Experiences of Young New Zealanders with Progressive Neuromuscular Conditions: Quality of Life and Mental Health

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Abstract

Progressive Neuromuscular conditions (PNMC) are rare and chronic disabilities that affect a small portion of New Zealanders. It is known that quality of life (QoL) is reduced for individuals with PNMC in the physical domain. Beyond this, results are inconsistent as to in what specific ways PNMCs impact other QoL domains. A qualitative methodology, Interpretative Phenomenological Analysis, was employed to describe young New Zealanders' experiences of how living with a progressive neuromuscular condition (PNMC) impacts their quality of life and mental health. Seven participants, ranging in age from 18 to 24, were interviewed. Five themes were identified. Living with a PNMC implies living with a condition that is constantly present, meaning this is both a part of normal life for participants but it also brings forth the uniqueness of living with a rare condition. The uncertainty of these conditions in terms of future wellbeing brings forth mental strain for participants. Participants experience the world as an 'Other', meaning they are aware of their position in society as different to those who do not have an impartment. Participants' acceptance of their condition comes in many different ways, and is aided through the support they receive in their relationships. The results provide insight into how life is like for young New Zealanders who live with PNMCs. This awareness of how the world is for them becomes valuable knowledge as it can inform how to help individuals in their day-to-day lives.

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Introduction

Over the past few decades, there have been many cultural shifts in the way we think and talk as a society. This shift can also be applied to way we as a society are changing the way we view and treat people who live with progressive neuromuscular conditions (Forman et al., 2012). Conversation and research is growing in the topic of what it means to be disabled, particularly with a rare disease.

Thanks to the advancement of medicine, technological aids, and support from many platforms (e.g., internet and advocacy groups) people with progressive neuromuscular conditions are living longer than before (Forman et al., 2012). People who live with a progressive chronic illness have to constantly adjust their lifestyle to meet the needs of a particular time and point in their lives. As these individuals reach young adulthood, new challenges present to them. These challenges deal with topics such as independence, education and employment prospects, romantic relationships and identity.

When individuals reach this point in their lives, they stand at a unique intersection where the combination of living with a chronic illness and developmental stage can have lasting impact for the their lives. Quality of life is a subjective and context specific experience. It therefore becomes important to understand *if* and *in* what ways quality of life is reduced for people with progressive neuromuscular conditions, both at an individual and social level. While there is a general understanding within the literature of the impact of chronic conditions, there is much to be explored about how life is experienced by a person with a neuromuscular condition in their day-to-day life. By exploring the accounts told by people within this specific group, conclusions might be made in regards to understanding physical, emotional and cognitive wellbeing and quality of life.

If we have a better understanding of the factors that influence quality of life then it may be possible to influence these factors to improve the subjective experience of individuals. As there is no cure for PNMCs yet, the success of interventions can be placed on the extent to which care improves quality of life for individuals (Graham et al 2011). The aim becomes providing aid for individuals to live the best life they can rather than solely focusing on the extent to which life can be lengthened.

In the following paragraphs, relevant literature on this topic will be explored. In particular, emphasis in critically understanding how disability is viewed in society, as well as the cultural assumptions of being disabled and a young person. Attention is given to the relevance of the New Zealand context. A critical examination of quality of life is discussed, along with how this connects to psychosocial well-being. The following chapters will discuss the methods behind this study, followed by the results and analysis. Finally, the conclusion will incorporate theory into the results and the author leaves her final remarks.

Literature Review

The umbrella of disability: chronic illness, rare disease and PNMCs

A PNMC is a progressive disability that can also be categorized as a chronic illness and rare disease. While these terms have overlapping characteristics, they are different. Disability can be thought of as the umbrella which encompasses the different terminology used to describe PNMCs. By definition, a chronic illness is a health problem that a) lasts at least three months, b) affects a person's daily life activities, and c) requires frequent hospitalizations, home health care, and/or extensive medical care (Mokkink et al., 2008). Chronic illnesses have prolonged duration, are unresolvable spontaneously and rarely completely cured (Stanton, Revenson & Tennen, 2007). The term rare disease, as defined by Forman et al (2012), is used to describe a group of disorders that do not have a cure and result in reduced quality of life due to their impairing characteristics. Rare diseases affect 1 per 2000 individuals in Europe or <200 000 people in the United States (Forman et al., 2012).

As with any illness, PNMCs are complex. There is usually more than one variant of a condition. The disease spectrum for PNMCs is usually divided into types. For example, Spinal Muscular Atrophy (SMA) is divided into types 1 through 4 depending on disease specific symptoms and characteristics (D'Amico et al., 2011). Common symptoms of PNMC include pain, fatigue, muscle weakness, loss of muscular control, and mobility problems (Theadom et al., 2014). PNMCs do not have a cure, but to help maintain functioning for as long as possible, there are treatments that focus on the prevention and management of symptoms. Treatment usually includes a multidisciplinary healthcare team, which can be made up of a general practitioner, neurologist, physiotherapist, occupational therapist, nutritionist and genetic counsellor, to name a few.

Disability

In order to critically assess the impact of PNMCs beyond the impairment they produce, it is important to be critical of how PNMCs are viewed and thought of in society. The literature argues there are different ways to conceptualize disability. There are models of disability that look at it from a biological and medical perspective. Other models look at disability through a social lens, where disability is seen as a social construct. It is important to make note of these different types of ways of thinking about disability because the way disability is thought of by an individual and culture has an impact on how it is experienced and lived by a person. It is through these daily experiences that the taken for granted ways in which the dominant discourse of disability permeates life (Willig, 2003). These daily interactions impact and shape the way an individual lives and experiences their condition.

Biomedical Model of Disability. Generally speaking, the bio-medical model of disability has dominated the mainstream discourse of disability. The bio-medical model of disability, also referred to as the medical model of disability, explains disability as a medical problem that is located in the body (Bickenbach, 1999). This problem is seen as a defect that causes the individual limitation in activity. The model views disability as an abnormality, where the treatment approach is focused on medical care that will either cure the problem, or at least lead the individual towards some level of normalisation (Fisher & Goodley, 2007). As Fisher and Goodley (2007) explain, this model views a healthy individual as a functioning 'biochemical machine'. Therefore, with medical intervention, the malfunctioning individual (i.e., disabled), should return to a state of normality, or at least be better off than without any treatment.

When one takes a critical lens to the bio-medical model, there are many assumptions made. At its core, this model's idea is that the body has a standard, 'normal' function. Think of an average person, who is assumingly free of any physical, mental, psychological or developmental 'malfunction.' This individual never has to think about their body or mental state because their machine is working with no problem. Now, consider an individual who lives with a disability. This person deviates from the standard normality, and one may say that their body is therefore in a state of deficit; their machine is not working up to the normal standard. They require frequent intervention, be it by medical professionals, assistance or treatment, in an attempt to reach normality. One could argue this model might render people who live with a physical disability as passive. That is to say, that people with a disability are passive and that their disability is happening to them. They are without any control of the effect their disability has on their lives due to this being a medical problem located in the body. The assumption is therefore that the person has no control over their experience.

Smart (2006) has challenged the Biomedical model, arguing that the model is too fragmented and does not take into account any factors beyond medical interpretations to explain disability. This model does not consider the role society plays in regards the definition of disability, the rights given to individuals with disabilities or how society has an impact on the daily-lived lives of people with disabilities (Smart, 2006).

Social Models of Disability. Social models of disability looks beyond the impartment a disabled person faces and also views the social construct of disability. Beyond impairment lies a complex interaction of social, environmental, and attitudinal barriers in society that impact a person with a disability. The argument proposed by this model is that a disabled person is an oppressed group in society. Individuals with disability are not given the chance for the same opportunities as their able-bodied counterparts. They argue that biological factors are not as important as the complex collection of social, environmental and attitudinal barriers present in society (Bickenbach, Chatterji, Badley & Üstün, 1999).

At its core, the social model defines disability as a social and political issue due to the limitations disabled people face due to social attitudes (Shakespeare & Watson, 2001). Limitations are present in areas such as education, employment, housing, transportation and accessibility in public spaces. For example, if a person is wheelchair bound due to their inability to walk then that is an impairment. But, when that person is unable to attend a university lecture due to the inaccessibility of the structural building then that is a socially constructed disability. Disabled individuals are an oppressed group due to their isolation and exclusion from full participation in society (Shakespeare & Watson, 2001).

PNMCs: What's happening in New Zealand?

It is estimated there are roughly 1,100 New Zealanders living with a PNMC. Figures from the literature (Rodrigues et al., 2017; Theadom et al., 2014) point to crude prevalence rates of PNMC at 22.7 per 100,000 people. These rates are lower than those seen in other countries, such as in the United Kingdom. Of the individuals counted for, the prevalence rate is almost twice as high for New Zealand Europeans. More specifically, differences in prevalence rates among ethnic groups are as follows: New Zealand Europeans 24.4 per 100,000 people, Māori 12.6 per 100,000 people, Pasifika 11.0 per 100,000 people and Asian 9.13 per 100,000 people (Theadom et al., 2014).

It is important to consider the possible cultural, social and genetic factors that may be accounting for the differences in PNMC prevalence rates between ethnic groups seen in New

Zealand. Prevalence was almost twice as high in New Zealand Europeans. Analysing the data, Theadom and colleagues (2014) controlled for factors such as social deprivation and living in rural or urban areas and found no significant associations between prevalence rates and these factors. While other studies need to be conducted in order to understand why there is a difference in prevalence rates of PNMC between different ethnic groups in the country, the authors theorized certain claims. One possible explanation for the lower prevalence rates of PNMC in ethnic minorities might be because of the overall lower rates of PNMC in New Zealand. As New Zealand has a relatively small population, compared to that of the United Kingdom or the United States, it would make sense that less of the population would be affected by these diseases. As the overall population is less likely to have a PNMC, then ethnic groups whose population sizes make up a smaller percentage of the population will present significantly lower rates of PNMCs. Additionally, the authors did not rule out the possibility that a combination of social and cultural factors may have an effect on the prevalence rates.

Factors such as attitudinal barriers, access to healthcare, communication and cultural responsiveness (Marrone, 2007) might be contributing to the discrepancy in the statistics. When talking about attitudinal barriers, Marrone (2007) refers to certain beliefs ethnic minorities might hold, associated with shame and pride of having a disability, and the stigma associated with them. Furthermore, individuals from certain ethnic communities might not want to involve non-family members or potentially do not see the need for accessing services.

Access to healthcare options might be limited in practical ways for ethnic minorities. For example, the majority of Māori communities in the country are located in rural areas. This makes accessing healthcare services located in urban centres challenging (Marrone, 2007). People might lack the practical accessible means to reach these locations. They might be limited because of financial reasons or might simply be unaware that there are services available to them.

Communicational barriers go beyond being able to communicate in the same language (Marrone, 2007). It is essential for health care professionals to be aware of differences in communication styles between different ethnic minorities. This could mean being able to provide interpreters to communicate in the language of choice for the patient. Communication also refers to being culturally aware of the different ways people might communicate symptoms. Overall, there appears to be a lack of cultural responsiveness to meet the cultural needs of diverse ethnic groups which might influence how often people access health services. In a national survey of health equity in the New Zealand health care system, Sheridan and colleagues (2011) found that less than ten percent of all District Health Board employees had undertaken diversity training. In fact, no District Health Board had information on which of the staff had undertaken cultural safety or diversity training. Lack of ethnic diversity within heath care staff and little cultural safety of diversity training reflect the Euro-centric mainstream standards that are present in the healthcare system. Incorporating culturally competent services is found to encourage individuals to access health services. When culturally competent services are included in the healthcare system, such as a Māori paradigm of health, individuals and their whānau (family) feel safe and comfortable to access services.

Although prevalence differences within ethnic minorities are real and a cause for concern, there is also no denying that life expectancy has improved for people diagnosed with PNMCs. Major advances in the diagnosis and treatment of PNMCs means people are living longer than they were a quarter century ago (Schieppati, Henter, Daina, & Aperia, 2008). Improvement in the early care of individuals with PNMCs and resources such as practice guidelines to promote better care have increased life expectancy (Schieppati, Henter, Daina, & Aperia, 2008). As more people with PNMC are reaching adulthood it is important to bear in mind the specific challenges young people face. The intersection of age, rare disease and social world must all be considered to be able to understand the experiences of young New Zealanders that live with a PNMC.

Emerging adulthood

When considering the targeted age group of the participants in this study, it is important to take into consideration the developmental stage and specific factors that accompany this stage in life. During this transitional phase in life, one is leaving adolescence but has not fully emerged into adulthood. This particular stage in life is filled with physical, emotional and social changes in roles, relationships, expectations and status (Pandey & Agarwal 2013). The individual is at an intersection where identity exploration and formation continues (Arnett, 2000 ; Erikson, 1968). With more young people with PNMCs living longer than ever before (Chen, Miller, Seo & Mendoza, 2010), its important they are able to successfully go through this stage in life.

Erikson's psychosocial theory of personality development (Erikson, 1968) claims the human life cycle is made up of 8 stages that are critical for a person's identity formation and psychosocial development. Three major processes underlie development which are the biological processes (i.e., a developing body), psychic processes (i.e., a developing mind) and the sociocultural environment of an individual.

Stage 5 and Stage 6 of Erikson's theory are of particular importance given this is the age bracket which individuals fall into during emerging adulthood. Stage 5, Adolescence, is characterised by identity versus role confusion (Erikson, 1968). Erikson argues that as our world becomes more technologically advanced, the result is there is more time between early school life and the individual's access to a specialised work. What this implies that this period in life becomes even more significant. This is the time in life where teenagers develop a sense of self and personal identity. If one completes this stage successfully, it is likely for the individual to have high self-esteem and confidence with themselves as they have formed an identity that is secure. Those who are not as successful through this stage, for a myriad of possible reasons, may be unclear of what their role in the world is. These individuals may have a weak sense of self. (Poole & Snarey 2011).

Stage 6, Young Adulthood, is characterised by intimacy versus isolation and emphasizes the importance of relationships. In particular, Erikson talks about the importance for young adults to form intimate, loving relationships with others. When successful in this stage, the individual develops a capacity to be mutually intimate on a psychosocial level with another person. That is to say the person is able to develop a friendship or romantic relationship, for example, and finds companionship and intimacy. When the individual fails to do so, feelings of rejection, loneliness and isolation arise as well as *distantiation* (e.g., mental or emotional distance) occurs (Erikson, 1968). Stage 6 becomes harder for those with disabilities because of the uncertainties surrounding the course and symptoms of their PNMC (Chen, Miller, Seo & Mendoza, 2010).

Emerging Adulthood. This theory describes the stage in life where one is leaving adolescence and entering adulthood Arnett (2000). Arnett (2000) argued that between the ages of 18 and 25 people go through a time of transition. Between the ages of 17 and 30, many changes occur in the lives of young adults, such as getting married, starting a career, and having children. The figures show that between 12 to 17 years of age, 98% of people are unmarried, 95% are enrolled in school and 10% have children. The figures change drastically by the time people reach 30 years of age. By then, 75% of individuals have married, roughly 75% have become parents and 10% are enrolled in school (Blum 2005). While these milestones are seen as inevitable for most people, those who live with a physical impairment are less likely to reach them. Those with physical impairment are one third less likely to be employed and one half less likely to attend post-secondary education (Pandey & Agarwal 2013). Individuals are also less likely to than their peers to get married and live independently (Blum 2005). Reaching of developmental tasks presents as a critical challenge for young adults with disabilities.

As Blum (2005) states, there is a discourse on adulthood present in society. Ideas around *how* the developmental progression of young adults should proceed include ideas on adult milestones. Adults in western society are seen as independent, self-sufficient, employed and productive. These ideas then become problematic as individuals with PNMCs often times will require dependency on others given the physical manifestation of symptoms and deterioration of the muscles. Therefore, individuals with PNMC may feel as if they are going in the opposite way of what is expected of them during adulthood. Many times, individuals with PNMC will not fit the mould which leads to problematic outcomes such as feelings of loneliness and isolation (Chen, Miller, Seo, & Mendoza, 2010). It is likely that this has the potential to affect a person’s psychosocial wellbeing and quality of life.

Quality of Life

Quality of Life (QoL) is a multidimensional concept used in psychological research as a measure of the extent individuals feel satisfied with their health and well-being (Karimi & Brazier, 2016). Therefore, investigation into people's quality of life will produce subjective responses depending on how satisfied people are with their own health and well-being. Research in this field uses the terms QoL and Health Related Quality of Life (HRQoL) interchangeably, which can cause some confusion. It is therefore important to make note of the different definitions for these terms (Karimi & Brazier, 2016). Some define QoL as subjective well-being, others on the individual's expectations, basic human needs, life satisfaction or phenomenological viewpoints (Ferrans, 1990). There is also disagreement as to whether QoL should only include subjective perspectives of the individuals or also objective lists (Peasgood, Brazier, Mukuria & Rowen, 2014). HRQoL definitions are just as varied, and multiple definitions exist in the literature. Broadly speaking, there are definitions that relate to daily functioning (e.g. activities) and well-being (subjective feelings) (Hays & Reeve, 2010). Other definitions for HRQoL exclude anything beyond health related factors that impact on a person's health (Torrance, 1987). Other definitions focus on aspects of QoL that are affected by health (Ebrahim, 1995).

Generally speaking, most of the recognised methodology in this field is derived from the World Health Organization's (WHO) definition of QoL. WHO defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (Whoqol Group, 1994 p. 6). More specifically, WHO's definition of QoL broadly encompasses several domains: psychological; social relations; physical health and environment. As will be discussed in the following paragraphs, there is no single unanimous relationship between PNMCs and QoL. Instead, the relationship is complex and there are many factors and individual differences that influence a person's perception of their QoL.

PNMC and QoL. Piccininni, Falsini and Pizzi (2004) set out to explore the different factors that affect QoL in adult patients with different neuromuscular conditions. 45 participants underwent the Sickness Impact Profile (SIP) and Psychological General Well-Being Index (PGWBI), as a measure of QoL. All patients had a poor QoL assessment with the SIP. The higher a person rated their level of disability was not related to a worse QoL perception, with the exception of the physical domain. The discomfort linked to the emotional and affective domains, assessed with PGWBI, appeared low in the study sample. Therefore, the authors concluded psychosocial aspects and economical and environmental factors may influence the QoL.

Padua and colleagues (2009) investigated quality of life in 65 adult (aged 16 – 71) participants with facioscapulohumeral muscular dystrophy (FSHD). They administered a battery of tests, including the Short Form-36 (SF-36) health survey to measure QoL and the Beck Depression Inventory (BDI) to evaluate the occurrence of depression in relation to illness severity. Results of participants were compared to a normative sample. Results showed the more clinically severe FSHD participants reported significant reduction in QoL scores in the physical domain (Padua, 2009). Aside from the physical domains of the SF-36, no other score was significantly different from that of the normative sample.

In regards to BDI scores, researchers found that depression was not related to illness severity. While the physical domain of QoL is reduced in those who have PNMCs, when it comes to psychosocial domains, the lines are blurry. Many times, psychosocial QoL will not be significantly different from able bodied peers in this domain (Graham et al., 2011). This is an interesting find as it points to the way QoL is viewed. Of course, in the physical aspect QoL is reduced for people with a physical disability. But, there does not seem to be a reduction in other aspects of QoL. People can have a condition that is very severe and report high levels of QoL. This phenomenon is called the disability paradox.

The Disability Paradox. Founded on the work of Sol Levine, Albrecht and Devlieger (1999) describe the disability paradox as a phenomenon that occurs when individuals have a disability and report their personal perception of their health, well-being and life satisfaction to be higher and conflicting with the individual's objective health status and disability severity. The authors introduce a balance theory explanation to further expand on the idea of the disability paradox. The balance theory is exactly as it sounds. It is a theory routed in there being a balance between the body, mind and spirit within an individual's social context and environment. Balance must be present in order for the person to achieve and experience well-being and life satisfaction. The authors therefore argue that when a balance between body, mind and spirit is present then the person will report a high quality of life.

Additionally, within the balance framework is the idea of 'secondary gain'. Secondary gain refers to the process of those with a disability adapting to new conditions and making sense of them. Secondary gains can occur, for example, when individuals with a disability use their particular circumstance and the implications of their disability to reinterpret their lives and adjust the personal meaning in their social roles.

Psychosocial well-being and QoL. The literature highlights how QoL is a subjective experience, and measuring it is very difficult to do. In quantitative studies, participants almost always rate their QoL significantly lower than able bodied peers in the domain of physical health (Graham et al., 2011). Psychosocial factors play a role in the relationship between condition severity and QoL. Psychosocial factors are important as they can either act independently or mediate the relationship between condition severity and QoL. Psychosocial wellbeing encompasses both mental health (i.e., psychological health) as well as social aspects.

Research shows anxiety seems to be present in populations of individuals with muscle disorders, both in children and adolescents (Woodgate, 1998) and adult groups (Pangalila et al., 2015). Anxiety seems to account for much of the variation in QoL scores seen in the literature. The positive side of this is that anxiety is treatable and can therefore help increase QoL for individuals with PNMCs. While psychological interventions have shown efficacy for improving QoL in other chronic diseases, there has only been one trial of psychological intervention that has involved people with PNMC (Graham et al., 2014). Graham et al (2014) suggest that the lack of psychological interventions is a reflection of poor understanding of how psychological factors relate to the QoL in people with PNMC.

Uzark and colleague's (2012) study of children and adolescents with MD found that boys with Duchenne Muscular Dystrophy (DMD) reported significantly lower QOL than their healthy counterparts. Older boys with DMD had decreased levels of functioning, but seemed to perceive their QOL better than how their parents perceived it to be. Older boys also perceived their QOL better than younger ones with DMD, independent of the older boys' need for mobility aids. The authors suggested there might be potential coping strategies older boys with DMD have adapted to navigate life which is why we see older boys rating their QOL better than younger ones (Uzark et al., 2012). Woodgate's (1998) qualitative study of adolescents' perspective on chronic illness concluded that having a chronic illness made life more difficult for adolescents. Extra worries due to having a chronic illness were experienced by these adolescents. Adolescents also had clear ways to deal with their illness and worries.

Aho, Hultsjö and Hjelm (2015) set out to understand the health perceptions of young adults living with recessive limb-girdle muscular dystrophy (LGMD) in 14 participants aged 20 to 30 years. Participants interpreted health as a combination of physical and mental wellbeing. Life with LGMD triggered negative emotions and thoughts from the participants, especially when participants were more dependent on others. When physical health was more problematic, participants felt more mental strain, and adjusting to physical changes lead to worries for the future. Sadness, anxiety, frustration and anger were expressed to be felt in some way or another. Participants reported mental health struggles (e.g. periods of depression) were harder to cope with than physical impairments (Aho, Hultsjö & Hjelm, 2015). Aside from internal struggles, participants also expressed the effect their environment had on them. They reported feeling negative attitudes from people in social contexts, described feeling socially excluded, and were aware of people's glances and comments. In turn, this resulted in some participants feeling socially inhibited by negative attitudes they encountered.

Criticism of quantitative studies is that QoL measurements are too simplistic and are unable to capture the whole picture of an individual's QoL. Additionally, there is an emphasis placed on the biomedical model to explain PNMCs. There is a lack of attention directed to the social consequences of being disabled. The majority of the research available uses quantitative measures that focus on biological aspects of conditions, QoL or treatments. Oftentimes, measures do not include environmental and contextual factors (Graham et al., 2011). What is then argued is that psychosocial factors are lumped together in the psychological domains of QoL measures. The measures used are not able to measure the discrepancies in the data due to individual differences. This results in large volatile shifts in QoL scores, resulting in less consistent patterns or effect sizes at the group level.

Qualitative studies (Aho, Hultsjo & Hjelm, 2015; Bakker & Abma, 2016; Woodgate, 1998) that shed light into the personal experiences of those who live with chronic conditions all report individuals view well-being as a combination of mental and physical health. Participants talk about how they perceive physical and mental to be connected, instead of independent to one another. They both influence one another in *some* aspects. When participants experience worse physical health, there is a possibility that this has an effect on their mental health and vice versa. Qualitative studies illuminate how individuals live in a world of meaning that is in part determined by their physical condition. Chronic illness poses a threat to overall wellbeing, not just in a physical domain but also psychological, social and environmental.

The Current Study

The aim of this study was to investigate how individuals who live with a PNMC perceive their quality of life to be impacted by their condition, and in turn if this has an impact on their mental health.

Specifically, the aim was to understand:

1. How does having a PNMC effect the individual's quality of life?
2. Do young people experience mental distress? If so, what strategies do the individuals use to deal with their experience of mental distress?
3. What forms of support do young people find helpful to feel better?

Method

Design

This research project was designed to assist the researcher to explore how young New Zealander's experience life when living with a PNMC. The research questions were framed to aid investigation into how adolescents and young adults perceive and manage the impact their condition has on their quality of life, and subsequently on their mental health. Additionally, research questions were framed to investigate what type of strategies individuals use to cope with experiences of mental distress as well as to understand what support they find helpful.

Methodology: Interpretative Phenomenological Analysis

The guiding methodological framework for this study was Interpretative Phenomenological Analysis. Interpretative Phenomenological Analysis (IPA for short) is a descriptive and interpretative method for conducting qualitative research in psychology (Eatough & Smith, 2008). This methodological framework is *not* what one would consider a traditional empirical method used in psychological research. That is to say, IPA does not rely on empirical evidence, objectivity and the controlling of variables in order to establish cause and effect (Pietkiewic & Smith, 2014). This methodology is not looking to estimate the likelihood that a certain phenomenon will occur under specific or controlled conditions.

When conducting research within this framework, several assumptions are made. At the core of IPA, people are regarded as 'self-interpreting beings' (Taylor, 1985). What this means is that IPA proposes an individual is constantly interpreting the meaning of events, objects and interactions with people in their lives in order to make sense of the world around them (Larkin & Thompson, 2012). What IPA is concerned with is *how* individuals make sense of their world. Researchers guided by IPA are attempting to understand what an experience is like from the perspective of the participant(s). The theoretical orientation of IPA incorporates the interweaving of Phenomenology, Hermeneutics and Idiography (Freeman, 2006; Larkin & Thompson, 2012). These three concepts are summarized below to give a better understanding of this methodological framework.

Phenomenology was developed by Edmund Husserl and deals with the way a phenomena (e.g., experience) appears to an individual that makes it unique from others (Larkin & Thompson, 2012). Studies that are guided by phenomenology focus on how people talk and interpret objects and events. The role of the researcher is to attempt to recognize what is unique about the components of an experience that make a phenomenon special (Larkin & Thompson, 2012).

Hermeneutics (Heidegger, 1996) focuses on attempting to understand the mind-set of a person and the language a person uses that mediates their experience of the world. Subjectivity as a researcher is expected due to the idea that *all* people are self-interpreting individuals. Both the researcher and the participant(s) are engaged in intersubjective meaning-making (Larkin & Thompson, 2012). Researchers are expected to use 'interpretative activity' meaning the researcher is making meaning of the participant's world through a double hermeneutic or dual interpretation process. In this dual interpretation process, as the participant sharing their experience is making meaning of their world, the researcher is decoding that meaning and making sense of the participant's meaning making (Freeman, 2006). Due to this, researchers are expected to take an active role in the research. This implies researchers are expected to consider their own experiences and assumptions and are therefore expected to engage in constant reflection.

Idiography (Smith, Harre & Van Langenhove, 1995) deals with the specific, rather than the universal. This implies that a researcher is able to make specific statements about participants in a study because the analysis is based on a detailed and specific case investigation. In case by case study analysis, the researcher moves between important themes generated in the analysis and illustrates them with individual narratives by comparing and contrasting them.

Participants

In IPA research, the emphasis is not so much on sample size, but rather on the quality of the data gathered through each individual participant. In IPA, it is the lived experience of the individual that matters most, and for this reason the recommended sample size is between six to eight participants (Braun, Clarke & Gray, 2017). In this study, Seven participants took part. Table 1 shows a general description of the participants.

The age of participants was between 18 to 24 years, with the average age being 20.9 years of age. One participant was male. Participants identified their ethnicity as New Zealand European (i.e., Pakeha). Of the seven participants, one identified as their ethnicity as half New Zealand European and half Māori. Participants had a range of PNMCs. These included Spinal Muscular Atrophy, Friedreich Ataxia, Limb Girdle Muscular Dystrophy, Myotonic Dystrophy, and Charcot-Marie-Tooth Disease. Three of the participants were wheelchair bound. In regards to living situations, three participants lived in university halls, two participants lived in shared accommodation (e.g., living independently with other flat mates) and two participants lived with their partners (e.g., someone they were in a romantic relationship with).

To be able to participate in this study participants had to meet the following inclusion criteria:

1. Must be between 16 to 24 years of age
2. Diagnosed with a PNMC for more than 6 months
3. Proficient English speaker, with the ability to communicate independently
4. Have a support person present on the day of the interview (although this person did not have to be in the room while the interview took place, they must have been in the vicinity for the duration of it)

Materials

This study required access to the internet. Other materials used in this study were a laptop, Skype software which allows for free video calls between users of the application and an audio recorder software called Ecamm Call Recorder for Skype. Participants needed to have access to the internet and a device (e.g., mobile phone, iPad, iPod, computer, etc.) on which they could launch the Skype application for the video call.

Data for this project was collected in the form of semi-structured online video calling interviews. Online video calling interviews are considered to be a fairly new, interactive data collection method (Braun, Clarke & Gray, 2017). Video calling interviews use information and communication technology as an alternative to traditional in-person interviews. Online interviews were seen as the most inclusive method to allow participation from a population that might have experienced barriers to participate if interviews would have been conducted in person. Many factors were considered when making the choice to collect data through video calls. For example, the age of the participants was considered (i.e., participant might lack access to transport). Potential constraints in mobility (i.e., if a participant is wheelchair bound) and time (i.e., if the participant goes to university, work, etc.) were also seen as important.

An interview schedule was generated with a specific set of questions. An example of the main interview questions can be found in table 1. The main interview questions were the questions that were asked to all participants during the interviews. The full interview schedule can be found in Appendix A. The full interview schedule shows an exhaustive list of questions that were prepared by the researcher if the participant did not engage with the main interview questions during the interview. If the researcher needed a prompt to elicit more conversation, this is where she would refer to the interview schedule to ask a different question from the same category (e.g., illness perception) to elicit a response from the participant.

Table 1

Main Interview Questions

Topic	Question
Illness Perception	Can you describe what it means to live with condition?
Illness Perception	How do you think condition impacts the lives of those who are diagnosed with it?
Managing Illness	What does being healthy mean to you?
Coping Methods	Do you believe it is important to talk about your condition with other people?
Mental Health	Are there ever times you feel angry/frustrated because of your condition?
Mental Health	Do you believe your condition has an impact on the way you think or act?
Mental Health	When you picture your future, what does it look like?
Spirituality	Do you have religious or spiritual beliefs?
Social Relationships	How would you describe your social life?
Environment	Is there anything about your school or work environment that you think can be improved to help you?

The questions for the interview schedule were generated by the researcher, but were very much grounded in the ideas of the World Health Organisation's definition of QoL (Group, 1998). In particular, special attention was given to the domains of QoL (Billington, Landon, Krägeloh & Shepherd, 2010). The domains considered when drafting the questions were: a) physical health, b) psychological health, c) level of independence, d) social relationships, e) environment and f) spiritual domain.

The aim of the interview schedule was to include key questions while at the same time allowing the researcher and participant to dive into any novel or interesting areas that developed from the conversation. As Smith and Osborn (2004) describe it, the participant is the 'experiential expert' and the researcher is the one who is enabling conversation about the specific phenomenon being discussed. Because IPA views participants as the experts of their psychological and social world (Smith & Osborn, 2004), interviews cannot be structed as there is a need for fluidity. Semi-structured interviews allow the researcher the flexibility to be receptive to novel and unexpected topics that arise. All in all, while the research must remain open and flexible to novel areas of discussion, there has to be a solid foundation in the questions asked. This is why a semi-structured interview was seen as the most appropriate method of data collection for this study.

Procedure

Data was collected between August and October 2018. Participants were recruited with the help of the Muscular Dystrophy Association of New Zealand, whom disseminated information about the study (e.g., an email with a recruitment flyer) through their networks. The email gave a brief description of the study and eligibility criteria. The text of this email can be found in Appendix B.

Individuals who were interested in participating were instructed to contact the researcher to receive more information and determine eligibility. Communication with participants was done through email. Potential participants were sent a participant information sheet (Appendix C). If participants met the inclusion criteria and wanted to proceed in participating in the study, written informed consent was obtained.

If the participant wanted a support person with them during the interview, a support person information sheet (Appendix D) was sent to that individual. Support persons gave assent for this study. After discussing any concerns or questions the participant and/or support person might have had, the interview was scheduled. At the end of each interview, participants received a 'thank you', or Koha, in the form of a $25 voucher for volunteering their time.

All interviews followed the same procedure where the researcher began the interviews by introducing herself to the participant (and if applicable, support person). The researcher read a short script describing how the interview would be conducted, and then proceeded to ask the participant six demographic questions before getting to the main interview questions. The script and demographic questions can be found in Appendix E. All participants were asked the same question to begin the interview, which was, 'Can you describe what it means to live with *your condition*?' In each interview, instead of saying 'your condition,' the researcher named the person's PNMC. Questions aimed to explore participant's perspective on quality of life and mental health were subsequently asked.

The participant chose the location they wanted for the interview. The researcher conducted each interview from her home office, in a room isolated from the main living areas, with a door that remained closed during interviews to maximise privacy. Interviews lasted between 40 to 50 minutes. Interviews were audio recorded and then transcribed verbatim by the researcher.

Ethical Considerations

Ethical approval for this study was obtained from the Massey University Human Ethics Committee (Appendix F). IPA considers existential issues when conducting research (Pietkiewicz & Smith, 2014) and it is therefore important to consider all possible risks to the participants. Particular ethical considerations were given to participant safety and risk, confidentially and privacy and cultural responsiveness.

Much though and consideration went into the design of this study to limit ethical issues as much as possible. The priority of the this study always remained centred on the wellbeing of the participants. Participants were given an information sheet detailing what the research was about in everyday language that was easy to understand. Written and oral information was given to participants detailing the study. Participants had the opportunity to ask questions and/or voice any concerns. Participants were also encouraged to contact the researcher at any point during, before or after the interview, if they needed to ask any questions or voice concerns.

Safety and risk. Given interviews were conducted virtually, it was essential to ensure the participant had a support person physically present with them the day of the interview. The support person was someone the participant nominated. This person did not necessarily have to be in the room while the interview was conducted, but they had to be present in the vicinity.

All, but one, of the participants lived in urban areas in New Zealand. Location was an important consideration because it related to the participant's ease of access to resources from the community. One participant lived on a farm in a rural location of the country and therefore may have been more limited by their physical location. Again, this was one of the main reasons a support person had to be present the day of the interview.

It was essential to provide the participants with sufficient resources for support as the researcher was not able to be physically present with them. Participants received a helpline information sheet (Appendix G) which outlined contact information for appropriate services (e.g. MDANZ Counselling Service for its members, mental health hotline numbers, online counselling services) available to participants for support.

While unlikely, the possibility for participants to feel psychological discomfort (e.g., sadness, stress, worry) over the topics discussed was taken into consideration. As the interviews engaged participants in real time, it was the responsibility of the researcher to monitor how the interview was affecting the participant. If the participant seemed distressed, the interview would have been stopped. The researcher would have asked to speak to the support person, whom would have been made aware of the participant's discomfort. Discussion would have then been had with the researcher's supervisor on the what to do next.

Confidentiality and privacy. Steps were taken to ensure confidentiality and privacy for all participants. Participants were audio recorded during the interviews. They were informed of when the audio recording began and when it stopped. Participants also had the option to request to stop the recording at any time, with no need to explain why. In order to maximise privacy as much as possible, the researcher transcribed all the audio recordings herself.

Once audio recordings were transcribed, the recordings were deleted. Participants were given a copy of the transcripts. They were allowed to redact any part of the text they felt they did not want included. Participants were not allowed to edit the text because to edit the text may therefore change the original context and meaning of the conversation.

The researcher conducted each interview in a private room, using earphones as to maximise the amount of privacy for the conversation. The participant had an active role in deciding how much privacy they wanted to have during the conversation. Participants could choose to conduct the interview from anywhere they saw fit.

Cultural responsiveness. For this particular study, cultural responsiveness dealt with two types of cultural considerations. The first cultural consideration was adhering to the Treaty of Waitangi and the other was obtaining guidance from within the PNMC community.

When conducting research that potentially involves Māori participants, it is vital for the researcher to take the appropriate steps to ensure cultural responsiveness. This implies adhering to the Treaty of Waitangi's principles of partnership, protection and participation (Massey University Human Ethics Committee, 2010) and meeting with a cultural advisor. The researcher met with a cultural advisor (Appendix H) for the purpose of requesting guidance on how to navigate working with Māori within an IPA framework. Additionally, it was of up most importance that the advisor reviewed the design of this study to make sure the research was being conducted in a culturally responsive way. Communication with the cultural advisor did not stop at the early stages of the design. The researcher communicated with the advisor after participants had been confirmed. At this stage, all but one of the participants identified as New Zealand European, or Pākehā. Gemma was the one participant who identified as mixed race. The researcher touched based again with the advisor at the analysis and write up phase of the research in order to make sure any cultural issues had been addressed.

In regards to the specific cultural knowledge that comes from living with a PNMC, the research felt it was vital to seek out the guidance of those with lived experience. The individuals at MDANZ (Appendix I) provided guidance and consultation to the researcher at many stages of this project. Communication was ongoing throughout this project. The researcher was able to ask questions about the intricacies of PNMCs and ask for insight into how best to approach certain topics with participants.

The aim of these measures to ensure cultural responsiveness were routed in the idea that the researcher should gain as much understanding as possible before the interviews. It was equally as important for the researcher to hear perspective that would aid reflexivity. By listening to perspectives and world views, that would otherwise be impossible for the researcher to place herself in, the researcher was able to become more self-aware of her own position within the research.

Analysis

Analysis is not a process that has a specific start and end point in IPA. When thinking in terms of general guidelines, there are four main steps in the process of analysis (Eatough & Smith, 2008). As always, when using an IPA framework, it was key for the researcher to remain flexible and creative in her thinking.

In order to begin the analytic process, it was essential to transcribe the audio recorded interviews. The first step of the analysis process involves the researcher becoming familiar with the data. To do this, the researcher must do multiple readings of the data (e.g., transcripts). The purpose of this immersion technique is for the research to obtain a holistic perspective of the data (Larkin & Thompson, 2012). Gaining a holistic perspective allows the researcher to remain grounded in the participants' accounts, as this is especially important. While reading the transcripts, the researcher began to make notes on anything that seemed significant. As the researcher engaged more and more with the participants' accounts through each reading of the transcript, the researcher became more attuned to participants' perspectives and as a result the researcher became more responsive to participants' responses.

In steps 2 and 3, the focus was on transforming notes into themes. The researcher took into account the holistic account of the transcripts read as well as the notes that she had made regarding important or interesting parts of the data. Initial themes were identified and organised into clusters (Larkin & Thompson, 2012). These initial themes were checked against the data to make sure that the connection between what the participant had said and what the researcher had interpreted was not lost. Themes were examined for connections between them in each data set. This was repeated with each data set until all transcripts had gone through the analytic process. In step 3, the themes were refined and complied (Smith & Osborn, 2004). Final themes were the outcome of a dynamic process of moving back and forth between various analytic stages ensuring that the integrity of what the participants had said was preserved while at the same time including psychological concepts and theories to the data.

Step 4 is the write up phase of the analysis. This step began when the final table of themes was formed from all datasets. The aim of the write up phase (of any IPA study) was centred around what Smith & Osborn (2004) refer to as the levels of interpretation. The researcher attempted to give a detailed description of the participant's account, while also moving between levels of interpretation. As the researcher moved from one level to another, more depth was required (going from description on phenomenon to interrogating the participant's sense making). The first level of interpretation gave a full description of the topic under investigation. The researcher described what the participant said, and for the most part took it at face value. The second level of interpretation dealt with more interpretative and theoretical aspects. This is where the researcher demonstrated hermeneutics while more or less accepting what the participant was saying at face value.

The interpretative role of the researcher

Reflexivity began with acknowledging my background and how I ended up choosing this topic for my research. My first introduction into the world of progressive neuromuscular conditions (PNMCs) was during my third year of undergraduate studies when I began to volunteer at Muscular Dystrophy Association of New Zealand (MDANZ) national office in Auckland. I had responded to an advertisement in the university's volunteer site which lead to a three year journey with MDANZ. This organisation deals with a wide range of PNMCs. MDANZ employs individuals who have PNMCs, use wheelchairs, or have other impairments.

Sadly, this was the first time in my life where I was around people who were visibly 'disabled.' My time at MDANZ gave me an enlightened perspective on disability. I began to acknowledge the privilege that I have as an able bodied 'healthy' person. I realised that there were many aspects of life that I took for granted or were invisible to me. To give a very simple example, I am someone who loves coffee. As an able bodied individual, I can decide to go to any coffee shop, at any time, and be fairly confident that I can sit anywhere I want in the coffee shop and enjoy my drink. If I was someone who relied on a wheelchair to move around, I would have to be mindful of many factors in order to get to the coffee shop. *Is it* *raining outside? Can I get to this location safely*? *Will there enough space for me to fit my wheelchair?* All these questions are valid examples of things that people who use wheelchairs have to consider on a daily basis.

Although I attempt to be as mindful as possible, there are still many taken for granted assumptions that I may have, as it is impossible for me fully understand the experiences of people with PNMCs. These assumptions, or biases, might be so ingrained through culture that I may be unaware of them. When it became time to choose a research topic, I knew I wanted to conduct research with individuals who live with PNMCs. It therefore became important to me to talk to these individuals and hear what their experiences are like, not what I assume or think their experiences might be like from my outsider's perspective.

I hope that this research gave participants a chance to describe their experiences of what is it like to live with a PNMC. I wanted to give voice to the experiences and concerns of the participants, as well as make sense of their claims from a psychological perspective. The aim was to discover themes on their experiences that not only matter to the participants, but that are meaningful to them and myself.

Results

The analysis process of this research resulted with five superordinate themes being identified – a condition that is constantly present, mental strain, living as an Other, acceptance and support. Each theme is described in detail, along with subordinate themes where appropriate. Table 2 provides a summary of the superordinate and subordinate themes.

Table 2

Superordinate and Subordinate Themes

Superordinate Theme	Subordinate Themes
1. A Condition that is Constantly Present	1.1 Part of normal life 1.2 Medicalised experience 1.3 Self-awareness required 1.4 Independence
2. Mental Strain	2.1 Worries and planning 2.2 Frustration and anger
3. Living as an Other	3.1 Self-perception 3.2 Stigma and messages received from the world
4. Acceptance	4.1 Holistic wellbeing 4.2 Extra voice 4.3 Blueprint
5. Support	

Living with a Condition that is Constantly Present

This theme deals with the experiences of participants in relation to living with a PNMC and how participants perceive their condition. Although it is somewhat obvious that life for the participants is different than their 'healthy' counterparts, participants expressed that living with a neuromuscular condition was part of their normal life. Participants described how their experience of living with a PNMC also becomes a medicalised experience due to the physical manifestation of the conditions which lead to interactions with a medicalised world. There is an idea that constant self-awareness is required when living with a PNMC. Lastly, living with a physically impairing condition means physical independence becomes increasingly important.

Part of normal life

Participants describe that although living with a progressive and chronic condition is challenging for a myriad of reasons, the condition is also part of their everyday life. One of the participants captures the sentiment with this statement:

> *"I suppose it's just sort of I kind of don't really think of it as any kind of different like it's just kind of part of life I suppose. So it's kind of hard to say what it means to live with it, but yeah, I suppose in some ways I kind of take it as an extra voice that I have... But, yeah I don't know I kind of just see it as part of life if that makes sense"*
> (Amy)

Amy described her condition as part of who she is, and that at the same time, living with a progressive condition has shaped her world in many ways. It is hard to separate the condition from who she is, as she would find it difficult to separate any other part of her core identity.

The following participant explained that for her, living with Myotonic Dystrophy is part of her normal, everyday life. When asked what it means to live with Myotonic Dystrophy, she described that for her, her life didn't change. It means living her life as always, but she mentioned that now she feels as though she can put a name to what was going on. When asked what it means to live with her condition, she responded by saying:

> *"To be honest getting the diagnosis wasn't like a big shock because I suppose that getting a diagnosis didn't really change anything. My hands are still the same. I walk the same way. I do the same things. It just means that I have a title and when I have medical problems or anything, I just have to identify that I have a disability. So yeah,*

> *it didn't really change my lifestyle or anything… it just more… I just have to be aware of it now."*
>
> (Paula)

The response of Paula is particularly interesting as there is much that can be interpreted through her answer. Her immediate response to the question of what it means to live with Myotonic Dystrophy was to talk about her medical diagnosis. On one hand, she described how the diagnosis did not change anything. Her life remained the same because her condition had been present in her life before the diagnosis. With or without an official diagnosis, she was still experiencing the effects of the condition in her life. Myotonic Dystrophy was part of her 'normality.' On the other hand, one could say that it is possible the participant is expressing some ambivalence towards her condition through her response. That is to say, it could be possible that the participant is in a way expressing some denial towards her diagnosis by saying that nothing changed for her. There is a real chance that her condition might progress and that she could experience more severe symptoms in the future. It could be that part of her accepts the condition, while the other part may be in denial. She could be grappling between two ideas: the idea that she sees herself as 'normal' as well as having to accept that she does have a medical condition that may impact her life in some ways.

Medicalised Experience

Apart from being a part of daily life, having to live with a PNMC is a very medicalised experience. Participants seem to view their condition through a medicalised lens. This is clear from the way in which participants described their condition, to how they attribute the symptoms of their condition and how they make sense of their experience. When asked what it is like to live with a PNMC, many participants responded with an extremely detailed medicalised response.

For example, here is Grace's response when asked if she could describe what it means for her to live with Myotonic Dystrophy:

> *"Well, I'm not very severe as Myotonic Dystrophy can be so it's not effecting in most things that I do. I don't know if you know much about it but there's a scale on how bad it can be. So it goes from 1 to 1200 on how bad your muscles can react and how bad it can affect you in your day to day sort of basis. Umm…and I sit at 400, so that's quite low on the spectrum so I'm not even pretty much half way there. So, the only thing that kind of reacts are my hands and my jaw which just kind of seize if I clench something too hard. My jaw usually happens when I yawn or my mouth is quite wide and it kind of just stays in a place for about 5 seconds and… umm… my hands do the same thing. So the only thing that really effects in my day to day basis is sometimes opening things... opening jars… opening anything like that is very hard cause I don't have the strength cause Myotonic Dystrophy also takes away a bit of muscular strength as most muscular problems so I don't have the strength as probably a normal person trying to open a jar. So those sorts of things I try, but if I can't do something there's my partner there or someone that can open things but other than that I'm pretty normal. There's nothing on the outside that states 'you have a problem.' So there's nothing that shows that I'm different to someone else besides that pretty much…"*
>
> (Grace)

Grace's response was deeply rooted in how much (*or how minimally*) her body and physical ability deviates from what the average 'healthy' person can do. She spent much of her time describing the condition from a medical perspective, which may be a way to make sense of her condition. It may be possible that this participant looks at 'normal' peers as the ideal benchmark of health. Therefore, when she talks about how other than a few minor challenges she may face she is still 'pretty normal' and there is 'nothing on the outside that states you have a problem' she may be attempting to minimalize the emotional and psychological effect living with Myotonic Dystrophy has. It could be possible that participants are rationalizing their condition as a form to cope with the emotional and psychological effects of living with a chronic condition.

Participants' experiences were also medicalised in the sense that their lives require them to use medical devices such as wheelchairs, walking frames or braces:

> *"At the moment, living with Frederick's Ataxia means that I can't go by myself without a wheelchair. So my powerchair gets me from one place to another ... I have three wheelchairs and a walking frame. So the manual wheelchair ... it's good for using my hands, it's good for arm movement. Then my power chair, I had that for about nearly 3 years... And my third wheelchair is called a Cogy. It's got pedals and a wheel, it's like a bike. I use it for exercise usually once a day, but twice a day on the weekends and like around the place is good exercise to get my legs moving. Gets my heart pumping."*
>
> (Lynn)

Medicalised experience also meant that now participants have an official diagnosis, which is part of their medical history. When they go to hospital they must identify this. Participants also adhere to specific medical routines, visit specialists and have frequent contact with multidisciplinary teams that help them manage their condition:

> *"... I have an occupational therapist and just a physiotherapist, obviously my GP and I have a counsellor... my neurologist ... physiotherapists, speech therapist and things like that ... they all work within the centre down here. And so they contact me personally and originally when I went and I saw them quite ... at the moment I don't see them as regularly ... I've recently just been to a counsellor. I've been seeing them for six months now, so I see them and adds more you know just something to download, you know...to express my feelings I suppose."*
>
> (Paula)

Although Paula mentioned that she goes to a counsellor, the psychological and emotional effect of the conditions were not frequently verbally expressed by participants. It could be possible that focusing away from the emotional effects is done as a way to control emotions and not feel as affected. This condition is part of the identity of the participants. It could potentially be difficult for the individual to attribute negative thoughts, behaviours and/or feelings they experience as being caused by their condition.

Participants live a life that is medical in essence. Just to name a few examples, participants have frequent contact with health professionals, use medical tools frequently/daily, and exercise with the intent to manage physical health. Their experiences and interactions are indeed very much medical. It seems as though these medicalised experiences put an emphasis on the body and the physical. The majority of the focus seems to be on the physical state of their condition. Given the nature of neuromuscular conditions, it is understandable as to why much of their experience is focused on the body.

Self-Awareness

Due to the progressive nature of these conditions, the body is always in a state of change. These conditions are very dynamic, as PNMCs are not static illnesses. For participants, this means that they have to constantly check the current state of their condition and body. There can be periods of time where the condition does not progress or cause the participants any extreme symptoms. In other words, there are times when the symptoms of the condition are easier to handle than at others. Because the body is always in a state of change, constant self-awareness on behalf of the participants is required to check progression, regulate their symptoms if possible and try to accommodate to their needs at any given time.

One of the youngest participants talked about how the progression of her condition is subtle in the sense she does not notice the progression happening on a daily basis. She finds that her condition fluctuates a lot, where some are better than others:

> *"Um, I'm told that it's deteriorating. But because… I don't know… it's hard for me to tell whether things are getting worse because it's just like so day-to-day. I don't really notice things, I've very unobservant."*
>
> (Gemma)

Progression of PNMCs happen at different rates. For Gemma, it may be that although she *knows* her condition is progressing (because she has been told by her parents and medical experts) she still finds it is difficult to see the progression herself. It seems that participants recognize that self-awareness to their changing bodies is important. But, it may be that self-awareness is a skill that participants have to learn how to do. It takes time for participants to develop the ability to understand one's own body. This is particularly noticeable from the contrast in statements between the youngest participant to the oldest participant. The oldest participant in this study described how he felt constant self-awareness is needed given the nature of this progressive condition:

> *"As I'm getting older it's [Spinal Muscular Atrophy] getting worse. I find it's almost a daily battle now. Especially during the winter, it just makes it a lot more worse.. you know.. cold weather weak lungs ...sometimes it makes me so less motivated to leave the house cause I can't be bothered, don't have the energy. And when you stay in the house too long it does things to your head... you know, so you don't want to go out and do too much and then wear yourself down and get sick because you're so worn out so it's just a real hard balancing act... It changes all the time you know... sometimes I could handle more and the balance will change and sometimes I need to take a step back and just not do so much for a while... Constant self-awareness. But I have to be careful not to turn into a hypochondriac."*
>
> (Blake)

The contrast between participants could potentially be due to a combination of factors. It may be that age plays a significant role. Age in the sense that as participants living with a PNMC will probably see an increase in symptoms as time goes on. Additionally, as the illness progresses so does the development of the person's maturity. There may be a parallel progression between maturing and the progression of the condition that allows for self-awareness to become more present.

For Blake, living with Spinal Muscular Atrophy means the condition is always present in his life. Life becomes a balancing act, where there are times when he feels his condition is easy to manage and then there are times when the condition is much more demanding to manage. The severity of his symptoms can change drastically within the span of a few weeks. There may be times where he feels he has more energy and the ability to do more physical activity and at other times where he may feel fatigued and in a state of poor health. Because of this, there is an aspect of constant self-awareness that is needed, but as he emphasizes, there is an importance of not turning into a ‘hypochondriac’. A balancing act is required because the body is always in a state a change. There is always a need to self-regulate and to adjust to meet the specific needs at a specific time. It requires the person to develop skills to be able to become self-aware of their changing body.

Independence

When speaking of independence, participants specifically spoke about physical independence, or the ability to do physical tasks on their own. Participants use independence as a way to gauge any change in their bodies as well as to determine condition severity. Physical independence acts as a tool participants use to ‘check’ for any change in the state of their condition.

Physical independence seems to be important for participants due to the (physical) restrictions their conditions place on them. One participant expressed how he can see that his condition is making it harder to move around independently out in public. When it comes to activities that require physical strength, he can see his physical limitations and how his condition is making him more physically dependent as time passes:

> *“Out in public as I got weaker it’s becoming more harder to be independent like that cause I need help like getting to my EFTPOS.. you know… navigating certain terrain.. stuff like that. When I was younger I used to just could shoot off myself for a while and do my own thing but yeah I can’t anymore. Yeah. Dependent.”*
>
> (Blake)

Blake can recognize that he is becoming less physically independent. Again, if independence acts as a marker to symptom severity, then in this particular instance, it may be that the participant can recognize the progression of the condition is catching up to him. He notes how as an adolescent he had more liberty and less complications.

For Gemma, independence is important for her because it means that she can do things for herself and that's important given the deteriorating nature of her condition. When she has an operation and is dependent on others, her mental health declines and she sees life as somewhat depressing. She feels the need to be able to do things for herself:

> *"Yeah, so independence is really important because for me because it means that I can do stuff for myself and that's important because like of my deteriorating condition, I'm aware that one day I won't be able to so it's like nice that at the moment I can do those things. Yeah, whenever I have an operation, I'm like suddenly not independent at all, and it's kind of like pretty depressing to be honest. Like some of my most, like the worst mental health I ever had was during those times. Yeah. Also I used to like live in a place that was like really far away from any shops or anything. So if ever needed anything, I would have to ask my parents for a drive. And it's just good to be able to do things for yourself and you know, feel like an adult."*
>
> (Gemma)

Physical freedom is a way for participants to feel as though they have control over their life and condition. It could be that feeling as though one has the physical freedom to do what they want implies they are feeling healthy in their bodies. Physical freedom might also mean that participants are in a state where they do not have to worry as much about the status of their condition. Instead, they are free to focus on other aspects of their lives, and the condition stays somewhat 'dormant.'

Mental Strain

Participants discussed how difficult it is to live with a condition that is progressive, particularly when coming to terms with the fact that the progression of their condition is inevitable. Participants expressed feeling worries associated with having a PNMC. In particular participants described the loss of control they felt as well as a fear of the unknown.

They described that the planning of their day-to-day life and future is an essential part of their lives. Additionally, participants described the anger and frustration that is sometimes experienced as a result of living with a PNMC.

Participants described that learning about potential prognoses is very difficult because they are dealing with the unknown. It is unknown whether their condition will have minimal progression throughout their lives or if it will result in fast deterioration of the muscles making them highly reliant on others for support. Dealing with the unknown might leave participants feeling worried and at a loss of control over their lives.

When first getting diagnosed, Paula described her immediate reaction as feeling loss of control, as she has no control over having the gene and of passing it down to her potential children in the future:

> *"…when I first got diagnosed my immediate worry was having children because I can pass the gene on and it's a 50/50 chance that my child will get it and they'll be worse than I am. So that was my immediate concern… that I can pass it on to future offspring."*
>
> (Paula)

This quotation features a conversation between myself and Blair, where she provides some insight as to what worries she associated with living with Frederick's Ataxia:

> Blair: *"Well, I'm in a wheelchair for like about 10 hours of the day. It's about probably two hours of the day that I'm not in wheelchair. I go for a walk with a support person and I can still walk a tiny bit, but I know that it's going to keep getting worse so that's kind of hard. I remember when I found out [diagnosis], I was quite young and I was really scared. So far it's not as bad as I imagined it to be at that point. I was scared of…like not being able to walk. It was all unknown, cause at that stage I could so it was like something was being taken away from me that I have no control over, and yeah."*
>
> Researcher: *"Can you describe a bit how that feels how it feels to know that your body will continue to change as you get older?"*

> Blair: *"I don't really know. I don't really think about it overly much anymore. Like I used to. But you just keep seeing stuff, maybe not every day, but stuff that you could do two weeks ago and now you can't and it's like oh, what am I not going to be able to do two weeks from now? You know?"*

Other participants have described the worry that accompanies receiving a diagnosis:

> *"It [Myotonic Dystrophy] has gotten worse and they told us that it would happen. They told us that it will get worse as you get older, which was quite scary to hear at such a young age ... it's not progressing as fast as they [doctors] initially thought it could .... They didn't know how it's going to progress or how slow is going to progress ... So it's just you finding different ways to deal with different things and I'm finding that I may struggle."*
>
> (Grace)

Participants have described hearing the prognosis of their condition from medical health professionals as something that is scary. The unknown aspect of how far or how severe the condition will get leaves participants feeling uncertain, worried, and in a state of constant self-assessment. It may be possible that participants are living with an underlying fear of the unknown. Living in the 'dark' might therefore increase anxiety, concerns and worries for the participants.

For this next participant, Amy, her condition contributes to, or exacerbates, her worries. She gets very nervous going places for fear that locations will not be accessible. Anything that has to do with physical accessibility is something that creates a lot of fear:

> *"Umm… I suppose the accessibility thing obviously just like physical accessibility, so getting around can be quite difficult especially being young and all of your friends are going out like walking around, and wanting to walk around cities and I have to drive around a lot more and even like university, so… just the most obvious accessibility stuff. Umm, but also I think it's quite a lot of nerves and anxiety that come with having Limb-Girdle Muscular Dystrophy or any type of disability, because of the problems with accessibility that is like the fear that if you go somewhere it's not going to be accessible and so there's that kind of challenge as well."*
>
> (Amy)

Worries about accessibility also tie into worries about being left behind. The same participant describes that she experienced fears of being left behind because she may not be able to do certain physical activities and that she felt would in turn hinder her friendships:

> *"Umm I think I have a fear of being left behind. And maybe exclusion, but not in a mean way. Like they're not purposely excluding me, but particularly at the beginning of the year I was worried that people would go off and do things and I'd be worried that I either be too scared to try to do so I just not do it and then I'd lose this time making friends, so yeah. I've never really been worried about people not liking me because I have a disability because I know people are better than that so yeah."*
>
> (Amy)

This sentiment was shared by other participants. The fear of being left behind might not just be in the physical sense, but also in the social, psychological and emotional sense. There is an expressed fear of not being able to do certain things, a fear of being left behind, or anxiety about physical limitations and how that may impact or play a role in friendships, romantic relationships, etc. It could be that this fear of the unknown (for example, if a place will be physically accessible) is very much present in their thoughts. It could be that for this reason, participants attempt to plan most of their lives as a way to gain some control over the unknown. It seems as though participants have positive beliefs about the benefit of worrying and planning. It might be that participants believe that if they are prepared for any event then it is beneficial to worry and plan.

Planning takes precedence in the participants' lives. They have to make sure they have enough time to do daily activities, such as going to the shopping centre, because they know that they take longer to complete than for the average person. Planning demands participants stick to routines and be responsible.

For example, Blake mentioned how planning is a big part of his life and how if he doesn't do it then his quality of life is reduced:

> *"I have to plan a lot more. And be on top of everything otherwise my quality of life goes downhill if I'm not on top of things. So it [Spinal Muscular Atrophy] forces me to be prepared and yeah.. and not let emotions get the better of me cause then being stuck in a body like this and stuck with an angry mind… yeah just a bad recipe…"*
>
> (Blake)

He continued talking about planning by saying he needs to plan many aspects of his life:

> *"My supports. My home. If I need to go somewhere I usually have to plan ten times more things than the average person. I can't just get in the car and just go. I have to plan where can I have a feed, the next toilet, is the place accessible? Just all those things."*
>
> (Blake)

Gemma mentions similar thoughts on planning her life:

> *"I have to make sure I have enough time to do things because I know they'll take longer. It's [planning] for everything ... it can be quite taxing."*
>
> (Gemma)

Planning seems to be a double edged sword. What is meant by this is that on one hand, planning *too* much, or worrying about a future situation, might leave the participants feeling anxious. This anxiety might then result in avoidant behaviour of certain situations. For example, participants might have anxiety over accessibility of a location which leads to not going somewhere. Planning also seems to require a lot of mental energy and can leave participants feeling quite drained which could factor into the negative side of having to plan your life. On the other hand, planning may allow for structure in their lives that can help ease their worries and anxieties. Planning might be a sign of self-awareness and acceptance of the condition. It might be one of the ways in which participants accept that they have a condition that requires them to dedicate extra time to certain things than a person without their condition would not have to.

Frustration and Anger

Participants expressed frustration at the constrain they feel in their bodies, the limitations that are placed on them and the loss of physical ability. There are times where participants want to express themselves physically, or would like to be able to 'do more', but feel limited or unable to do so.

Many times, the physical and mental experience of symptoms are connected. Participants made it a point to express how their intelligence is not affected by their condition. Therefore, they are aware of the physical impact their condition has. They are constantly checking the progression. When they are no longer able to do things they could before, they feel constrained and that part of their independence is lost. They express frustration and anger at not being able to do 'the simplest things in life.' Frustration then leads to feelings of sadness as this makes the individuals realise there are things they cannot do and there are things that they will need assistance for.

Amy talks about the anger and frustration she feels over the physical limitations her condition places on her:

> *"Yeah, definitely ... if I'm feeling more tired I tend to get more angry and tried just at the fact that I can't physically do stuff it can be really frustrating at times when you want to do something but you can't or you want to get somewhere quicker but you can't... So at those times yeah I get quite frustrated."*
>
> (Amy)

In the following extended quotation, Paula described how her physical symptoms can frustrate her, especially when she needs assistance to do something. When her emotions are high and she is feeling frustrated with her body, she described she may have a 'meltdown':

> Paula: *"Yeah, definitely. I get frustrated very easily. Especially doing my own hair. When my symptoms started that used to frustrate the hell out of me. Now I'm just more accepting*

> *of it, but it does still frustrate me because I can't do it myself… I get frustrated all the time because it takes my independence away and I don't like that at all. I hate getting my independence taken away and not being able to do things … It's just, you know, my hands sometimes frustrate the hell out of me because I can't do things myself and that's frustrating. I think I get more frustrated a lot because I can't do things myself, but most of the time I'm pretty good and I've only had, I suppose, a couple meltdowns."*
>
> Researcher: "*Right, so how do you feel on those days where your hands might be a bit of an issue for you or you find that sometimes there's certain things you can't do yourself?"*
>
> Paula: *"…I like to say that I'm quite positive about my disability and I don't really worry about it so much. But yeah, like as an example… on the weekend I was so overtired and everything was just you know coming on top of me. My hands were being really tricky that week. They had just been a bit of a struggle so, you know I just had to have a meltdown and let all the emotions out cause it had all just come to too much."*
>
> Researcher: *"Do you feel like you lose control?"*
>
> Paula: *"Yeah, because there's no real drug I can take to stop it. There's nothing I can do about it. .. I don't know how bad it's going to get. I might be able to walk till the day I die. I might need help walking. You know, when I get older, or my hands might become really bad. We never know I suppose."*

For some participants, frustration seems to be routed in their illness progressing and the inability to be able to do anything to stop the progression. Additionally, it is not just about the progression of the illness that is causing the frustration, but probably also the feelings associated with the loss of control one must feel. Participants know their body is not fully under their control and therefore might experience feelings related to a loss of independence when one realises they are not capable to do certain things that they want to do, no matter how big or small the task is. The restriction their condition places on their ability to be able to do what they want, when they want must be very frustrating.

Living life as an 'Other'

Living life as an Other refers to participants' experiences of feeling like outsiders within their social worlds. Two subordinate themes are explored. The first is the participants' perception of being an Other in social spaces. Spaces such as school, university, or within the general community setting are some examples of places where daily interactions shape participants' experience of living with a PNMC. The other subordinate theme is the sigma and messages participants received from the outside world for being different than their peers.

Experience of being an Other

In one way or another, participants have felt different from their 'healthy' counterparts. Gemma describes how she has always felt different due to her condition. From an early age, she attributes her condition for making her hyper aware of her physical body. She felt as though this hyper awareness lead her to have many insecurities, which have affected her confidence and self-esteem growing up.

When asked if her condition impacted the way she felt, Gemma responded:

> *"It's related a lot to like, I guess my insecurities when I was like... I used to do dancing in primary school and stuff and I think that because I was so hyper aware that it was harder for me to do things and like it was hard for me to achieve like a perfect stance or whatever. So I think that impacted a lot on my confidence up until like year 12 I would say. I was really not very confident and so I quit dancing. And yeah. That's a big impact on me. And I guess like I have a very strong value of like independence. I need to do things by myself ... so I think that [its] shaped my values and what not."*
>
> (Gemma)

As one is developmentally maturing, it must be difficult to feel as though your body is different from your peers. At a stage in life where conformity and similarity are what one strives for, or at least not to stand out in a negative way from peers, not being able to meet an ideal physical image (in this case of a healthy body with no foot deformities) is a hard realisation. It must impact on the confidence of the individual. Adolescence is a conflictive time where body image and physical changes can have an impact on self-image and confidence. If one adds in the additional layer of going through this stage in life with a physical condition, it may very well be possible that this will impact participants' view of themselves. It is a very big possibility that participants are aware of the external pressures to look a certain way and how they do not fit those ideal body standards.

Gemma went on to say:

> Gemma: *"Um, I do feel a bit insecure sometimes. It's just like this big.. you know self-image is such a big thing. It's like sometimes I'll never be able to match up to that ideal image. Like sometimes when I see myself in the reflection, and I see how I walk I'm like, "oh." ... It's just a realization of like how the world sees me and that's like a bit upsetting."*
>
> Researcher: *"Can I ask you how you think the world sees you or people with CMT in general?"*
>
> Gemma: *"Um, hmm. long pause. Maybe like a bit lesser than, or something."*

Grace seems to centre much of her self-image around the extent to which she feels she is an Other. She had described how the symptoms of her condition are quite low. She stated her condition does not affect her much other than in her hands and jaws. In a way, she may have attempted to put her condition at a distance from her self-perception. For example, she says her only issue with having this condition is in her hands and jaw. She then rationalizes the rest of herself as a healthy person and may do this in an attempt to minimize her condition so her identity is still that of a relatively healthy person.

> Grace: *"I'm very open like even at school I decided to do a speech on Myotonic Dystrophy. So my whole class then found out, which was fine. I didn't mind doing it. It kind of just for something about me that I've kind of accepted over the years. It's just*

> *who I am. It's part of who I am and as you can see there's nothing physical that you can see that's wrong with me."*
>
> Researcher: *"Do you think that you would feel differently about disclosing or talking about it if you had a more visible condition?"*
>
> Grace: *"I think so. I think if it affects me in my life, it would kind of make me, not sort of depressed but kind of sad that I couldn't do everything else that someone else could do. Like it would have made me feel different and I think because I am still pretty normal and can do everything someone else can do or can at least attempt it. It makes me feel quite open because I'm not visibly different sort of thing. So if I may have been worse or if it affects me a lot more in my life, it might have been a lot harder to talk to people about it."*

Grace specifically mentions how she *is* willing to talk about her condition, and is able to accept her condition, because her condition is not visible. It may be that Grace copes with being different to her peers by attempting (on some conscious or unconscious level) to hide the parts of herself that she does not feel are accepted. There are interactions participants have with the public that provide feedback that they are Others in society. Feedback from the world, whether verbal or non-verbal, may lead participants to feel different from the rest of their peers which in turn has an impact on how they view themselves.

Stigma and Messages Received from the Outside World

Here, the idea of how participants perceive how the world perceives people with PNMCs is explored. These are the interpretations of participants' interactions with the world that shape the way they see themselves as an Other. Stigma, or messages participants have received from interactions with people in their world can include interactions with anyone from friends to complete strangers.

For example, Blair describes her experience of receiving 'faux' support in her high school when it came to being an Other in a public space. She used the example of how her school did not acknowledge the differences between students:

> *"I feel like they [the college staff] often forgot about certain things and they didn't seem to want to have to acknowledge the differences between students. I know a lot people who were part of the LGBT community felt that although the school claimed they were supportive they never actually wanted them to talk about it in a public setting. It was kind of like that faux supportive…keep it quiet."*

(Blair)

Using the example of her LGBTQ peers, who live in the Other sphere too, this participant shares the messages she received from her school about being an Other in a public space. Those who deviate from the norm of society are treated differently. It could be that the messages she has received about occupying space as an Other is that certain individuals are not valued, and made to feel as though they are invisible in society.

Gemma talked about her interaction with peers in social settings, and the messages she felt she received through these interactions:

> Gemma: *"Umm I remember earlier this year. I was like feeling really sore and it was like when I first moved into the halls and we were doing lots of fun activities, on the way back I was like feeling so sore and I had to ask the people I was with if I could take a break and they were really like "cheer up a bit" and stuff, you know? But, yeah umm sometimes when I'm with my main group, they understand that I need to take breaks."*
>
> Researcher: *"So if you're not with that main group, how do you feel when have to take a break and it might be a situation where everybody's wanting to walk?"*
>
> Gemma: *"Yeah, a bit awkward. I'm unsure of how they would react in that sort of thing."*

She also discussed her worry when playing social netball:

> Gemma: *"I feel like I couldn't do a lot of it [netball] and also I couldn't do a lot of it at a like competitive level. I feel like social netball is fine because it is social. I do feel like… I bring the team down a bit because I get much more tired and it's hard for me to run around and stuff… The last time I played I felt really bad because the ball would go faster than I could go…So I felt like I sort of brought the team down."*

> Researcher: *"And how did you think the team responded to that? Do you think that they responded in a particular way?"*
>
> Gemma: *"Um, they said that they were like, oh, it's fine. It's just like social netball. You know, we're just here to have fun. I'm not sure if they internally felt a bit annoyed. […] Maybe. I do worry about it. I'm not sure if it's how close to reality that worry is."*

Here, Gemma expresses feelings of being a burden, or annoyance. It's possible she feels as though because she needs extra support that she is 'bothering' or disrupting her peers. Being an Other can mean that there is presence of resistance to the 'natural' flow of interaction between peers. It could make people feel different and unaccepted, especially when social circles might not understand the specific needs of a person, or understand what the person is experiencing.

In the following conversations, some of the participants talk about their reasons for not openly speaking about their condition.

Paula shares her decision to not disclose she has a disability to her employer:

> Paula: *"I get a sense that if I say I have a disability, you know, you're not really that desirable for work, so I didn't tell him but also it's because like I can manage by myself. I am perfectly independent. So to tell him that I couldn't do a job just because I had a disability seemed a bit of a useless thing when I could do it perfectly fine."*
>
> Researcher: *"So do you think that the second you would say I have a disability would be looked at differently?"*
>
> Paula: *"Possibly, yeah. They would think, 'Ah, okay. Well, she has a disability.' I feel like there's like the stigma around it, you know? You say you have a disability and then people are a bit weird about it."*
>
> Researcher: *"In what way would you say that they're weird?"*
>
> Paula: *I feel like people pity you… you got this sense of being like, you know, pity you… like you 'Oh, that's really unfortunate.'*

Here, the participant shares her ideas around the stigma that disabled people are less desirable for work. Some participants may feel the need to justify, or explain, that they are just as 'normal' as their peers in society and that they do not need to be treated differently. They almost have to justify or validate their capacity to be able to work and meet the demands of their job.

Amy talked about how she limits herself on talking about her disability for fear of perpetuating stereotypes:

> *"Yeah.. it's really hard sometimes. Because even I should probably talk to people more than I do. Because, like often when you have a disability there is often the perception that you're kind of like…quite pitiful and that people should feel sorry for you so you don't want to perpetuate that and also I think people think that if they talk to their friends or family or someone about how they're feeling then they might be perpetuating that stereotype which is not true, but I kind of… like myself personally have felt that in the past. I've tried to be like extremely like strong and like very, but I think that sometimes that why…"*
>
> (Amy)

Amy goes on to share what she believes are the assumptions form the public on people with disabilities:

> *"From what I've kind of understood from internet and yeah… also some friends… it's like… it seems very prevalent and almost expected that people with disabilities are going to have mental illnesses and I feel like a lot of the time society kind of sees it as not ok but as something that is a given, you know? Like, 'oh of course they're going to have… they're living this hard life' which is not true… it's something that needs to be worked on. So yeah, I know like personally it's something that I struggled a lot with like… some like difficulties and stuff so yeah. […] Sometimes I feel like you get written off as a person with a disability and other times you know you get too much like attention. Like I had a lecturer come up to me the other day and he's like, 'Is there anything else I can help you with?' and like, 'Are you doing ok?' which is very frustrating for me because I've always been very academic and I do quite well at university so it's kind of annoying that he almost assumed that I was going to struggle with the academics just cause I have a disability when I'm often within the higher bracket, so yeah. That kind of thing often from the community."*

(Amy)

Participants here have discussed barriers for talking about their condition to other people. One participant mentions her fears around perpetuating what she believes are stereotypes of people who have a disability. She does not want to appear weak or have people feel sorry for her. It seems as though participants have a clear idea in their minds of what the dominant discourse is around physically disabled people in society. There is stigma that follows disclosing a disability which leads participants to feel concerned that as soon as they disclose their disability they will be treated differently and put in the Other sphere. It seems as though the problem for participants is not actually sharing that they have a disability, but it is about the reaction and the way they are treated after the disclosure.

In the following extended quotation, Amy continued by expressing her concerns for when the time comes she has to use a wheelchair, and the perception people will have of her then:

> Amy: *"Yeah, it's not too bad now cause I'm still walking so people only really know my disability when they know me. But when I'm in a wheelchair I think it will come a lot and sometimes like with that lecturer it kind of shows how it will get worse in terms of how people just jump to conclusions and stuff."*
>
> Researcher: *"Do you feel anxious about that?"*
>
> Amy: *"Yeah, definitely. I struggled a lot with it last year and like it's still something I struggle with, especially because it is a choice its quite difficult because it's not something that just happens I have to actually make the choice to do it which is a bit scary and I'm not sure if I'm ready… like what I was saying to be seen differently. Cause now the general public who don't know me they see me just like a normal person, so yeah I'm not really quite ready for the different ways that people can see you. Cause you hear all these horror stories of people going to dinner with their friends and the waiter talking to everyone but them and like that's going to be really hard for me I think just cause I won't be used to it like I demand more."*

Some participants do not have the ability to disclose their condition, as they live with a more visible form of condition. That is to say, participants that use wheelchair or other medical tools have a different interaction in the public sphere.

Blair, for example, is not particularly keen on talking to complete strangers about her condition. The interactions she has with strangers give her some insight into what ideas the public have when they see individuals in wheelchairs:

> Researcher: *"Do you believe it's important to talk about your condition to other people?"*
>
> Blair: *"Yes. I prefer to know them first…But some people just come up to me and asked me, and like, I don't even know you."*
>
> Researcher: *"How does that feel when people just come up to you and talk to you about it?"*
>
> Blair: *"I'm never sure what to say. I usually like answer what they ask, but not like tell them anything more. It feels a bit awkward sometimes ... I think that lots of people think because I'm in a wheelchair my brain doesn't work probably either which is false, but like anyone that knows me doesn't think that but yeah."*
>
> Researcher: *"Do you think people make assumptions about you?"*
>
> Blair: *"Yeah, definitely ... Some people like I said, would assume that I'm mentally retarded. Some people don't realize the things that I can do. So they would try and do too much for me when I really am able and would like to do them myself. But, I'm not always that good at telling people, no I can do that."*

Additionally, Blake shares what he believes are people's perceptions of him as a person who is in a wheelchair:

> *"I think sometimes people are quite… unsure about me. And what level to communicate to me on. And I'll see that in people's body languages in shops and that. They're really unsure or some will talk to me like it's nothing or yeah."*
>
> (Blake)

People do not know how to interact with individuals in wheelchairs. The public will either ignore the fact that the person is in a wheelchair or they will not know how to interact. It seems as though the public is curious and does want to know more, but because there is a lack of awareness of how to interact with those who are in wheelchairs, assumptions tend to be made and the public has misinformed conceptions.

Paula describes how she experiences that people seem to want to ask more questions but she feels as though there is a barrier in interaction between herself and other people:

> *"I don't know if I feel like some people would like to ask more questions, but I feel like it is like kind of that barrier...you don't want to tell them and they don't want to ask because they don't want to be rude, so they just you know suppose they just 'Oh, that's okay' and then just move on kind of thing ... I did have one lady. I was at a family friend's dinner and I had a lot of family friends around for a dinner party and I was wearing my brace on the outside of my clothes and she asked me and I said "I trip a lot" and she kept asking questions ... Which I didn't really like, I really didn't think she needed to pry so much. So then I had to tell the big story that I have a disability. I mean like she feels awkward because she feels like she shouldn't have asked but then I suppose, you know. I suppose I can't really explain it anymore. Unless I want to go into a big old story about it."*
>
> (Paula)

For Paula, and the other participants, it could be that explaining this 'big story' of why she is wearing a brace is another reminder of her condition and how she is seen by others. It is almost as if she has to relive the experience of feeling different every time she has to explain why she is wearing a brace. Explaining her condition once again, under circumstances where she did not want to, is a reminder for her about the reality that people see her as an Other, someone who is different.

Acceptance

Acceptance of the PNMC leads to better management of the condition. Participants are able to engage in proactive health behaviour and emotion regulation, which is discussed in the subordinate theme of holistic wellbeing. The subordinate theme, extra voice, talks about participants' acceptance of their condition and how it gives them the opportunity to use their voice to talk about their conditions with the public in a prosocial way. Lastly, when discussing the subordinate theme of the blueprint, participants discuss that through acceptance they are able to accommodate for their needs in both the present and the future, which ultimately leads to better mental and physical health outcomes.

The topic of acceptance almost always surfaces when asking participants if they ever felt angry of frustrated because of their condition. The sort answer is yes - there have definitely been times where participants express they have felt anger and frustration. Feeling frustration, especially because the frustration seems to be connected with the physical limitations of their conditions is something all participants can attest to. Acceptance then acts as a coping strategy for these individuals. The idea is that acceptance is a way of learning to live with this condition. Participants seem to have developed ways to manage these feelings of frustration and live in a more positive way. Participants mention the idea of acceptance in relation to accepting the body they were born with, and the impacts that this condition has, whether physical or psychological or both.

When asked if there were ever times she felt angry or frustrated by her condition, Gemma responded by saying:

> *"I did a lot when I was younger, but I've been able to like accept that this is the way things are… just accepting that being born into this body I can manage most of the symptoms and yeah saying, 'This is the way things are and I can do things to make my situation better."*
>
> (Gemma)

Blake does not seem to be frustrated with his body, as says he can’t be angry with something that can’t be changed:

> *“Being stuck in a body like this with an angry mind.. yeah.. just a bad recipe.”*
>
> (Blake)

He accepts his body for the state it is in, and views his condition as something that can be helped with treatment. For him, acceptance of his body leads to searching for alternative treatments and trying to improve his quality of life.

Grace mentions:

> *“There’s really no point in being angry because it is a condition that I have and it can’t be cured. You need to understand it and find a way to overcome it. You can be angry at the time but it doesn’t help to stay that way … it just kind of made me realize that there are things I can't do and things I might need help for. But because I do have people to talk about these sort of things I kind of am able to go ‘yup they're a part of me, but I’ll just deal with them.’ … I kind of go from angry to being understanding... it is what it is and what I have. And I go, ‘okay, let's see find a way I can deal with this’... And there’s really no point in being angry because it is a condition that I have and it can't be cured…You just need to understand it and find a way to overcome or get through or a way of having to deal with it. It's not worth being angry about it. You can be angry at the time but it doesn't help to stay that way.”*
>
> (Grace)

A similar idea is shared by Paula, who states:

> *“Now I'm just more accepting of it… but it does still frustrate because it takes my independence away and I don't like that at all…I suppose I don't cope with it great because it's kind of always there. But yeah, I have to be kind of accepting. I feel like I need to be calm and accept it and just go, ‘Okay. It's okay. It's fine.’”*
>
> (Paula)

There possibly comes a time in living with their condition that participants realise holding onto the anger they have will only cause them more strain, and the feelings of anger will only lead to negative mental and emotional outcomes. Participants make the connection with the idea that being angry does not bring about any positive outcomes in their lives, but it is possible that not all participants reach acceptance at the same time. It seems as though participants start out angry and then move towards this state of acceptance of their condition A participant might need to go through stages to reach acceptance, or they may need to reach a certain understanding and psychological maturity in order to let go of the anger. Participants realise that to live and cope with their condition, there is a need to be able to accept that this is how it is. They learn to find ways to get through bad situations or moments in their illness.

Holistic wellbeing

Holistic wellbeing refers to the idea that physical and mental health are connected. Participants view health as a multidimensional concept and by accepting their PNMC they were able to use positive ways to cope and manage their symptoms. Participants expressed that there is a connection between their physical health, or symptom severity and mental distress they may have experienced. That is to say, participants realised that emotion regulation and symptom severity are connected.

Participants expressed what it meant for them to be healthy. All participants talked about how being healthy involved a balanced lifestyle. The underlying nature of the condition – one that is progressive and in a constant state of change – impacts how they view health. Health for the participants is not a static, never changing state of being. It is instead a lifestyle that they recognise fluctuates but in general, it is encompassed by healthy relationships, positive health promoting behaviours, a mentality that focuses on the present, and being in a stage in life where they are not experiencing illness.

Participants talked about living a balanced lifestyle. This lifestyle is dynamic and made up of many factors. When participants are behaving in a way that promotes what 'being healthy' is for them, they are more likely to feel content emotionally. They feel less irritable and angry, are happy and motivated.

When asked on what being healthy means, Amy expressed the connection between mental and physical wellbeing:

> *"I suppose it means like to be… if I feel healthy usually means that I'm eating healthy and getting enough sleep and just feeling quite energized. Like I don't feel like I need to sleep all the time so it's like definitely about what I am eating and how I am living and also like if I wake up and feel energized and also emotionally… if I'm feeling content or happy and also motivated to go to uni and stuff then I'm like… that's a healthy mindset. And if I'm not too like irritable or getting angry at people and stuff. I suppose it's yeah like a whole bunch of factors usually, like to do with my emotional state or how stressed I am. But if I'm like feeling quite down or just having some other emotional problems then the extra problem of the physical issue is usually a lot harder to deal with then when everything is going well."*
>
> (Amy)

What being healthy means to other participants:

> *"Hmm…. Being able to do things without my health stopping me. Just feeling happy and somewhat fulfilled without always questioning what's coming… what do I have to do. Just being happy in the moment."*
>
> (Blake)

> *"Eating healthy, exercising, having healthy relationships around you like having people around you and just enjoying life and not thinking about little things that might not be going right at the time. Yeah. I just I'm feeling happy and healthy at the moment. And I think that's pretty important when it comes to my condition because exercise is hard and eating healthy can be hard. But yeah, I'm happy and healthy and I just feel like that's cause I've got I've got a cool job. I love living with my partner. I eat as healthy as I can when I try and I do a bit of exercise when I can. Yeah, I think happy and healthy kind of comes in one category if you're happy, you can be healthy."*
>
> (Grace)

> *"Like eating healthy would be a part of that, and exercise. And also healthy like a healthy balance of university work and friends and God. It's all about balance I think."*
>
> (Blair)

Being healthy means one has to keep pushing forward through all stages of life. Health, like life, fluctuates and there will be moments where participants will feel healthier than at others. Participants expressed being healthy to them means living in the moment. It means possessing the freedom to do whatever they want and feeling in control of their bodies.

Living in the moment can be seen as an emotional strategy used by the participants in order to cope with anxious thoughts and worries. Living in the moment means staying in the present and not thinking too far ahead into the future. For participants, it means focusing on what you can do today, in the exact moment, rather than what you cannot do. In a way, participants attempt to reframe their thoughts. There is an attempt to try to focus away from a negative or worrisome mindset to a mindset that is more mindful of the exact moment they are in, their current situation and their current physical capacitates. Instead of looking at the deficits in the lack of physical ability, participants try to remain positive and focus their attention on other things. There is a sense of distraction that also comes into play when talking about living in the moment. For some participants, this means doing activities they like (e.g., watching documentaries, talking to friends, playing music).

Participants talked about health promoting behaviours, such as getting enough sleep. This is a fundamental behaviour for participants as fatigue is a symptom commonly experienced. It implies that participants require long rest periods. When they get enough sleep, they feel more energised and this in turn boosts their mood and ability to cope with challenges throughout the day.

Once participants being to accept the body they were born into, they typically begin to behave in ways that promote symptom management. The strategies that they employ to try to delay the deterioration of their muscles for as long as possible seems to be crucial in the mind of participants as they share the sentiment that every little bit of help is important. As they know that what they have is progressive, anything that can slow the progress for them is important. They are in a fight against time, so they are fighting against time to slow down the condition as much as possible. The goal of participants is to slow down further deterioration. In order to do this, participants are forced to be proactive. That means that participants will actively pursue multiple methods of symptom management. This involves strategies such as sleeping, going to the physiotherapist, eating a healthy diet, massages, stretches and proactively researching new treatments to name a few.

Extra Voice

Extra voice refers to a statement one of the participants made where she said that by living with a PNMC she felt as she was given an ‘extra voice’ in life. In this statement, she explained that for her, her extra voice was an additional way of looking at the world. It is a specific perspective that allows her to understand what it’s like to feel like an ‘Other’ in society. Due to this, she feels an innate drive to use her extra voice to advocate and try to make changes in society for those who like her, are marginalized, in some way.

This socially conscious perspective where the aim is to raise public awareness of PNMCs has been expressed by some participants. In one way or another, participants express an internal desire to talk about their condition to others, whether that means speaking to the general public/members in their community, participating in studies like this one, speaking to health professionals, etc.

Blake talked about his experience in using his extra voice:

> *" Medical professionals because a lot of them don't have a clue at all. So I'm constantly educating them. Even people who should know that don't know. Talking to them quite a bit about it. Umm.. with people who are interested in my normal day to day life when they ask me something, sure I'll talk, whatever. If they're interested about it then yeah. I guess it helps society as a whole if you're open to discussing things and educating people and finding a better way to do things if something needs to change instead of being closed off and angry which doesn't solve anything for anyone, you know? ... I'm getting pretty used to it to be honest…Gets results and yeah. And the next generation of disabled people getting older and society will be more aware and helpful because they know about things and yeah."*
>
> (Blake)

This participant views his extra voice as an opportunity. He mentioned how he did not like to talk about his condition when he was younger. As he matured, his view changed as he began to see the positive effects that can occur. Talking to health professionals about his condition seems to be a mutually benefiting situation. He is increasing knowledge and awareness to a community of professionals who will be encountering other individuals with PNMC at some stage in the future. His extra voice is used in a prosocial way where he feels as though he is helping future generations both in the medicalised part of life that comes with living with a PNMC and also in the social world of interaction with the public. Furthermore, by using his extra voice, Blake is shifting the dynamics of his social world. What this means is that Blake is becoming more integrated into his world, and slowly can start to feel more accepted and less of an Other.

In the following excerpt from her interview, Amy described the importance of using the extra voice:

> *"I suppose that having a disability and being in a minority it kind of helps you understand other minorities, so you kind of just see more issues but also I feel like a lot of the issues that people with disabilities face are very… not many people know about it and so I feel like by having it, it's made me know about it and made me want*

> *to do something about it. Like so whatever I do I kind of hope to make some sort of difference and try and widen peoples' understanding I guess… yeah… I suppose like I'm particularly interested in Media and film. Cause I think it's really important for young people to see someone that is like them and that they want to be as well. So I don't really think that people like me are represented that well and that's something I really want to do and yeah so I think that through like film we can hopefully change attitudes and then hopefully improve mental health of young people with disabilities and just general living standards and stuff, yeah."*
>
> *(*Amy*)*

Amy views her condition as something that has given her a different life perspective. She has found something positive from her condition. It may be that some of Amy's identity has been shaped by her condition. Her personal interests align with using her extra voice in the world. She understands the importance of media representation and wants to use her extra voice in a political way. Ultimately, she would like to improve living conditions for people in situations similar to her. She took the unique illness she has and used it to empower her life and try to do the same for others that live with a PNMC.

On average, if there is a chance for participants' voice and life perspective to be heard, they are more likely than not to take the opportunity. The concept of being open about their condition is one that is talked about frequently. In general, the idea of being open and talking about their condition with the public, health professionals, strangers seems to be driven by a few factors. Participants view being open about their condition as a way to make a positive social impact. Exposing the public to people like 'them' begins to take away some of the assumptions, stigma and preconceptions people may have about those with physical disabilities.

Participants use their extra voice not only in an attempt to increase social awareness, but also to feel more accepted and included in their communities. By being open, participants no longer have to hide their condition. There is a dual acceptance happening. Participants must be able to accept themselves, and their bodies in order to be able to speak about their condition publicly. It could be interpreted as participants taking something 'negative' in their lives and reframing it into something positive. As participants accept themselves and talk about their condition, others in their world begin to gain a better understanding of PNMC. Acceptance from the community is essential to living a more liberated life.

Blueprint

Given that all PNMCs are progressive, thinking of the future can be something that brings participants negative emotions such as worry, stress or anxiety. There are ideas in society about what the future for young adults should look like. There are certain milestones that society expects young people to achieve, in a certain order and within a certain timeframe. The idea of a blueprint is the acceptance that the future might not exactly fit into the blueprint society has drawn.

When specifically asked about how he pictured his future to be, Blake spoke about the idea of the ideal blueprint in society and how he fit into that:

> *"It took me a few years to understand that way of thinking... seeing my friends do life and everyone has a 'blueprint' of what they're supposed to do.. school... university.. travel.. work.. family. You know? It's all kind of the way you usually do things. But with me, it's quite different. Like I can still do those things but maybe just different times, different ways."*
>
> (Blake)

Instead of implying he is unable to do the things that are expected, or that his future will be extremely unknown, turbulent and anxiety provoking, Blake's outlook was one where he recognises the differences between his future and those who do not live with a PNMC. He accepts the possible differences, but that does not stop him from pursing a future he wants, even if this future looks different to what is 'normal.'

Additionally, blueprint also means adjusting ones desires and wishes to meet their needs given their current circumstance:

> *"I have my very ideal future which is where I live on a farm and I grow crops and I have a cool motorbike and a sword that I hang on my wall … But when I see myself, I see myself doing… hopefully journalistic work or like freelance anthropology stuff. Hopefully working from home. I like to live in an apartment in the city so I can get around easier, that sort of thing."*
>
> (Gemma)

Thinking of the future for participants means having to adjust to meet the reality of their situation. They have to adjust their blueprint to become practical, but this does not change the desires of the future:

> *"I've always wanted a farm and I've always wanted kids, but the things now like I think I want a one level house, I don't want stairs, I want a one level house that's all on the same level, you know, something that is easy to clean and things like that. But most of the things are the same. It's more just the practical things now, you know. Just a little things like we have salt and pepper shakers now because I can't grind them. So it's just little things like that. Just make it even easier I suppose, so for the future I'm more thinking now that I just want things to be easier and more accessible, you know. Like cars now have all these fancy buttons on that you only have to press one and it does it for you. So as far as the future now is more just getting things that make it easier for me."*
>
> (Paula)

Participants have to accept their situation and think in practical ways in order to be able to accommodate their needs. Acceptance is a key way participants cope and manage with their condition and their worries and anxieties of the future. Participants have to readjust the ideal dreams they may have for more realistic ones. This adjustment does not mean that they will not feel fulfilled or that their desires have not been met. Understanding what their ideal blueprint looks like and being able to readjust it so it is congruent with their physical abilities is essential. Participants demonstrate a sense of psychological maturity and ability to cope when they develop the capacity to reframe their ideal hopes.

Support

When speaking about support, the focus is on support participants have found or need in order to feel better in their lives. Support can come in many forms. Sometimes, it is just about the physical presence of being with friends that is enough to help participants. For other participants, support systems act as a balance to help keep a positive mindset. Other times, support is more practical in that an individual may need physical support (i.e., assistance) from people.

when asked what she has learned that has helped her deal with her condition, Paula shared her experience of the support she has found:

> *"It's helpful that I have my partner who doesn't worry about it, and, you know my parents ... my friends know I have it but they don't treat me any differently. They just realized it. Sometimes I need help and you know things like that... having a good support system definitely helps keep a positive mind and dealing with your bad days and your good days and things like that."*
>
> (Paula)

Grace shares a very similar experience of feeling supported through her family and partner:

> *" My family. They are a huge support network as is my partner. I feel like I can talk to them about anything. It doesn't just have to be about my condition and they are so supportive that that's the only support network I kind of need... my partner is amazing to go and talk to if I need to. Not that he can answer anything or knows much about it, but just to kind of listen is amazing. And I do that with my nana. I kind of open up to her like all the time...So anyone that will listen to me is a good thing."*
>
> (Grace)

For participants, being treated the same as everyone else is fundamental in the support they need to receive. Having the option to discuss issues about their condition is important, but it is important to have people around who do not put their condition at the centre of their interactions. Having support systems who understand how to interact with them, makes participants feel accepted and ‘normal’ in the sense that the support systems are not overbearing or looking after them too much.

The way Paula described how her partner does not worry about her condition too much is important. When participants have people in their life who do not live with a PNMC, who do not have to constantly think about the condition, and who are not in a body that is restricted then they are able to provide the participant a different perspective. It would be normal for participants to get ‘stuck’ in ridged mindsets, especially when going through though periods when symptoms manifest more. This is when support systems are able to give their understanding and support by acting like a balance. The balance helps centre negative thoughts associated with worries, fears and possible anxiety. Essentially, support systems understand the needs of participants and their presence allows participants to feel accepted and understood.

Sometimes, understanding from support systems can come in nonverbal ways. For example, Amy shares that just being around friends when she is upset is enough:

> *“ Umm.. sometimes I talk to my friends which is good [...] Because even if I don’t explicitly talk to them, because obviously they’re understanding, but obviously can’t understand [her condition]. So I don’t talk about it too explicitly but just knowing that they’re there does really help.”*
>
> (Amy)

For this participant, just having people in her proximity is enough support. She does not need to talk about her condition explicitly to feel better. Instead, having company can make her feel supported and cared for.

Nonverbal understanding can also come in the form of physical support, as the following participant mentions:

> *"Yeah, they're [friends] really good…Always fine with taking breaks and what not … I think the support I get is really helpful. Just like understanding when I need to take breaks…just like physical support. I don't know if I've ever been like emotionally supported for my condition. I've never really talked about the emotional aspects of having Charcot Marie Tooth."*
>
> (Gemma)

Support systems are an essential component of the lives of the participants. Support systems act as a balance to what may sometimes be participants' very clouded mindset. What is meant by clouded mindset is that it possible that it is easy for participants to fall into a negative mindset as they are constantly faced with challenges associated with living with their condition. Having people around who are not experiencing these challenges might bring a different perspective to the participants which might help them 'readjust' their perspective of their experience.

Additionally, having the support from friends and partners who accept the person for who they are is very important. While support systems may not necessarily understand what it is like to live with a progressive neuromuscular condition, the acceptance they bring to the relationship is helpful for the individual. Through their support networks, participants might not only feel accepted in society, but they may also feel 'normal' through these relationships. They may not feel as tied down to their condition and may feel less of an Other in the world. In other words, support systems give acceptance and normalise life for participants.

Discussion

Progressive neuromuscular conditions are rare and chronic illnesses that manifest in the physical deterioration of muscles and organs in the body (Chen, Miller, Seo & Mendoza, 2010). These conditions are not yet curable, but given advancements within the last 25 years, individuals are living longer than ever before (Forman et al., 2012). The purpose of this study was to gain an understanding of what the experience is like for young New Zealanders who live with a PNMC. This research investigated how individuals perceived their quality of life to be impacted by their condition, and in turn if this had an impact on their mental health. The research question was how do adolescents and young adults with a PNMC perceive and manage the impact their condition has on their quality of life. More specifically, the aims research set out to understand:

1) If having a PNMC effects the individual's quality of life
2) If individuals experience mental distress, such as worries or concerns, due to their condition and how they deal with these challenges
3) What kind of support young people find helpful to feel better during times of mental distress

Seven semi-structured online video-calling interviews were held. An interview schedule had been previously generated with a set of specific questions. At its core, IPA puts those who live the phenomenon in question as the experts of their psychosocial world (Larkin, Watts & Clifton, 2006) and therefore if noteworthy topics developed during interviews then they were explored. Five superordinate themes were developed from the interviews: a) a condition that is constantly present, b) mental strain, c) living as an Other, d) acceptance and e) support. Several subordinate themes emerged within the superordinate themes which will be discussed below.

Theme 1: A condition that is constantly present

This theme relates to the first aim of this study, which was to understand how having a PNMC effects an individual's QoL. Living with this condition was part of normal life for participants. Living with a PNMC implies living with a condition that is permanently physically present. Having a condition always present meant that for some participants, life stayed exactly the same before and after diagnosis. Participants described this presence as something that is part of their normal life. The condition had helped them shape part of their core identity, which is a topic that is further discussed in theme 3, Living as an Other.

Medicalised Experience. Participants describe the medicalised experience that comes from living with a chronic condition. Given that PNMCs manifest through multiple physical symptoms, participants were inclined to view their conditions through a medicalised lens. Medicalised experience meant receiving a diagnosis, and for some participants it also meant the need to use a wheelchair or other medical tools or aids to move around. Participants made sense of their condition through the biomedical explanations they've received from health care professionals. Emphasis was placed on the body and the physical experience. This is how participants rationalised the condition that they had and how they made sense of the impact of its symptoms.

Self-awareness. Given the body is in a constant state of change, the participants' need to continuously check the state of their body. There is a potential learning period involved before participants can become fully self-aware. Participants must learn to read the changes in their bodies and understand when there is cause for concern. There is a balancing act constantly going on, with the importance of not being too critical and turning into a hypochondriac.

Independence. The level of physical independence a participant has at a given time acts as a tool to gauge the progression of the condition. The ability to be physically independent and have the ability to do things on your own is important for participants because it is a sign that they are in control of their bodies. When participants feel more physically independent, they experience positive emotions, and ultimately, are in better state of mental health. Independence ties into the second theme, Mental Strain. It seems as though it is when participants perceive their physical independence to decrease that they experience anger and frustration. It is very possible that when independence is reduced for the participants, they also experience anxiety.

The subordinate themes that are encompassed in this superordinate theme of living with a PNMC that is constantly present deal with two psychological concepts: how participants perceive their illness and how they regulate this perception. Graham, Rose, Hankins, Chalder and Weinman (2013) define illness perceptions as how people make sense of the symptoms they experience. The way people make sense of their experience determines the emotional response and coping strategies that they use. Illness perceptions can predict behaviours. For example, if someone has the perception that they can manage their symptoms through their behaviours, they will probably be more likely to adhere to medication than someone who does not have this perception about their illness.

Leventhal's Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) is a cognitive behavioural model of patient's response to illness. This model suggests that hardship experienced by people with PNMC has two parallel coping methods. The first coping method is the management of the physical symptoms and impairment. The other coping method is the regulation of stress. What is fundamental to this model is the concept of illness perceptions. Here, illness perceptions are ideas such as the duration of the illness (i.e., chronic), symptoms frequency (i.e., constant), and the potential to which the individual believes their illness can be controlled by their behaviour. Essentially, individual's cognition about their illness affect how they manage their illness, and ultimately this has an influence on their QoL.

Again, this population of emerging adults with progressive conditions are in a transitory period in life. This time in life in some ways is categorised by identity exploration and change (Poole & Snarey, 2011). Realistically, the participants are becoming physically weaker and more dependent on others at a time in life where independence is sought. This, therefore, may have an effect on how participants view themselves and their illness. It is possible that participant's illness perceptions are medicalised and seen through a biomedical model. This implies that their lives are very medicalised, and to regulate this perception, they are always self-aware of their bodies. They might be using physical independence as a regulation tool to see if their bodies are deteriorating, as would be in line with the idea of PNMC under the biomedical model of explaining illness.

In a study by Graham and colleagues (2014), the authors set out to establish if illness perceptions influence quality of life in adults with PNMC. A total of 226 participants completed questionnaires on QoL, mood, illness perceptions, optimism, coping and functional impairment. Results found that while functional impairment explained some of the variance seen in QoL domains, it was illness perceptions that explained the majority of variance of QoL. These results reinforce the idea that illness perceptions are influential in terms of how participants view their QoL. It is likely that the illness perceptions of individuals with better QoL scores have a realistic acceptance of this PNMC, opposed to those whose QoL scores might be lower. In these individuals, it is possible that maladaptive coping methods, such as avoidance, are used instead of acceptance (Graham et al., 2014).

Theme 2: Mental strain

This theme is connected to aims 1 and 2 of the study. The participants' experiences of mental strain gives some understanding as to how PNMCs effect QoL as well as helping to understand the type of mental distress that is experienced.

Participants expressed feelings of worry associated with loss of control, fear of the unknown, the need to plan. Learning about what can happen in the future regarding their condition progression generated feelings of worry and loss of control. Participants experienced feelings of frustration and anger as well. Frustration and anger come from the inability to do every day physical tasks, such as needing help to get ready in the morning. Frustration is routed in the inability to stop the progression of the illness. This makes participants feel at a loss of control.

Living with a fear of the unknown, of what can happen in two weeks' time or how their condition will have progressed by the time they have children, increases feelings of anxiety and worry. For some participants, living with a PNMC means their condition exacerbates their worries of life. Fear was also related to being left behind by friend groups or missing out on certain experiences due to the physical restrictions their condition places on them. Participants are forced to plan their lives very carefully. They need to check that wherever they go is accessible, that they will have enough time in their day and that the decision to go somewhere is a sensible one. Planning their lives out too much might actually have a negative effect and increase the anxiety they feel. On the other hand, planning allows for structure that can ease anxieties and worries when a person has enough self-awareness of the needs of their condition.

What participants described seems to be a generalised anxiety. Whether this is at a clinical level is impossible to say from a one-off interview, but one can speculate the possibility of some participants dealing with generalised anxiety disorder. This idea would be consistent with the study by Antonini, Soscia and Giubilei's (2006) where 20 adult participants with Myotonic Dystrophy were given the Short-Form 36. Half of the participants scored significantly high in domain of anxiety. The authors concluded that health-related QoL is negatively influenced by living with Myotonic Dystrophy.). As the name states, generalised anxiety disorder (GAD) (Newman, Llera, Erickson, Przeworski & Castonguay, 2013) is an anxiety disorder that is defined by excessive and uncontrollable worry about events, activities, or everyday matters (e.g., health, relationships, family). It is when these worries begin to affect daily functioning that there is cause for concern.

Newman and Llera (2011) proposed the Contrast Avoidance model which is a model that essentially suggests those with GAD engage in chronic worry as a way to be in control of events by emotionally preparing for the worst. Newman and Llera (2011) explain the negative emotional contrast experience. This is when individuals with GAD experience worse feelings of anguish (as opposed to non-anxious control groups) when experiencing a state of relaxation, or neutrality, to a state of negative emotions. In order to avoid these extreme negative feelings, individuals therefore attempt to maintain their high level of worry at all times. Thus, for example, when participants who might have GAD experience a new loss of physical ability (however subtle) following a stable period where symptoms have been consistent, they experience an extreme negative emotional reaction.

Theme 3: Living as an Other

This theme allows for more insight into aim 1, that is how a PNMC effects the way they live in the world. Participants faced both stigma and messages from the outside world. Participants felt as though society had a negative perspective on people with disabilities in general. In particular, participants expressed the thought that society took pity on them. Being physically different in a public space meant that participants felt they were not treated the same as everyone else. Feelings of being invisible and marginalised were discussed. Participants expressed how uninformed and incorrect assumptions from the public were made about participants' mental capacity.

The theory of the Looking Glass Self, originally developed by Charles Cooley in 1902 argues that how a person perceives oneself is how their identity is developed. Identity development is formed through the internalisation of the perceptions of how others in society view us (Yeung & Martin, 2003). The result of this being our identity is product that is the result of how others see us. The self-perception of participants is partly shaped by how they interpret how the world views them. Participants noted that they feel different to their 'healthy' peers. They are positioned as Others in society – those who are not part of the able-bodied mainstream. Feeling as though society views them differently, participants began to view themselves differently too. Feeling this way stirs up doubts about one's body and insecurities. This is especially potent for people during adolescence.

Going beyond this, Yeung and Martin (2003) also contributed to this theory by suggesting that people are able to change the way they view themselves by changing the way others perceive them. This is accomplished through a person's consistent acts. This idea ties into theme 4, Acceptance. In particular, when participants use their 'extra voice' in prosocial ways to inform the public about people with PNMC, they are essentially attempting to change their identity from an Other to another individual in their community.

Theme 4: Acceptance

This theme is significant because it helps understand part two of aim 2. That is, to explore what strategies young people use to deal with their experiences of mental distress. Acceptance is a coping strategy participants use to live with their condition. Acceptance means different things to the participants - acceptance of being born into a body that has a progressive illness, acceptance in coming to terms with the idea that frustration and anger towards your own body will only get you so far, acceptance is reframing negative feelings and thoughts.

Acceptance lead to a better management of symptoms and overall better mental wellbeing. Acceptance by the participants lead them to interpret their health as holistic. Recognising that there is a connection between the mental and the physical states lead participants to attempt to live a more balanced lifestyle. This implies participants are more inclined to enjoy their lives in the current moment and refrain from thinking about any possible troubles their bodies might cause in the future. Participants are practicing mindfulness. Mindfulness is a process where attention and awareness is of the present moment and the current experience (Sharp & Curran, 2006). Masuda and Tully (2012) study suggest mindfulness and psychological flexibility, concepts which participants in this study exhibit, are negatively associated with mental distress.

Additionally, when participants shift their mindset of how they define health, going from health as purely physical to viewing health as holistic, they are displaying psychological flexibility. Psychological flexibility is a mental and behavioural process of living in the present moment without avoidance or judgement while also maintaining or changing behaviour given the context of a situation with the goal to reduce psychological distress (Sharp & Curran, 2006). Sharpe and Curran's (2006) study of 137 people with a range of PNMC set out to identify which processes are important when adjusting to illness. Participants filled out questionnaires and the researchers concluded that psychological flexibility increases life satisfaction and decreases anxiety. Participants in this study showed the same ability to respond to change in their environment, which lead to a more balanced QoL and mood.

Participants learned to accept that this is their life and that the condition is a part of it. Extra voice is the acceptance of the unique life position and perspective participants have because they live with a progressive chronic condition. An extra voice is a political and social tool participants use. Extra voice is political in the sense that participants use their experience and knowledge as a way to increase quality of life for others who live with PNMC. Participants try to advocate for better accessibility and to increase social awareness of PNMCs with the intent of making life better for future generations. Participants believe if they can use their extra voice to inform the public, then awareness and acceptance will increase. Participants engage in a dual acceptance process. By accepting themselves and the condition that they have they are able to talk to the wider community about problems they face which in turn leads to more acceptance and openness form the community.

When participants talk about coming to terms, or accepting, that their future might be different to that of their able bodied peers they are referring to the ‘blueprint.’ They may not achieve all expected milestones in life, or if they do, they may achieve them at a different pace. Participants accept they have to adjust their blueprint so that their goals in life are achievable and their physical and psychological needs are still being met. The idea of the blueprint resonates with Kranz and colleagues’ (2010) study where chronic pain and affective wellbeing were studied from a coping perspective. The authors obtained self-report data on pain, acceptance, and accommodative flexibility from 150 patients. Results found that the ability and readiness to adjust personal goals was positively related to well-being and accepting attitudes.

Theme 5: Support

This theme deals with aim three of this research, which was to investigate what type of support, if any, young people find helpful to cope with living with a PNMC. Support through understanding and relationships was something participants expressed as important in their lives. Understanding was found within relationships. Individuals found it supportive to be treated like everyone else. It was important for participants to feel as though they are like any other able-bodied person. Understanding within relationship means that people understand how to treat the person with a PNMC. The condition is not placed at the centre of the relationship. Instead, it is not frequently discussed, unless the participant chooses to do so. This helped participants feel ‘normal’ which also helps participants feel as though they shift from being in the Other sphere into a social world where they are accepted.

These relationships helped balance the worries that come from constantly thinking about their condition. Understanding also came in the form of nonverbal communication. Just having people present in the same space was enough for some participants. Other participants found it helpful to receive actual physical support as well. The actual presence of people around is sometimes all participants need.

These findings are important, as they coincide with other studies in the literature. For example, Miró and colleagues (2009) conducted a study where they assessed the role of many psychosocial factors in 182 patients with two types of PNMC – myotonic and facioscapulohumeral muscular dystrophy. Participants completed surveys assessing psychological functioning amongst psychosocial variables. Greater perceived social support was associated with healthy psychological functioning (Miró et al., 2009). Those who showed low levels of perceived social support had higher levels of pain and mental health complications. The finding that greater perceived social support is associated with greater psychological functioning overall is seen in other studies (Osborne, Jensen, Ehde, Hanley & Kraft, 2007) which suggests that support is essential in maintaining psychological functioning in individual with disabilities.

Limitations

This study had limitations that need to be addressed. First and foremost, the data collection phase of this study used innovative methods. Interviews were conducted online via Skype. This is a relatively new mode to communicate and gather data for studies. Some practical issues occurred during some of the interviews. At times, there were some connectivity issues, where the conversation might have gotten broken up due to lag or bad connection. This could potentially result in misunderstanding or miscommunication, from both the researcher and the participant. Additionally, as Deakin and Wakefield (2014) mention, the lack of visual cues sometimes makes it more challenge to establish an initial rapport with the participant. This becomes especially problematic when interviewing someone that is more reserved or less responsive to the questions. While online video calling interviews have the potential to be great data collection tools, there is always a possibility that issues may arise. Some issues are very difficult to fix, for example the strength of the internet connection or the quality of the device the participant used.

Other issues, such as requesting the participant to be in a quiet space during the interview, can be addressed more hands on. In the future, it would be beneficial to have a set of recommendations for the participants in order to decrease any communicational barriers. The setting in which participants chose to conduct the interviews was a possible hinderance. Participants were encouraged to choose a private location for their interview but ultimately had the freedom to choose wherever they felt appropriate or comfortable. One participant chose to conduct her interview in a public space. There was a lot of noise and distraction. This could have also limited the participant from being able to answer the interview questions as freely as she might have if she was in a more private setting.

Participants were given the option to have a support person in the room with them during their interviews. When having an additional person present in the space there is a change in dynamic. Both individuals are physically in the room together and the researcher is on screen. This can create a divide, where the participant might direct more attention or communicate with the support person more directly. The participant clearly knows the support person well, and therefore this may influence the way the participant answers the questions. In one of the interviews, the participant began to have a conversation with the support person, and this limited the interaction with the researcher. It was almost as if it created a block in the initial moments of the interview where the participant and researcher begin to get to know each other. This therefore sets the rest of the interview up as a challenge, because it is almost as if the researcher has to work twice as hard to sustain the attention of the participant.

Finally, an important note that should be taken into account is the actual participants themselves. The participants were an incredible group of individuals who took time out of their day to sit down and have an interview about their lives. That being said, this particular group of individuals were a group of highly functioning people that had an innate drive to want to talk about their experiences. Their internal motivation to want to talk about their experience with a PNMC might suggest they have reached a level of acceptance and functioning in their lives. It may be that other individuals who may be more reluctant to participate in studies and share their experiences are voices that also need to be heard as they may offer a different perspective.

Recommendations

There are a few recommendations that need to be mentioned for when conducting future research. It would be beneficial to get a larger and more diverse sample of individuals for a future study. Most of the participants in this study were female. Although there was a male perspective heard, it would be interesting to see if there are any gender differences in experience of living with a PNMC. Additionally, most of the participants identified as New Zealand European. It is imperative to get a more ethnically diverse sample of participants to see if and how experiences differ to the ones that have been shared in this study. Lastly, finding a way to access the ‘silent’ voices of young New Zealanders that live with a PNMC is essential as their experience is one that is vital to understanding this topic with more depth. The participants in this current study actively wanted to share their experience of what life was life for them. It may be that these participants’ are more ‘highly functional’ and have the ability to speak on these topics. Reluctance to speak about personal experiences might be due to lack of self-awareness, or because individuals may find themselves struggling. Hearing from individuals who are struggling more with their mental health or that perceive their QoL to be low would give insight into the exact type of support and assistance these populations need.

Conclusion

This study helped gain insight into the unique stage in life of emerging adulthood for individuals who live with a PNMC. This particular period in life for individuals is a significant developmental stage which can contribute to determining future success and wellness. Five themes were identified: 1) a condition that is constantly present, 2) mental strain, 3) living as an Other, 4) acceptance and 5) support.

With regards to the question one of this study, how does having a PNMC effect the individual's QoL, themes 1, 2 and 3 tell us some information. Due to the fact that individuals live with a condition that is always present, the condition is part of normal life for the person. But, this does not mean that the condition goes unnoticed. Instead, individuals interpret their experience as a very medicalised one. This is a condition where there is frequent interaction with health care professionals. Symptoms are constantly monitored and participants attempt to be as self-aware of the changes in their bodies as to try to prevent as much deterioration as possible. Having a PNMC impacted mental health. This will be further discussed in relation to theme 2, but overall anxiety and worries are a common experience for participants due to their PNMC. Lastly, due to the stigma and messages participants receive, they feel as though they are outsiders in their communities. The feeling of being an Other was discussed by all participants.

Question two of this study asked if young people experienced mental distress. If they did, this study further investigated what strategies are employed to deal with these negative emotions and thoughts. Participants expressed feelings of anger and frustration when it came to the physical limitations their conditions placed on them. These feelings stemmed from feeling as though they were losing control of their bodies and becoming more dependent on others at a time in their life when independence is highly valued. Participants experienced frequent worries and anxieties related to their condition and daily life. Participants worried about the practical aspects of life as well as the future, and what was going to happen to them given the deteriorative nature of PNMCs.

In order to combat the experiences of mental distress, participants utilised some coping strategies. Participants reached a level of acceptance of their condition, where they began to view health as a holistic concept. Health was not just centred around physical health, but also about being happy and proactive in behaviours that promote wellbeing. Participants learned to adjust their expectations as to coincide with their physical capacities. For example, if a participant really enjoyed cooking, but they were no longer able to chop vegetables they would buy frozen vegetables to aid the process of cooking. Participants learned to do things they enjoy, but within their limits which allowed them to still get joy out of hobbies or daily activities. Lastly, by accepting themselves, participants were able to speak about their PNMC or experience to members of the community. In doing so, participants engaged in a dual acceptance, where by accepting themselves they were more receptive to strangers. Participants were able to inform the public about their particular condition and in turn, strangers began to understand and accept them.

Question three asked what forms of support do young people find helpful. Overall, participants need support from the people that close to them: their friends and family. Support from their relationships means participants not only feel accepted, but they feel ‘normal.’ Being supported, directly and indirectly, helps participants balance their life. They are around people who are not living with a PNMC and therefore their condition is not a constant thought.

On a community level, this project allows for the generation of data relevant to young New Zealanders who live with PNMCs. This project might help individuals who live with PNMC feel more connected, and that their thoughts and experiences are shared with others. This is especially relevant given the fact that in many instances individuals do not meet anyone else with their condition due to the rarity of PNMCs. The insight gained from this study can potentially be used as a starting point to explore topics relevant to young adults with PNMCs in the hopes of improving quality of life and psychosocial wellbeing.

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Appendix A - Interview Questions

Complete Set of Interview Questions

Sequence	Topic	Question
Question 1	Illness Perception	Can you describe what it means to live with condition?
Question 2	Illness Perception	How do you think condition impacts the lives of those who are diagnosed with it?
Question 3	Illness Perception	Do you ever feel pain and fatigue?
Question 4	Illness Perception	How would you describe your energy level on a day to day basis?
Question 5	Illness Perception	How easy is it for you to move around independently?
Question 6	Managing Illness	How do you manage symptoms when they are tough to handle?
Question 7	Managing Illness	What does being healthy mean to you?
Question 8	Coping Methods	What kind of support would be helpful for you to feel better? A. Do you have people in your life you can talk to when you need support?
Question 9	Coping Methods	Do you believe it is important to talk about your condition with other people? (E.g. medical and non-medical people)
Question 10	Coping Methods	How do you feel on days you have a lot of pain?
Question 11	Coping Methods	How do you act on those days?
Question 12	Mental Health	Are there ever times you feel angry/frustrated because of your condition?
Question 13	Mental Health	Do you believe your condition has an impact on the way you think or act?
Question 14	Mental Health	When you picture your future, what does it look like?
Question 15	Spirituality	Do you have religious or spiritual beliefs? A. Do you feel those beliefs help you manage your condition?
Question 16	Social Relationships	How would you describe your social life?

Question 17	Social Relationships	Do you get along well with others?
Question 18	Social Relationships	Do you have any difficulty keeping up with people your age? A. Does your physical condition ever limit you from being social?
Question 19	Social Relationships	Do you feel you are supported through your family, friends, or other community groups?
Question 20	Work/School	Do you ever have to miss school or work because of your condition? *(E.g. because you are not feeling well or have a doctor's appointment)* A. Do you have trouble keeping up with your school work/ work?
Question 21	Environment	Is there anything about your school or work environment that you think can be improved to help you?
Question 22	Environment	Do you feel your community offers you enough opportunities to participate in recreational activities? (e.g. Sports, clubs)
Question 23	Environment	Do you have any hobbies/activities that you enjoy doing?

Note. All interviews began with question 1. After question 1, the sequence of the questions was determined based on the response given by the participant. A question from each research topic was asked, but not all 23 questions were asked.

Appendix B - Recruitment Advertisement Email to Participants

Subject: Volunteers need for research study!

Text of email:

Kia Ora! My name is Romina and I am looking for volunteers to participate in a study about the experience of living with a neuromuscular condition.

This study involves a confidential Skype interview (around 40 to 60 minutes in length). We will talk about topics related to the quality of life and mental health of young people who live with neuromuscular conditions.

The purpose of this interview is to hear from you what it's like to live with a neuromuscular condition. There are no right or wrong answers – I'm interested in hearing your thoughts!

You might be eligible to participate if you are:

- Between 16 to 24 years old
- Someone who lives with a progressive neuromuscular condition
- An English speaker

FYI: Participants will receive a 'thank you' voucher for volunteering their time.

Are you interested in participating? Please contact Romina at romina.gfellerdarosa.1@uni.massey.ac.nz to express interest in being a part of this study.

Appendix C – Participant Information Sheet

School of Psychology
Private Bag 102904, North Shore, Auckland 0745
T: 0800 627 739
www.massey.ac.nz

Experiences of Adolescents and Young Adults with Progressive Neuromuscular Conditions: Quality of Life & Mental Health

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Participant Information Sheet

Kia Ora! My name is Romina and I am a psychology student at Massey University. I began volunteering at the Muscular Dystrophy Association of New Zealand (MDANZ) when I was an undergraduate student. During my time at MDANZ, I have had the opportunity to meet individuals with who live with progressive neuromuscular conditions (PNMC) that I would have not otherwise met. I am conducting a research project focused on understanding the impact of PNMCs. This research is based on the question: *how do adolescents and young adults with a progressive neuromuscular condition perceive and manage the impact their condition has on their quality of life?* To break that question down into smaller bits, the main aim of my research is to have participants describe, in their own words, what their day to day lives are like and how living with their condition has shaped their lives, thoughts and feelings.

I am looking to recruit 6 to 8 participants, between the ages of 16 to 24 years. To be eligible to participate in this study you must, (a) have been diagnosed with a progressive neuromuscular disorder for at least 6 months and (b) be a fluent English speaker. Additionally, you must have someone with you on the day of the interview (e.g. your whānau, support person, caregiver). It is up to you whether this person is present in the room with you during the interview.

Participation is completely voluntary and involves taking part in a one-off interview of approximately 40 to 60 minutes, that will be audio recorded. The interview will be relaxed and informal, as we discuss questions. Your identity will be kept anonymous, and no participant will be identified in any reports or presentations resulting from this study. You can withdraw from the study at any point up until two weeks after their interview, in which case your audio recording and signed consent form will be destroyed. If you wish to withdraw you do not need to provide a reason for this.

As a participant, you have the right to:

- Decline to answer any particular question
- Stop the interview at any time
- Ask any questions about the study at any time during participation
- Provide information on the understanding that your name or any identifying information about you will not be used in any reporting of the project
- To be given access to a summary of the project findings when it is concluded.

Privacy and Confidentiality

At no point will your full identity be revealed to anyone else. Confidentiality between the participant and myself (and whānau/support person if present) will only be broken if the participant tells me of abuse, suicide or serious life-threatening self-harm is disclosed, and following discussion with my supervisor.

Respect for your privacy will be followed. You can choose to remain anonymous throughout the study, and if excerpts of dialogue are used, your name or any other identifying information will not be used. The data gained from the interview will be stored electronically, along with all other study materials, on a password protected computer, and on Massey's secure file server. When the study has been completed, the data will be archived by the study supervisor.

Koha

You will have the option of selecting a $25 mobile top up, an iTunes gift card, or Google Play gift card as a 'thank you' for your participation.

Project Contacts and Questions

Please feel free to contact me directly if you have any questions about this study, want to know more about your rights as a participant, or have any concerns.

Alternatively, you can contact my supervisor, John Fitzgerald.

Researcher:
Romina Gfeller
Email:
romina.gfellerdarosa.1@uni.massey.ac.nz

Supervisor:
John Fitzgerald PhD
Senior Lecturer in Clinical Psychology
Phone: (04) 801 5799 extn: 63620
Email: j.m.fitzgerald1@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/28. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Chair) Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz.

Appendix D – Support Person Information Sheet

School of Psychology
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Experiences of Adolescents and Young Adults with Progressive Neuromuscular Conditions: Quality of Life & Mental Health

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Whānau/Support Person Information Sheet

Kia Ora! My name is Romina and I am a psychology student at Massey University. I began volunteering at the Muscular Dystrophy Association of New Zealand (MDANZ) when I was an undergraduate student. During my time at MDANZ, I have had the opportunity to meet individuals with who live with progressive neuromuscular conditions (PNMC) that I would have not otherwise met. I am conducting a research project focused on understanding the impact of PNMCs. This research is based on the question: *how do adolescents and young adults with a progressive neuromuscular condition perceive and manage the impact their condition has on their quality of life?* To break that question down into smaller bits, the main aim of my research is to have participants describe, in their own words, what their day to day lives are like and how living with their condition has shaped their lives, thoughts and feelings.

I am looking to recruit 6 to 8 participants, between the ages of 16 to 24 years. To be eligible to participate in this study participants must, (a) have been diagnosed with a progressive neuromuscular disorder for at least 6 months and (b) be a fluent English speaker. Additionally, participants must have someone with them on the day of the interview (e.g. whānau, support person, caregiver). It is up to the participant whether this person (i.e. you) is present in the room during the interview.

Your participation is completely voluntary and involves providing support to the participant during their interview. This means that you may be present during the interview, and you may contribute your thoughts during the interview, but all questions will be directed to the participant. The one-off interview will last approximately 40 to 60 minutes and will be audio recorded. The interview will be relaxed and informal. All identities will be kept anonymous, and no one will be identified in any reports or presentations resulting from this study. You can withdraw from the study at any point up until two weeks after their interview, in which case your audio recording and signed consent form will be destroyed. If you wish to withdraw you do not need to provide a reason for this.

As a support person to the participant, you have the right to:

- Decline to answer any particular question
- Ask any questions about the study at any time during participation

- Provide information on the understanding that your name or any identifying information about you will not be used in any reporting of the project
- Be given access to a summary of the project findings when it is concluded.

Privacy and Confidentiality

At no point will your full identity be revealed to anyone else. Confidentiality only be breached if you or the participant discloses information of abuse, suicide or serious life-threatening self-harm is disclosed, and following discussion with my supervisor.

Respect for your privacy will be followed. You can choose to remain anonymous throughout the study, and if excerpts of dialogue are used, your name or any other identifying information will not be used. The data gained from the interview will be stored electronically, along with all other study materials, on a password protected computer, and on Massey's secure file server. When the study has been completed, the data will be archived by the study supervisor.

Project Contacts and Questions

Please feel free to contact me directly if you have any questions about this study, want to know more about your rights as a participant, or have any concerns.

Alternatively, you can contact my supervisor, John Fitzgerald.

Researcher:
Romina Gfeller
Email:
romina.gfellerdarosa.1@uni.massey.ac.nz

Supervisor:
John Fitzgerald PhD
Senior Lecturer in Clinical Psychology
Phone: (04) 801 5799 extn: 63620
Email: j.m.fitzgerald1@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/28. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Chair) Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz.

Appendix E – Interview Procedure: Script and Demographic Questions

1. Greet and introduce myself to the participant *(and if applicable, support person)* and thank them for volunteering their time to take part in this research study.
2. By this stage, participants *(and if applicable, support person)* will have read the information sheet, will have signed and sent back the consent form. I will read the information sheet to them, and allow them to ask any questions.
3. If participant chooses to conduct interview alone: I will ask to briefly speak to their caregiver.
    a. This is done to confirm caregiver is in the same vicinity as the participant, and that they will be available for support if the participant should need it.
    b. Inform the caregiver: "It is very important for you not to be in the room during the interview due to confidentiality, but it is important for you to be in the house. If the interview is cut short because [participant] does not want to continue, I will ask [participant] to ask you to come into the room so we can have a quick chat to debrief before we end the skype call."
4. Inform caregiver the interview will last around 40 to 60 minutes, and they are welcomed to enter the room once interview is over. Politely ask caregiver to leave the room.

Script read to participants:

'To give you an idea of how the interview will go, we will break the interview down into two parts. In the first part I will ask you some basic demographic questions. In the second part, I will ask you questions about your opinion on living with a neuromuscular condition. I will ask you a few questions on your personal experience living with a neuromuscular condition. There are no right or wrong answers. Please don't feel rushed to answer a question, and if at any time you get stuck or don't want to answer something, we can move on. Once we finished the questions, we'll have a chance to debrief. You can ask me any questions, or clarify anything you want. Whenever you're ready we can get started.'

Demographic Questions

Sequence	Question
Question 1	**How old are you?**
Question 2	**Do you go to school and/or work?** A. School: What year are you in? B. Work: What sort of work do you do?
Question 3	**What are your living arrangements?** For example, who do you live with?
Question 4	**Do you mind telling me what your primary diagnosis is?** A. At what age did you receive this diagnosis? OR How long have you been living with this diagnosis?
Question 5	**What's your ethnicity?** *(Prompt: For example, do you identify as European, Māori, Asian, Pacific peoples, Middle Eastern, Latin American, African?)*
Question 6	**What is your gender?** *(Prompt: Do you identify as male, female, neither, both or somewhere in between?)*

Note. Prompts are in place in case the participant asks for clarification on the question or does not know how to answer.

Appendix F – Human Ethics Committee Approval

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 30 July 2018

Dear Romina Gfeller

Re: Ethics Notification - **NOR 18/28 - Experiences of Adolescents and Young Adults with Progressive Neuromuscular Conditions: Quality of Life and Mental Health**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Northern Committee** at their meeting held on **Monday, 30 July, 2018**.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Associate Professor Tracy Riley, Dean Research
Acting Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
E humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz

Appendix G – Post Interview Information Sheet

Do you need to talk to someone?

Although unlikely it is possible that some of the topics discussed today may be difficult to think about, and have raised some feelings for you. I would like to remind you that there are a number of services you can access for support.

In case of an emergency call 111 or go to the emergency department of the hospital

MDANZ Counselling Service

Counselling service is a service offered to MDANZ Members. As an MDANZ member, you are able to receive counselling sessions. Sessions are free and confidential.

For more information, check out the MDANZ website:
http://mda.org.nz/What-we-Offer/Counselling-Service

➔ Lifeline Aotearoa

Phone counselling service that provides 24/7 counselling and support.

Lifeline 24/7: 0800 543 354
TAUTOKO Suicide Crisis Line: 0508 828 865
Website: www.lifeline.org.nz

➔ Healthline

Open 24/7. Phone calls are free from within New Zealand.

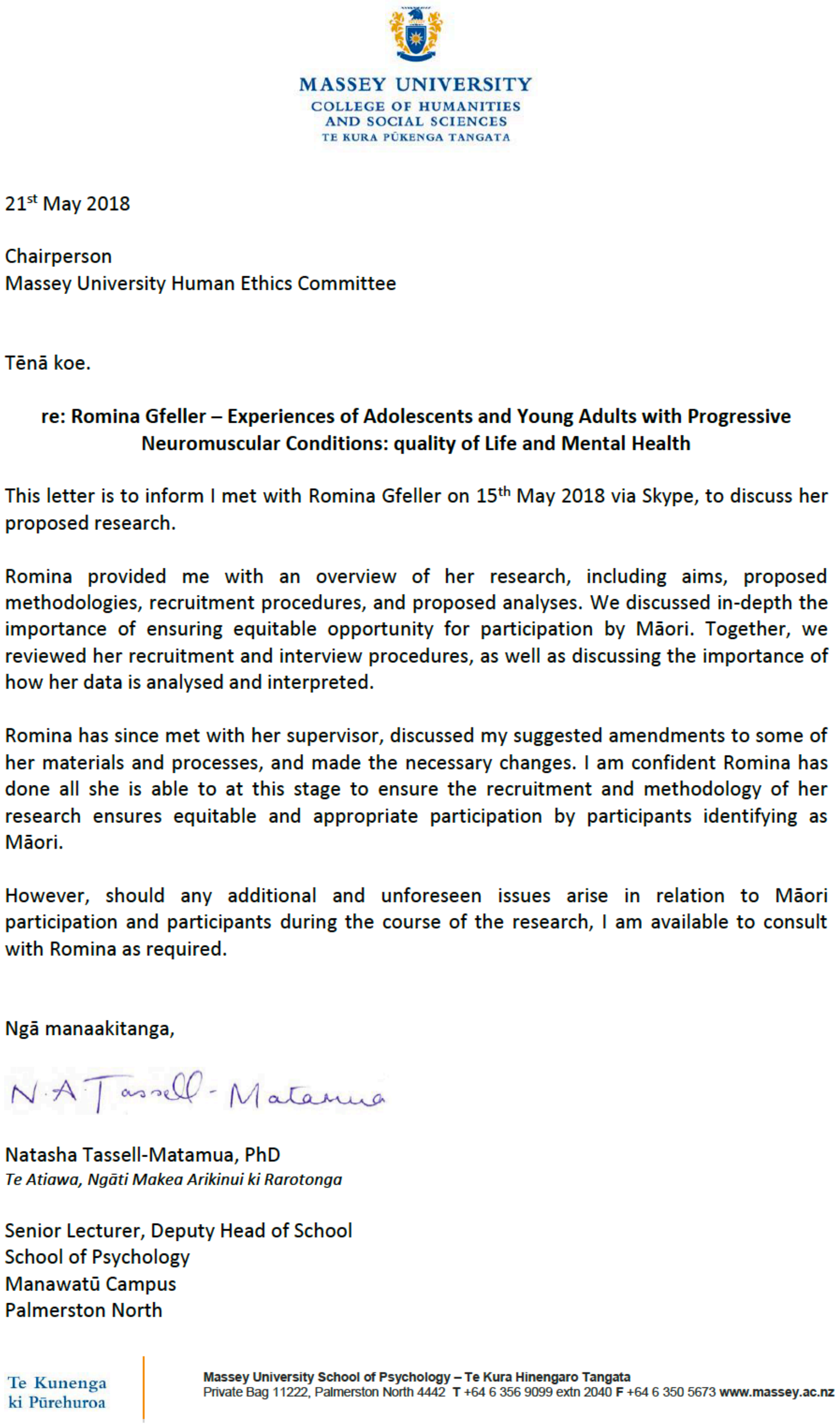
Phone: 0800 611 116

➔ Youthline

Youthline is a service available to all individuals who wish to talk. This can be anything from just wanting to talk something through (big or small) via TXT, email or phone.

Phone: 0800 376 633
Free Txt: 234
Online Chat: http://www.youthline.co.nz/
Email: talk@youthline.co.nz

Appendix H – Cultural Consolation



MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

21st May 2018

Chairperson
Massey University Human Ethics Committee

Tēnā koe.

re: Romina Gfeller – Experiences of Adolescents and Young Adults with Progressive Neuromuscular Conditions: quality of Life and Mental Health

This letter is to inform I met with Romina Gfeller on 15th May 2018 via Skype, to discuss her proposed research.

Romina provided me with an overview of her research, including aims, proposed methodologies, recruitment procedures, and proposed analyses. We discussed in-depth the importance of ensuring equitable opportunity for participation by Māori. Together, we reviewed her recruitment and interview procedures, as well as discussing the importance of how her data is analysed and interpreted.

Romina has since met with her supervisor, discussed my suggested amendments to some of her materials and processes, and made the necessary changes. I am confident Romina has done all she is able to at this stage to ensure the recruitment and methodology of her research ensures equitable and appropriate participation by participants identifying as Māori.

However, should any additional and unforeseen issues arise in relation to Māori participation and participants during the course of the research, I am available to consult with Romina as required.

Ngā manaakitanga,

N.A Tassell-Matamua

Natasha Tassell-Matamua, PhD
Te Atiawa, Ngāti Makea Arikinui ki Rarotonga

Senior Lecturer, Deputy Head of School
School of Psychology
Manawatū Campus
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Te Kunenga
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Appendix I – MDANZ Letter of Support

Muscular Dystrophy
New Zealand

23 April 2018

To whom it may concern

Re; Masters research proposal – Romina Gfeller

This letter is to verify our organisation's support for the research project proposed by Romina Gfeller entitled *Experiences of Adolescents and Young Adults with Progressive Neuromuscular Conditions: Quality of Life & Mental Health*.

The Muscular Dystrophy Association of New Zealand (MDANZ) is a member-led New Zealand not for profit organisation that provides information and practical support to individuals and families affected by progressive neuromuscular conditions. We have four regional branches throughout the country that are supported by the National Office based in Auckland. We also have a research arm that funds local research and helps to link New Zealanders with clinical trials happening both here and overseas.

Romina Gfeller has consulted with us regarding her research project and we support this research as an opportunity for young people to voice their experiences and to identify the strengths and supports that contribute to improved quality of life and health outcomes. During the scoping phase of this project, we have provided advice based on our personal knowledge, experience and expertise in the neuromuscular field. Additionally, we have agreed to support the recruitment of potential participants by disseminating information through our networks.

We understand that this research will meet ethical principles, that participant involvement in this study is strictly voluntary and that Romina will meet required standards for privacy and confidentiality of research data. We are therefore confident to offer our support to Romina Gfeller's research project and agree to act as a resource and to provide peer review and advice throughout the implementation of her research, if requested.

Nga mihi

Ronelle Baker
Chief Executive

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Charity Registration Number CC31123