participating in this research?

There is no cost to you being involved in this research beyond your time. The interview will require about 60-90 minutes of your time. Completing the 7-day journal will take approximately 30 minutes in total.

What opportunity do I have to consider this invitation?

If you wish to participate in this study, please contact Asmita Patel (details below). Recruitment to the study will cease once we have interviewed 30 participants.

Will I receive feedback on the results of this research?

If you wish, we will send you a brief summary report of the findings upon completion of the study.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Primary Investigator, Dr Wendy Wrapson, **Phone: 09 921-9999 extn 6136, email: wwrapson@aut.ac.nz.**

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Whom do I contact for further information about this research?

You are able to contact the research team as follows:

Researcher Contact Details:

Dr Asmita Patel, Research Fellow, School of Public Health and Psychosocial Studies, Auckland University of Technology, North Shore Campus, 90 Akoranga Drive, Northcote, Auckland 0627, **Phone: 09 921-9999 Extn 7661, email: asmita.patel@aut.ac.nz.**

Approved by the Auckland University of Technology Ethics Committee on 26 March 2018, AUTEC Reference number 18/86.

Consent Form

Project title: *Living with a complex medical condition*

Project Supervisor: *Dr Wendy Wrapson*

Researcher: *Dr Asmita Patel*

- ○ I have read and understood the information provided about this research project in the Information Sheet dated March 2018.
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that the interview will be audio-taped and transcribed.
- ○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ○ I agree to take part in this research.
- ○ I wish to receive a summary of the research findings (please tick one): Yes○ No○

Participant's signature:

.....……

Participant's name:

.....……

Participant's Contact Details (if appropriate):

……..

……..

……..

……..

Date:

Approved by the Auckland University of Technology Ethics Committee on 26 March 2018, AUTEC Reference number 18/86.

Note: The Participant should retain a copy of this form.

Demographic Data Sheet

Living with a complex medical condition.

Information about you ID No. [ ]

1. Age:

   _____

2. Married / separated / divorced / de facto / single

   _____

3. Ethnicity:

   _____

4. Name of medical condition:

   _____

5. Years since diagnosis:

   _____

6. Years living in New Zealand:

   _____

7. Number of children:

   _____

8. Ages of children:

   _____

9. Number of people in household

   _____

10. Employment status:

    _____

Interview Topic Guide

Living with a complex medical condition.

1. Can you tell me a little bit about *[medical condition]*, and how it affects your day-to-day life?
    a. Impact on carrying out personal tasks (showering, dressing etc)
    b. Impact on household chores (cleaning house, shopping etc)
    c. Impact on employment
2. We are particularly interested in how people with complex medical conditions maintain their social networks. Social networks can include family members, friends, and work colleagues. First of all, are there any family members that you see on a regular basis?
    a. How often do you see or hear from each person, and what is the purpose of your interactions with them?
    b. Are there any activities you regularly do with the family members you have mentioned?
3. Do you have any friends that you see on a regular basis?
    a. How often do you see or hear from each person, and what is the purpose of your interactions with them?
    b. Are there any activities you regularly do with the friends you have mentioned?
4. *[If relevant]* Do you ever socialise with any work colleagues?
    a. If so, who with and what does this entail?
5. Is there anyone you see less regularly – who are they and how often do you see them or hear from them?
6. Do you still see the same friends as you did before your diagnosis?
    a. If not, why do you think that is?
7. Do you encounter any barriers in relation to keeping up with existing friends?
    a. If so, what are these barriers?
    b. How could these barriers be addressed?
8. What about making new friends? Have you found you have been able to do this?
    a. If not, can you tell me why that is?
9. Do you ever experience feeling lonely?
    a. If so, how does this feeling manifest itself?
    b. Have you ever taken any action to try to reduce your feeling of loneliness (i.e., joined a club or other social group)?
10. Do you ever feel as if you are isolated from other people?
    a. If so, how and when does this feeling manifest itself?

   b. Have you ever taken any action to try to reduce this feeling?

11. Do you belong to a support group for *[medical condition]* sufferers?
    a. If so, what are the benefits you gain from belonging to such a group?
    b. If not, can you tell me why that is?
12. In terms of maintaining their social networks, what advice would you provide to someone who has been newly diagnosed with *[name of medical condition]*?
13. In conclusion, is there anything else we haven't discussed today that you wish we had?