Testing the Theory of Self-Determination as a predictor of quality of life in neurological conditions in long-term care

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Abstract

Self-determination theory (SDT; Deci & Ryan, 2008; Ryan & Deci, 2017) provides a framework for intervention development by setting out a comprehensive approach to motivation and health behaviour through its theory and measurement of autonomy, perceived competence and relatedness to others (Deci and Ryan, 1985), whilst also considering the influential role of social context and how this supports or debilitates motivation. SDT has been applied across a number of different health care settings. However, to date there is little existing research that investigates the application of SDT to those with neurological conditions. There is also limited research that looks at the application of SDT within long-term health care settings, but rather the current literature focuses on acute or outpatient settings.

The key aim of this research is to therefore test the applicableness of the SDT to those with neurological conditions, residing in long-term care settings. To address this gap in literature, a mixed-methods design has been implemented to first quantitatively test the theory of self-determination and then to qualitatively explore the lived experiences of such individuals, in order to gain an understanding of how to support the basic psychological needs of such individuals. For the first phase of data collection (quantitative), fifty-four participants (25 female, 29 male) with neurological conditions, living in long-term care completed SDT and QoL questionnaires. A multiple regression analysis was then ran to establish whether SDT predicts QoL in neurological conditions. Whilst overall, the three key constructs (autonomy, relatedness and competence) did not significantly predict QoL, autonomy was found to be the biggest predictor of QoL.

To explore these results further, in-depth semi-structured interviews were carried out with five participants (1 female, 4 male). Using Interpretative Phenomenological Analysis (IPA), three themes were generated, 1) Living with a neurological condition; 2) What autonomy means to me; 3) Life as a permanent resident. The qualitative results support SDT research and highlight an importance of autonomy-supportive contexts and health care approaches. The results also indicate a need for competence and relatedness to maintain wellbeing and caregivers require training to support these needs adequately. What also became apparent within this research is that an environment can be more disabling than a physical condition and that autonomy becomes more important, as one’s sense of autonomy reduces. As such, research in the future should consider ways to support feelings of autonomy, competence and relatedness of those with neurological conditions residing in long-term care.

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Covid-19 statement;

During the completion of this doctoral thesis, data collection for both phases occurred during the Covid-19 global pandemic. Whilst the engagement with this research was sustained and remained within predicted timeframes, a number of unprecedented challenges were faced. These will be discussed in more detail within this thesis.

Key Researcher;

The key researcher of this study has worked to support those with neurological conditions, residing in long-term care settings for over 5 years. This applied experience led to the initial question posed for this piece of research; how do we best support those with neurological conditions to achieve quality of life and how do we maintain this? The maintenance part is particularly important when working with those who have degenerative conditions and those who are reliant on 24-hour care.

As discussed in the literature review, there is a plethora of good quality research surrounding the theory of self-determination as a predictor of quality of life and improved wellbeing in health outcome measures. This, and the key considerations of this theory; the social context and the three basic needs for autonomy, competence and relatedness which are needed in order to yield quality of life is why this theory has been chosen. As the theory of self-determination has been found to predict quality of life in a number of different health care settings, it felt pertinent to apply it to a setting supporting those who are physically limited in a number of different ways by their own physical condition to meet these three basic needs. It was felt by the key researcher that the main parts of the SDT are the three key areas that are changed and limited by neurological conditions, for example, one's competency to complete tasks can be changed by the physical limitations of a neurological condition. One's autonomy is threatened by the lack of control over the condition and increased reliance on others and undoubtedly key relationships can change for those with neurological conditions.It was therefore the key researcher's personal perspective and experience of working within neurorehabilitation and supporting those whose basic needs are constantly threatened that motivated this research.

Due to the key researcher's professional working role within the long-term care centre involved in this study, this research could be carried out during the Covid-19 pandemic with minor adjustments made to adhere to health and safety measures.

Chapter 1: Literature review

1.1. Self-Determination Theory

Self-Determination Theory (SDT; Deci & Ryan, 2008; Ryan & Deci, 2017) represents a broad framework for the study of human motivation and personality, and is centrally concerned with the social conditions that facilitate or hinder human flourishing.

Firstly, SDT provides a theory that defines internal and external sources of motivation and describes how these different types and roles of motivation can impact behaviour. SDT propose a motivational continuum whereby *external* motivations, such as engaging in a behaviour to gain a reward, are the least internalised form of regulation and as such, the least effective in changing behaviour. *Introjected* regulation is the next most internalised form of regulation and involves engaging in a behaviour because an individual feels obliged to or out of a sense of guilt. *Identified* regulation (the first level of autonomous regulation) involves an individual engaging in a behaviour that is important to them. The most internalised form of motivation is *integrated* regulations which are motives for behaviour that are consistent with an individual's goals and beliefs and thus, behaviour change is more effective and lasting (Ng et al, 2012). Establishing what conditions promote integrated regulations is therefore key for effective behaviour change interventions.

Secondly, SDT proposes a set of core basic psychological needs; autonomy, competence and relatedness that are essential for human flourishing and well-being (Ryan & Deci, 2017). Ideally, all three psychological needs are satisfied to foster the process of internalisation and integrated regulations, if one of the needs is frustrated, internalisation for motivation of a behaviour is hampered (Milyasvkaya et al, 2014). The satisfaction of these three needs has been found to foster the most volitional and effective forms of motivation and engagement resulting in enhanced performance of a behaviour, persistency and creativity (Ng et al, 2012). The satisfaction of these needs has also shown to be essential for wellness, both developmentally (Grolnick et al. 1991) and situationally (Reis et al. 2000). Autonomy, competence and relatedness each uniquely but also in interactive ways (Kluwer et al. 2019) have been found to be essential for individuals' wellbeing across ages, contexts, and cultures (Ryan & Deci, 2017).

In addition to the above considerations for effective behaviour change, SDT also considers the influence of the social context and how the environment can either facilitate or undermine an individual's sense of choice and initiative, wellbeing and subsequently the quality in their performance of a certain behaviour. Conditions that support the core basic psychological needs can encourage autonomous regulation and lead to improved mental and physical health, as well as leading to more-conducive health behaviours (Ryan, 1995; Deci & Ryan, 2008). The degree to which any of these three psychological needs is unsupported within a social context will have a robust detrimental impact on wellness within that setting (Ryan & Deci, 2017).

SDT is therefore key in understanding the effectiveness and maintenance of health behaviour change (Kwasnicka, Dombrowski, White & Sneihotta, 2016), by providing a comprehensive approach to motivation and behaviour through its theory and measurement of autonomy, perceived competence and relatedness (Deci & Ryan, 1985; Fortier, Sweet, O'Sullivan & Williams, 2007; Halvari & Halvari, 2006) and its consideration of social contexts. As such, SDT provides a framework for interventions by highlighting features of contexts that facilitate or hinder the motivations and satisfactions underlying effective self-regulation and wellbeing. By establishing various types of motivational regulation and the conditions that promote them, SDT can be applied and transferred across a number of social contexts.

Within the framework of SDT there are six mini-theories; including the development and maintenance of intrinsic motivation (Cognitive Evaluation Theory), the gradual endorsement of externally offered regulations, norms and attitudes (Organismic Evaluation Theory), the study of personality differences (Causality Orientation Theory), life aspirations (Goal Content Theory), healthy and mature relationships (Relationship Motivation Theory), and finally the psychological need for autonomy, competence and relatedness (Basic Psychological Need Theory).

The three basic psychological needs discussed above within the latter mini-theory, the Basic Psychological Need Theory (BPNT), help to connect the different phenomena that are studied within the other mini-theories. As such, the BPNT is described as being the necessary 'glue' between the mini-theories, to bring it all together under the umbrella of the SDT framework (Ryan & Deci, 2017). For the purpose of this research, the BNPT as an integral part of the SDT framework will be discussed further.

1.1.1. Basic Psychological Needs

As mentioned above, SDT proposes a core set of basic psychological needs; autonomy, relatedness and competence, derived from the BPNT. The term basic psychological need is defined as *'a psychological nutrient that is essential for individuals' adjustment, integrity, and growth'* (Ryan, 1995). Within the BPNT, the satisfaction of autonomy, competence and relatedness is said to be essential for a person's wellbeing. A dissatisfaction of such needs leads to increased risks of passivity, ill-being, and defensiveness (Ryan & Deci, 2000; Vansteenkiste & Ryan, 2013). Some people may fall into submissive or fragmented ways of functioning, others may attempt to compensate for the loss of these needs with negative health behaviours such as addiction or aggression (Deci & Ryan, 2008; Ryan & Deci, 2017).

Deci and Ryan (2000) formally identified these three needs as basic psychological needs, arguing that support for and satisfaction of these needs accounts for a broad range of phenomena across developmental periods, cultures, and individual differences. Abundant research supports the notion of these three basic psychological needs, highlighting the prominent role they play in development, adjustment, and wellness across cultures (Ng et al. 2012; Slemp et al. 2018; Van den Broeck et al. 2016; Vasquez et al. 2016; Yu et al. 2018), with strong implications for applied practices (Ryan & Deci, 2017).

Autonomy, or the need to self-regulate one's experiences and actions, is described as a form of functioning that is associated with feeling a sense of freedom and volition (de Charms, 1968; Ryan, 1995). Autonomy is that one's behaviours are self-endorsed, or congruent with one's interest and values. SDT view only some intentional actions as autonomous with others regulated by external factors. As such, an individual may behave without a sense of autonomy of his or her actions.

Competence is a well-studied concept in psychology and is widely recognised as a key factor of motivation (Bandura, 1996; Deci, 1975; Harter, 2012; White, 1959). In SDT, competence refers to our basic human need to feel effectance (the impact of overcoming a difficult task that was done well) and mastery. It is said to promote behaviours across a range of different situations and contexts. However, in contexts in which challenges are too difficult, feelings of effectance and mastery are hindered (Ryan & Deci, 2017).

Relatedness refers to feeling socially connected to others (Bowlby, 1979; Baumeister & Leary, 1995; Ryan, 1995). Relatedness is about feeling cared for by others, as well as feeling a sense of belonging and a sense of significance among others (Deci & Ryan, 2014). By feeling close to others and by being a significant member of social groups, relatedness and belonging are experienced.

The satisfaction of all three needs has shown to be essential to psychological health and the development of internalised motivation, and as such, facilitating and maintaining effective behaviour change (Patrick & Williams, 2012). For example, if we use engagement in exercise as a potential health behaviour change, ones' experiences of competence will vary upon success or failure of the physical task or as a function of feedback from a fitness professional. Perceptions of personal connection (relatedness) with others (e.g., fellow gym goers) can vary greatly as a function of the interpersonal environment. Feelings of autonomy (vs. feelings of control) differ as a function of communication styles within the exercise setting or freedom of choice around task.

As shown within the example, the need fulfilment is closely associated with the social context and whether important others support the needs for autonomy (e.g., take the perspective of the client/patient, support their choices, minimize pressure), relatedness (e.g., create an empathetic and positive environment, show unconditional regard), and competence (e.g., limit negative feedback, provide optimally challenging tasks).

Social Context

SDT characterize the social context or environment in terms of the extent to which they are; autonomy supportive (versus controlling), competence supporting (versus overly challenging), relationally supportive (versus rejecting). Autonomy supportive environments encourage choice and self-regulation. Provisions of structure and positive feedback encourage competence supportive environments and relatedness supportive environments include the caring involvement of others (Ryan & Deci, 2017). Such environments will maintain or enhance internal, autonomously-regulated motivation. Conversely, social contexts that engender perceptions of control or are externally regulated via means such as surveillance, negative feedback or strict deadlines are likely to induce external motivations. For example, engaging in a behaviour to gain a reward. According to SDT this is the least internalised form of regulation and as such, the least effective in changing behaviour (Ryan & Deci, 2017).

Aspects of a social context that are likely to support satisfaction of the three fundamental needs are predicted to promote effective high-quality functioning and wellbeing, whereas aspects of a social context that are unlikely to support these basic needs are predicted to diminish and hinder effective behavioural functioning (Deci & Ryan, 2008; Ryan & Deci, 2017; Joussemet et al, 2008). Therefore, the extent to which an individual requires support from a social context (for example, within a care home environment) can be largely predictive of how autonomously-regulated and motivated an individual is toward a given behaviour.

1.1.2. SDT within the Health Domain

SDT and the needs-based approach has been successfully applied to various different domains such as education; to support a motivating teaching approach (Reeve & Cheon, 2021; Ryan & Deci, 2020; Jang, Kim & Reeve, 2012), work, to promote effective performance and support work place satisfaction (Gagne & Deci, 2005), and sport to improve persistence and reduce drop out from commitments such as training groups (Calvo et al, 2010).

In order to demonstrate a critical understanding of the theory of self-determination within the field of health care, relevant to this study, the following section with review previous and current literature focusing on SDT within the health domain.

There is strong evidence for the efficacy of interventions based on SDT across a wide range of health domains (Ntoumanis et al, 2021; Gillison, Rouse, Standage, Sebire & Ryan, 2019; Pelletier & Sharp, 2008). Within health SDT argues that developing a sense of autonomy, competence and relatedness are critical to the processes of internalization and integration, through which a person comes to self-regulate and sustain behaviours conducive to health and wellbeing. Thus, treatment environments that afford autonomy, support confidence are entrusted are likely to enhance adherence and health outcomes (Ryan, Patrick, Deci & Williams, 2008).

Interestingly, when considering the needs-based approach, within healthcare there is a tendency for much of the research to place a greater emphasis or focus on autonomy support and its impact on adaptive self-regulated behaviours. When considering the BPNT, it is reasonable to assume that in order to maintain autonomous self-regulated behaviours the need for competence and relatedness has also been met, even when it is not the main focus of the literature. For example, Williams, Rodin, Ryan, Grolnick, and Deci (1998) completed a study into autonomous regulation and long-term medication adherence in adult outpatients. They found that perceived autonomy support was associated with adherence, and its effects were mediated through autonomous regulation. Previous research has also shown that regulation becomes more autonomous when healthcare providers and treatment programmes are autonomy supportive (Curry, Wagner, & Grothaus, 1991; Deci et al, 1994; Williams & Deci, 1996; Williams, Grow, et al, 1996). This is important because of its implications for much-needed interventions to improve adherence (Haynes et al, 1996).

In addition, Williams, Niemiec, Patrick, Ryan and Deci (2009), conducted a randomised controlled trial focusing on autonomous support and found positive associations between an increase in autonomous self-regulation, abstinence from tobacco, and adherence to medication. Similar results have also been found in studies of diabetes management using a guided self-determination intervention that increased perceived autonomy support from health care professionals, increased the frequency of self-monitored blood glucose, which led to an increased perceived competence in managing diabetes that overall decreased diabetes-related distress and ultimately improved glycaemic control (Ng et al, 2012; Williams, Gagne, Ryan & Deci, 2002; Williams, McGregor, Zeldman, Freedman, & Deci, 2004). Silva et al. (2011) also found that autonomous self-regulation for exercise directly predicted moderate and vigorous physical activity as well as reduction in body weight. Accordingly, substantial research into SDT confirms that health care interventions implemented in an autonomy-supportive way increases the likelihood of positive outcomes (Ng et al, 2012). As such, suggesting that health interventions should focus on supporting patients' autonomy to enhance autonomous regulation, which in turn would be expected to improve adherence and health outcomes. This is an applicable finding to health care as other studies have also demonstrated that health care practitioners can be taught to be supportive of autonomy.

Experimental field studies and clinical trials (Fortier, Sweet, O'Sullivan & Williams, 2007; Niemiec, Ryan, Deci & Williams, 2009) have trained health care professionals to support the patients' basic psychological needs. Training that supports autonomy involves techniques such as ensuring that consideration is made for the perspective of the patient, choices are provided and facilitated and patient choice is respected, even if the choice is seen as 'unwise' (Williams & Deci, 2001; Williams et al, 2006). Practitioners may also provide relevant information and meaningful rationales for change, without applying external controls and pressures, whilst supporting patients as they explore resistances and barriers to change, and helping them identify congruent pathways to healthier behaviours (Ryan, Patrick, Deci & Williams, 2008). Practitioners can promote competence by providing the patient with skills and tools for change, without over challenging the patient but rather setting realistic goals to support the mastery of health behaviour change. To ensure an effective patient-practitioner relationship, and promote a sense of relatedness, practitioners need to provide the patient with a sense of being respected, understood and cared for (Ryan, Patrick, Deci & Williams, 2008). In training health care professions to support these needs, significant changes in behavioural adherence, motivation and wellbeing have been observed. Posttreatment follow-up periods in such studies extended up to 24 months with behaviour change generally having been sustained, and the long-term effects of the intervention supported. These such studies using an SDT-based model of health behaviour change highlight how the SDT constructs interrelate and can predict outcomes of mental and physical health (Ryan, Patrick, Deci & Williams, 2008).

This is evidenced further by Halvari et al. (2010) who adopted an SDT based approach to explore how motivation improves dental outcomes. They found that the satisfaction of psychological needs via the promotion and facilitation of self-care, choice and the approach of the dental hygienist was related to positive behaviour change toward dental health and attendance at dental clinics. Edmunds et al. (2007) also found that the satisfaction of the three psychological needs, with practitioners using similar techniques to those mentioned above, was associated with life satisfaction, positive affect and levels of adherence to exercise among obese individuals referred to an exercise programme. When a patient's psychological needs are supported, participation in treatment is likely to be more self-determined, meaning that it is driven by valued benefits and a willingness to participate, and long-term adherence is more likely.

In contrast, a controlling health care environment can hinder people’s need satisfaction by using external regulations such as tangible rewards or pressure to attempt to motivate and move the patient toward a specific outcome (Ryan & Deci, 2000). For example, for an individual who is residing in a care home and fully reliant on others to mobilise and move around the building, might engage in a physiotherapy session under the premise that they can then be supported with accessing the community. Or, an individual may feel obliged to attend a ‘bingo night’ in order to please the staff member running the event despite not actually wanting to go. Such controlled regulation for behaviour change concerns regulations reflecting a lower level of perceived autonomy and includes introjected regulation (motivation reflecting internal pressures such as contingent self-worth, guilt, shame, and feelings of approval) and external regulation (motivation to comply with external pressures or rewards). All of which are largely unrelated to long-term behaviour change and adherence (Ryan, Patrick, Deci & Williams, 2008).

Moreover, a practitioner who adopts a paternalistic style of care would oppose that of a practitioner using the self-determinism patient choice approach described above. There is, unfortunately, evidence that some health care practitioners still adopt a paternalistic model of patient care, over a SDT model (Murray et al. 2015; Braddock at al. 1999; Pelto-Piri, Engstrom & Engstrom, 2013). Medical paternalism is a set of attitudes and practices in medicine in which the practitioner determines that a patients' wishes or choices should not be honoured (Gillon, 1985), and as such, all sense of autonomy is lost. The practitioner chooses to act in a way that they believe is in the best interests of their patient, without consideration for the patients' own choice, values or beliefs. As previously mentioned, when the basic psychological needs are not fulfilled, patients' motivations for behaviour change do not become internalised and the likelihood of people engaging in behaviours over time is poor. It therefore seems reasonable to assume that the paternalistic approach may not always be effective in maintaining health behaviour change. In fact, evidence suggests that the frustration of the basic needs, such as not considering the patients' own choice, could be harmful to an individual and lead to an increased risk of ill-being and negative health behaviours such as addiction and aggression (Deci & Ryan, 2008; Ryan & Deci, 2017).

From reviewing previous and current research of the application of SDT within the health care domain, a vast amount of evidence supports the BPNT that satisfaction of the three basic psychological needs leads to improved mental health (e.g. lower depression, anxiety, and higher quality of life), as well as more-conducive behaviours and improved physical health (diabetes management, tobacco cessation, exercise, healthier diet etc.) (Edmunds et al., 2007; Ng et al, 2012; Williams, Gagne, Ryan & Deci, 2002; Williams, McGregor, Zeldman, Freedman, & Deci, 2004; Silva et al. 2011). The SDT model identifies the contextual and individual factors that optimise these outcomes and these factors seem to be an autonomy-supportive health care climate (e.g. taking the perspectives of patients, providing choices; Markland & Tobin, 2010; Williams, 2002); autonomous self-regulation and internalised motivation towards behaviour change. As such, the effectiveness of interventions can be somewhat predicted by the degree to which the intervention supports the basic psychological needs for both children (Ziviani & Poulson, 2015) and adults (Zuroff et al, 2012).

Whilst the SDT model has shown to be transferrable across a number of domains, health conditions and ages, to date there is no current research that looks into the applicability of the SDT within a long-term or a permanent health care setting. Instead, the focus has been on acute settings or outpatient health care settings. Ensuring a supportive healthcare environment within a long-term care setting is arguably one of the most influential factors to improving wellbeing and quality of life for its service users and it is surprising to see a lack of focus within this domain across the SDT research. In addition to this, there has been no research completed into the applicability of the BPNT on neurological conditions despite the well documented, substantial mental and physical health problems arising from these conditions. Furthermore, it could be argued that most neurological conditions threaten the basic psychological needs of autonomy, competence and relatedness, more so than any other health condition.

With this argument in mind, an exploration of these factors will commence from herewithin.

1.2. Psychosocial Consequences of Neurological Conditions

Extensive research has documented the complex and comprehensive psychosocial and physical consequences of neurological conditions such as stroke (Kirkevold, Martinsen, Arnesveen Bronken & Kvinge, 2014); multiple sclerosis (Halper, 2007), brain injury (Gainotti, 1993) and motor neurone disease (Knight & Godfrey, 1996).

The impact of neurological conditions can be extremely debilitating both physically and mentally. The psychosocial impact is massive and can effect individuals in a number of ways. Depressive symptoms; anxiety, general psychological distress, sexual dysfunction, cognitive changes, demoralization, grief associated with loss, reduced self-esteem, reduced self-efficacy, reduced motivation and social isolation are all commonly reported symptoms following a neurological change (Kouwenhoven, Kirkevold, Engedal & Kim, 2011; Hackett, Yapa, Parag & Anderson, 2005; Ferro, Caeiro & Santos, 2009; Campbell Burton et al, 2013; Chang, Mackenzie, Yip & Dhillon, 1999). Evidence shows that the psychosocial factors appear to have, at least, just as much impact on an individuals' life as the physiological consequences (Naess, Nyland, Thomassen, Asrseth & Myhr, 2005; Banks & Pearson, 2004; Roding, Lindstrom, Malm & Ohman, 2003). Such psychosocial difficulties can impede significantly on long-term functioning and engagement in rehabilitation services (Ferro, Caeiro & Santos, 2009), reduce quality of life and lead to higher mortality rates (Hackett, Anderson, House & Haleh, 2008).

To date, research into interventions aimed at preventing and treating psychosocial problems in neurological conditions has had modest results (Knapp & Hewison 1998; Hackett et al. 2008a, 2008b). However research does indicate that practitioners who provide information, emotional support, practical advice and motivational support can be vital in promoting the quality of life of the patient (Forster et al. 2012). Conversely, patients who experience of a lack of control and autonomy over of their situation and condition, have been found to be at a significantly increased risk of reduced wellbeing (Donnellan et al. 2006, Knapp et al. 2000; Barker-Collo 2007, Ferro et al. 2009, Hackett et al. 2008a, 2008b).

Whilst neurological conditions vary significantly, the broad range of conditions fall under two distinct headings; acquired brain injury and progressive conditions. An acquired brain injury can be an instant life altering event and progressive conditions result in a neurodegenerative deterioration in functioning. With most neurological conditions, following onset illness, it is not uncommon for ones' ability to participate in meaningful activities to reduce. This could be as a result of changes to physical, psychological or cognitive function. Meaningful activities are seen as important for ones' wellbeing and quality of life and could be seen as the main goal of rehabilitation (Desrosiers, 2005). In the International Classification of Functioning, Disability and Health (ICF), participation is defined as ones' involvement in a life situation (World Health Organization, 2013). However, there are a number of factors that may also influence ones' ability to be involved in, and to maintain a level of participation within, a life situation.

Participation could therefore be viewed as a combination of what a person can do (abilities - competence), wants to do (choice - autonomy), has the opportunity to do (support from others - relatedness), and is not prevented from doing by the context in which the person lives or seeks to participate (Mallinson & Hammel, 2010). Autonomy implies that people have the right to make their own choices and decide how, when, and where to participate in activities (Cardol et al, 2002). As such, the concepts of participation and autonomy are strongly connected and therefore the reduced ability to complete and participate in a meaningful activity, or an activity of daily living (ADL), as a result of a neurological condition will undoubtedly impact on ones' sense of autonomy, competency and relatedness. What can threaten these basic psychological needs even further, following the onset of illness, is that many neurological conditions are degenerative. As such, ones' abilities to participate within life situations is on a downward trajectory.

This is why it is vital that such individuals receive appropriate, adequate and ongoing support for their health and wellbeing from the onset of diagnosis and onwards. Due to the somewhat unique, and changing status of these conditions it is acknowledged that supporting such individuals can be extremely challenging. It is therefore firstly important that we try to understand the lived experiences of individuals with chronic illnesses.

1.2.1. The Shifting Perspectives Model of Chronic Illness

The Shifting Perspectives Model (Paterson, 2001) gives some insight and explanation of chronically ill individuals' variations in their attention to their illness and their symptoms overtime, of which at times can seem negative, self-destructive and harmful to their health. The model also provides some direction to health professionals support those with chronic illness.

To date, the majority of literature available that focuses on chronic illness describes living with a chronic illness as a phased process with an end goal of acceptance. Some research considers that people may have periods of regression through this process, however most denote that a person has to have lived with the chronic condition long enough to progress through the stages (Paterson, 2001). This does not seem applicable to individuals with degenerative conditions who may never reach the phase of acceptance because they are continually adjusting to new change.

In contrast, the shifting perspectives model of chronic illness (Paterson, 2001) describes living with a chronic illness as an ongoing, continually shifting process, whereby people live in ‘’the dual kingdom of the well and the sick’’ (Donelly, 1993). It takes on the view that people's perspectives of chronic illness determine how they respond to the disease and argues that each perspective contains elements of illness and wellness.

Illness-in-the-foreground perspective is characterised by focusing on the condition, losses and suffering and has a protective/avoidant function. Whipple et al. (1996) provides an example of this function reporting that after spinal cord injuries, women feared sexual pleasure was unattainable, they therefore avoided sexual intimacy. This type of protective/avoidant behaviour can translate to the avoidance of health-related behaviours such as physical exercise (Whipple et al, 1996). For example, people with reduced physical abilities may see physical activity as unattainable, and therefore avoid engaging in it. People with this perspective often experience relationship breakdowns because they tend to be absorbed in their condition and have difficulty attending to the needs of others (Paterson, 2001).

Wellness-in-the-foreground perspective is where the person shifts from ‘’a victim of circumstances to a creator of circumstances’’ (Barroso, 1995). People view the self, not the diseased body as their source of identity. They distance themselves from the condition which allows for a focus on emotional, spiritual and social aspects of life. They attempt to take control of their situation, they increase their own knowledge of their condition and they create supportive environments.

However, threats to control can quickly shift a perspective from a wellness to an illness. An example of certain threats might be signs of disease progression, lack of skill to manage disease and interactions with others that might emphasise dependency and hopelessness. All of which are inevitable in a progressive neurological condition.

Paterson and Sloan (1994) found that individuals diagnosed and living with diabetes often sought practitioners with a wellness-in-the-foreground perspective. A perspective that coincides with the assumptions of self-determination theory around autonomy and control, enabling people to do things for themselves and promoting social interaction. The shifting perspectives model also considers additional factors such as social context that may influence perspectives of chronic illness. For example, it has also been reported that people often assume an illness-in-the-foreground perspective if they receive support from healthcare services (Larson, 1998).

Whilst it may be speculated that this, in part, could be due to the approach of the healthcare service (i.e. paternalistic over SDT), it still indicates that there is an increased risk of adopting an illness-in-the-foreground for those individuals who are reliant on healthcare services to function i.e. those with neurological conditions who permanently reside in a health care setting.

1.3. SDT in a long-term care setting

For those with neurological impairment, particularly progressive conditions, often the level of need can be so high that residing in a 24-hr care home is the only option. The move into a nursing home can bring about a number of changes for an individual. Such as a change in social status and social contacts; reduced volition, altered identity, differing habitual activities and an increased influence of external pressures (Porter & Clinton, 1992). To some degree, an individual is required to adapt to the 'institutionalisation' of processes and routines already imposed within the health care setting (Hwang et al, 2006). When certain decisions are already made, and actions are already imposed, it seems fair to assume that the motivation one may possess within such a setting is introjected and externalised.

As SDT is the only theory of motivation that describes autonomy as a basic human need (Deci & Ryan, 2008), for those individuals residing in a full-time care facility, the threat to a loss of autonomy is significant and well documented (Welford, Murphy, Rodgers & Frauenlob, 2012; Murphy & Welford, 2012; Hillcoat-Nalletamby, 2014; Rodgers & Neville, 2007). As such, the threat to the wellbeing and quality of life of those with neurological conditions, residing in neurorehabilitation centres, must be considered within research moving forward.

The importance of this issue can be emphasised by changes to recent health care legislation which has adopted a new charter that raises the respect for patient autonomy and the elimination of social injustice to the highest level of priority for all practitioners in health care settings (Beauchamp and Childress, 2009; Project of the ABIM Foundation, ACP-ASIM Foundation, & European Federation of Internal Medicine, 2002). This now precedes patient welfare as the previous single-highest priority and means that health care practitioners should support patient autonomy as well as enhancing their welfare. The development of this new health care goal of respecting patients' autonomy (Beauchamp & Childress, 2009), along with rising health care costs associated with poorly maintained health-promoting behaviours, highlights the importance of understanding of supporting autonomy within health care settings and adopting a self-deterministic approach to care. It does however seem important to note that when considering the BPNT, the need for autonomy has once again took precedent within healthcare literature and the above legislation.

As previously discussed current and growing research grounded in SDT does examine the importance of this within certain health care settings to support motivation for health-related behaviours. However, no such study has examined the applicability of SDT framework to those with neurological conditions, arguably some of the most debilitating conditions, within a full time health care facility (neurorehabilitation setting). At present, it is unclear if the BPNT is applicable to this population as a predictor for wellbeing and quality of life for such a sample, and it is currently unclear as to how best to support such individuals. It is without a doubt that such research is vital and could play an essential role in informing clinical practice in the future to improve the health and wellbeing of millions of people.

2. Research Rational

2.1. Research Aims

Key aims: a) to support wellbeing and quality of life for those with neurological conditions, b) to inform clinical practice and future interventions within neurorehabilitation settings, c) to expand the field of health psychology with regards to supporting chronic conditions

In order to create and interpret new knowledge through original research, this study has been designed to address a major deficit in knowledge regarding the support of psychosocial wellbeing for those with neurological conditions, residing in neurorehabilitation care homes, through the application of the Self-Determination Theory. The focus of the study is on the three key constructs of the SDT and BPNT; autonomy, relatedness and competence and the impact that the satisfaction or frustration of these needs has on the overall quality of life to individuals with neurological conditions. Previously a meta-analysis has been completed reviewing the application of SDT to health contexts (Johan et al. 2012). The analysis found that SDT is a viable conceptual framework to study antecedents and outcomes of motivation for health-related behaviours. However the studies examined did not include individuals with neurological conditions and/or a neurorehabilitation setting.

As such, this project aims to test the theory of self-determination, as a predictor of quality of life in those with chronic neurological conditions, reliant on 24-hr care and support. In doing so, this research also aims to expand the field of health psychology further across differing chronic conditions. Typically, chronic conditions within the health psychology sector are considered to be cardiovascular disease; chronic obstructive pulmonary disease, chronic fatigue, irritable bowel syndrome, diabetes, obesity and chronic pain. A chronic condition is a long-term (more than three months) condition that is generally not curable. It must be managed or controlled with medication and/or other therapeutic techniques and it can significantly impact on quality of life. An acquired brain injury or a progressive neurological disease satisfies all of the above.

A final aim is to provide some much needed insight into the adequate care and support for those suffering with neurological conditions, living in either long-term or permanently within a healthcare settings. Findings can then be used to inform future practice of health care professionals and the implementation of interventions working with this subgroup to improve health-related outcomes and quality of life.

2.1.1. Research Questions

As SDT states that the satisfaction of the three basic psychological needs can predict self-regulation and motivation of behaviours which can subsequently lead to improved wellbeing, irrespective of one's condition, the following prediction for this research was made;

Hypothesis 1: Feelings of increased autonomy, competence and relatedness, predicts increased quality of life for individuals with neurological conditions in neurorehabilitation settings.

As much of the SDT health research and current health legislation prioritises discussions around the importance of patient autonomy, the following prediction was also made;

Hypothesis 2: Feelings of increased autonomy will be the most significant predictor of quality of life for individuals with neurological conditions in neurorehabilitation settings.

Chapter 3: Methods and Methodology

3.1. Sampling and selection

A non-probability convenience sampling approach was applied to this explanatory study. Whilst this sampling approach may typically limit representativeness and generalisability of results to the general population, due to the very specific sample required for this research a non-probability sample enables representation of the key characteristics of the specific population being studied. As such, this research does not intend to generate results that will generalise the entire population but rather it aims to provide an in-depth analysis into a specific sample within a certain context which can later provide insight into lived experiences through qualitative analysis.

Convenience sampling techniques were used as the selected population were already available to the key researcher. It is important to note that such a sample would typically be extremely challenging to recruit due to the complex and sensitive nature of both neurological conditions and long-term care users. In line with this notion, the sample criteria was not limited to be condition specific to ensure that a large enough sample could be accessible. Further rationale for a sample of mixed neurological conditions is that this research does not intend to look at specific differences between conditions but rather it aims to study neurological conditions in general within long-term care settings. As the care home setting is also a key consideration within this research, generalizability within this specific sample is limited to those with neurological conditions outside of full time care.

3.1.1. Recruitment process

For this explanatory study recruitment took place within the two neuro-rehabilitation centres of Castel Froma Neuro Care (CFNC). The two centres are situated closely in proximity, within the West Midlands area of the United Kingdom. Across the centres there is a maximum capacity of 98 long-term or permanent residents, all of which have a neurological condition that has limited their abilities for daily functioning. The residents have access to 24-hr specialist care and support.

Approval to work collaboratively with CFNC was gained following a meeting held with key members of the management team. The key criteria set by CFNC for research to be completed onsite was that the research would be of benefit to service users and staff in the future. Research also needed to have ethical approval and to comply with GDPR and mental capacity laws.

Initial PPI input was completed with care (carers and care coordinators), medical (nurses) and therapy staff (occupational therapists, physiotherapists, and speech and language therapists) via staff forums and general discussions from multi-disciplinary team (MDT) working. This involved the key researcher providing staff with a brief outline of the proposed ideas for this research project and staff members giving feedback as appropriate.

Such open discussions provided invaluable insight into the varying perspectives of staff working to support those with neurological conditions within CFNC. It also helped to generate important information from each differing discipline that supported with both the appropriate planning of this research and subsequently the implementation of different phases of this study as research progressed. For example, discussions with therapy team members ensured that appropriate screening tools were chosen as part of the recruitment process and appropriate assessments were considered for data collection. Discussions with the care coordinators and the Occupational Therapists ensured that consideration was made for optimal timings to engage with participants, to both manage fatigue of the individual but also to fit in with the daily routine of the site (i.e. meal times, care routines etc.). Discussions with the Speech and Language Therapists ensured the consideration for the appropriate use of communication styles (i.e. advertisements both visual and verbal) and potential communication aids and/or additional support that might be required (i.e. to support handfunction for the use of a pen). Such discussions enabled careful consideration around how best to facilitate research within such a complex and varying population. Whilst initial input was sought by the key research from all areas of the MDT to support the formulation of this research, such input from the team at CFNC remained ongoing (where appropriate) throughout.

Visual advertisements about the research were placed on notice boards at both sites and verbal discussions were held with residents through the attendance of planned resident meetings.

The aims of the research were fully explained to respondents and study information sheets were provided (see appendix 1). Open discussions were held and questions were encouraged and answered thoroughly.

Recruitment took place via a recruitment afternoon held separately, on the two different sites but atsimilar times. The respondents were recruited at the site of which they resided in.

3.1.2. Inclusion and exclusion criteria

The inclusion criteria were English speaking adults aged >18 years old with a diagnosis of a neurological condition i.e. an acquired brain injury, a progressive condition (as described in section one). All respondents must have experience of, or are experiencing, long-term or permanent residency within a specialist care home setting. All participants were assessed as having the mental capacity to give informed consent (Mental Capacity Act, 2005).

Initial screening of cognitive abilities was completed using the Mini-Mental State Examination (MMSE), those with a cut off score of <25 were excluded from participation. Participants with communication problems due to severe aphasia or hearing loss were also excluded from the study.

3.1.3. The participants

In total, 58 individuals expressed a wish to the researcher to participate in the study. Four were later unable to take part due to an inability to obtain informed consent as a result of severely impaired cognition. These individuals were thanked for their interest and informed, in a sensitive manner, that they would not be able to take part on this occasion. Of the 54 participants who took part, 25 were female (46%) and 29 were male (54%) with ages ranging from 37 years to 68 years old (mean age of 54 years). 31 participants identified themselves as White British (57%); 8 identified as White Other (15%), 2 identified as black (4%), 7 identified as Asian (13%) and 6 identified as mixed race (11%). The following neurological conditions were present amongst the study sample; traumatic brain injury (12), multiple sclerosis (13), stroke (ischaemic or haemorrhagic) (18), spina bifida (1), muscular dystrophy (6) and spinal cord injury (2). The average years of experience of residing in a specialist care home setting amongst the sample was 7 years and 3 months.

3.2. Mixed-method (MM) approach

3.2.1. Rational for MM

A mixed methods, sequential explanatory design (Creswell et al. 2003) has been adopted for this research project. When conducting mixed methods research, Creswell et al. (2003) recommend that researchers should consider the sequence of methods, whether the research is driven by a particular method and how they are to be integrated.

Sequence of methods

The first part of this research involves quantitative data collection via the use of SDT and QoL related questionnaire surveys. Following analysis of this data, the significant results from the quantitative methods will then be used to inform the interview structure for the qualitative data collection. As such, these semi-structured interviews will allow for exploration and expansion of the quantitative results, to test the theory of SDT and to better inform future interventions for neurological conditions. In support of this, another consideration made when designing this research was that following on from completing the questionnaire surveys, participants may feel that they want to spend further time reflecting on their own personal and unique experiences and expand on any issues identified in the questionnaires via the interviews.

Some methodological issues to consider within a sequential design relate to whether the same or different participants should be involved in both data collection stages, as well as how many participants are required to take part. In this research, the second stage of data collection builds upon the first, rather than compares, and therefore the same participants will be used throughout.

In terms of sample size, a power analysis was completed using GPower software for a multiple regression analysis, random effects model, 56 participants were required for a medium effect size, 29 for large.

All 54 participants were used in the quantitative data collection phase and five of these were then used to support the qualitative data collection. Smith, Flowers and Larkin (2009) suggest between four and ten participants for an IPA doctoral study, therefore five participants were deemed sufficient enough for this phase.

Is the research driven by a particular method?

Whilst this is a mixed-methods design, there is a strong orientation to quantitative methods. This sequence was adopted as, due to a significant lack of research within this field (as discussed in chapter one), it was initially unclear as to what SDT constructs were of relevance to neurological conditions and as such, an informed interview structure could not be reliably developed without the quantitative analysis.

Strengths of quantitative data allow for a focused examination of specific constructs; the ability to make comparisons, to examine association between variables and to test hypotheses (Castro et al, 2010). Quantitative research tests theory and predicts, and as such, by placing greater weighting and emphasis on the quantitative methods a general understanding of the research question, whether or not SDT predicts wellbeing in neurological conditions, could be established prior to the qualitative exploration of participants' views in more depth (Rossman & Wilson, 1985; Tashakkori & Teddlie, 1998, Creswell at al., 2003). Quantitative data is also useful within this research domain as it can be utilised to inform care and support provision, in order to plan interventions delivered by health care professionals.

However, some researchers argue that within a mixed methods approach the strengths of qualitative data can become secondary to that of quantitative data (Denzin & Lincoln, 2005). This was not the intention for this study. Whilst the quantitative analysis will support with answering the research question, the qualitative phase will provide great insight into the 'lived experiences' of the participants and as there is little research that concentrates specifically on this, it is necessary that the participants are provided with the opportunity to tell their story. It also allows a more nuanced and sophisticated interpretation of the data around the issues of concern.

Integration of methods

A limitation to mixed methods research is that it is often insufficiently justified and a lack of detail is provided around how the methods are mixed (Bryman, 2008). For this study, there are three key points whereby the methods are mixed. Firstly, the analysis of the survey questionnaires provide the framework for the development of the interview structure for the semi-structured interviews. Secondly, the key SDT constructs analysed in the questionnaires formed the integral basis for the themes identified in the qualitative findings. Finally, thirdly in the concluding chapter of this research the findings across this thesis are brought together and synthesised in a final discussion.

3.3. Quantitative approach

3.3.1. Rational for Multiple regression

A forward multiple linear regression model was opted for over a correlational approach within this study. Whilst a correlation analysis proves a significant linear relationship between the autonomy variables and the quality of life measure within this research, which is of great importance, a multiple linear regression analysis shows how one or more of the SDT variables might predict QoL, and this will enable testing of the research questions.

A forward regression model, whereby each variable is added randomly was opted for over a stepwise regression model. A stepwise regression involves adding variables in a certain order based on theory. Whilst this project hypothesises that the autonomy measure will be the most significant predictor of QoL in comparison to competence and relatedness, the theory of SDT states that all three constructs are required in order to achieve a QoL. It was therefore felt that a forward regression model would be sufficient enough to answer both research questions in relation to this, particularly as stepwise regression models have been criticised for being biased, since they are based on the same data. For example, Wilkinson and Dallal (1981) argue that final regressions obtained by forward step-wise regression have shown to yield more significant results.

A hierarchical multiple regression model was also not used in this study. Whilst hierarchical regression is a way of showing if specific variables explain a statistically significant amount of variance in in the dependant variable after accounting for all other variables, within this study each construct of SDT was tested individually and then collectively against the quality of life measure rather than testing how autonomy, competence and relatedness impact on each other for quality of life.

3.4. Qualitative approach

3.4.1. Rational for Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis (IPA) was chosen as the most appropriate method of qualitative data analysis for this study as it provides an idiographic focus to the research. IPA as an approach originates from methods and ideologies associated with phenomenological philosophy (Giorgi,2009). Its strengths regard the comprehensive examination of how people make sense of, or find meaning in, their experiences (Smith et al. 2011). It involves a two-stage process of interpretation known as double hermeneutic, whereby the participant is trying to make sense of their world, whilst the researcher is also trying to make sense of the participant making sense of their world (Farrell, Keenan & Keubbs, 2013). The participants' psychological state needs to be interpreted by the researcher by assuming a chain of connection between use of language and the participants thinking and emotional state. The researcher is then responsible for making such interpretations elicit and open to challenge andmodification (Danivas et al, 2016).

By seeking to explore the lived experiences of the participants, it aims to offer valuable insight into how a given person, in a given context, makes sense of a given phenomenon. That so, IPA does recognise that it is wholly impossible to gain an insider's perspective completely, as the process depends upon the interpretations of the researcher (Murray & Chamberlain, 1999).

For this study, IPA enables the exploration of perspectives, meanings and interpretations whilst remaining sensitive to all types of diversity (Willig, 2001). This is key to supporting the aims and objectives of this current study, by exploring the interpretations and meanings of lived experiences, greater insight is gained into the lives of those with neurological conditions residing in full time care settings. Thus, as such, gaining in-depth interpretations will support the effective implementation of future interventions amongst this population.

As mentioned above, IPA has a dual focus on the unique characteristics of individual participants and on patterning of meaning across participants. In contrast, thematic analysis (TA), the qualitative approach initially considered for this research, focuses mainly on the patterning of meaning across participants (this is not to say that is cannot capture difference and divergence in data). IPA and TA analysis differ due to the distinction between idiographic and nomothetic conclusions. IPA generates two sets of themes and conclusions; one set of themes and conclusions to the individual (idiographic) and one set of themes and conclusions across the individuals (nomothetic). Whereas TA adopts a nomothetic approach and does not generate themes that are relevant to only one or two individuals. A solely nomothetic approach has its strengths over IPA as it can be applied in a broader range of circumstances with a larger sample size and has a more flexible approach. It can also offer a descriptive analysis of data and provides and objective statement of an event (Danivas et al., 2016). However, whilst it is important to note that whilst TA could yield key information from the participants relevant to this research and research questions, as discussed in chapter 3, the sample for this research is very specific and a more in-depth analysis is required therefore adopting such a flexible approach for this study may have led to phenomena that occur in only one individual being overlooked with TA focusing on patterns across the data set (Braun & Clarke, Smith, 2015). It was therefore decided that such key information regarding the participants' personal perceptions could be carefully analysed using IPA.

Other qualitative methods such as narrative analysis, discourse analysis and grounded analysis were not considered as appropriate or suitable methods for this specific piece research and research questions.

3.4.2. Semi-structured interviews

Semi- structured interviews are a well-established data collection method in qualitative studies (DiCicco-Bloom & Crabtree, 2009). Charmaz (2006) suggests that questions used within a semi-structured interview schedule should be 'sufficiently general to cover a wide range of experiences and narrow enough to elicit and elaborate the participant's specific experience'. The open-ended style of semi-structured interviews enables the researcher to pursue novel responses and work at depth whilst being able to confirm an understanding of the participant's point of view (Willig, 2008).

Interviews, as a data collection method, also allow participants to challenge the researcher's assumptions and beliefs about meaning and relevance of the concepts being explored (Willig, 2008). This allowed flexibility enables participants to clarify and explain their experiences.

Smith, Flowers & Larkin (2009) suggest that interviews allow for a rapport to develop and are easily managed. As a rapport had already been established between the researcher and the participants' prior to data collection (see reflexivity section), it was presumed that semi-structured interviews would be the most effective method for gained rich data.

3.5. Research approval

This study was approved by the Research Ethics Committee of the Faculty of Health and Life Sciences (HAS) at The University of the West of England (UWE), Bristol. A letter of collaboration was also obtained from CFNC to allow for the study to be completed across both neurorehabilitation sites (see Appendix 2).

3.6. Ethical considerations

All participants are deemed as ‘vulnerable adults’, as defined by the Care Act, 2014. Therefore all participants were assessed as having the mental capacity to give informed consent (in-line with the Mental Capacity Act, 2005) prior to participation.

A thorough risk assessment was completed to ensure the safety of all involved in the study (see Appendix 3).

3.7. Data management planning

All data collected within this study remained anonymised and confidential. All participant data had direct identifiers removed and no identifiable information was kept longer than necessary. All information related to this study was stored in a lockable cabinet with access only for the author/researcher. Following analysis, all data was destroyed.

The semi-structured interviews were recorded using a Dictaphone and were transcribed only by the author, in compliance with General Data Protection Regulations (GDPR) and subject to the safeguarding limitations outlined by the British Psychological Society (2009). All interviews, and quantitative data collection methods were completed in private rooms.

Chapter 4: Data Collection Phase 1 (Quantitative)

4.1. Procedure

Participants were recruited via advertisements at each site, verbal discussions and the attendance at a recruitment afternoon. The advertisements included a brief summary of the study, the aims of the research and requirements of participating. The research was described as exploring a theory of motivation and behaviour to see if this predicts quality of life and wellbeing in neurological conditions in neurorehabilitation settings. The study was advertised as recruiting any long-term or permanent resident with a neurological condition, subject to certain inclusion criteria. Participants were encouraged to make contact via the email address provided, to attend the recruitment afternoon, or request to speak to a member of the psychology team if they wanted further information regarding the study. Upon expressing interest, an information sheet was provided (Appendix 1) which offered further details about the study and included assurances of anonymity together with reassurance that participants could withdraw from the study at any point within 14 days after participation by making contact with the key researcher. This contact could be made via telephone, email or a face to face meeting.

Informed consent

If participants chose to take part, preliminary screens and medical discussions were held, and formal tests of mental capacity were completed (where appropriate) to ensure that all participants had the mental capacity to give informed consent for their participation (in line with the Mental Capacity Act, 2005). All such screens were completed by the appropriate multi-disciplinary team members at each site.

Cognitive screening

The Mini-Mental State Examination (MMSE) cognitive screen was completed with all respondents to measure cognitive impairment. The MMSE (Folstein, Folstein & McHugh, 1975) is a standardized screen for evaluating the cognitive performance of subjects, and where appropriate to quality and quantify their deficit (Lewis, Clement & Trempe, 2017). It is the most frequently used screening scale to identify cognitive impairment in neurological conditions (Hall & Frith, 2010). It is very brief (5-10 minutes), easily administered (non-professionals can administer it in survey settings) with a high interrater reliability of 0.69 and 0.78. Any score greater than or equal to 25 points (out of 30) is effectively normal (intact cognition) (Pangman, Sloan & Guse, 2000). Therefore, respondents were required to obtain a score of 25 or more to participate. The MMSE screens were completed by members of the psychology team.

Once the necessary cognitive screens were completed, a consent form (Appendix 4 & 5) was then completed by the participant. If written consent could not be obtained, due to physical limitations, verbal consent was obtained and witnessed.

Upon obtaining consent, an appropriate time was arranged with the participant to complete the psychometric measures. Upon the completion of psychometric measures (self-reported questionnaires), a number of demographic questions were also asked (see demographic table 1). The psychometric measures were administered by the key researcher. The psychometric measures were presented verbally and/or visually (depending on the participants' needs) and likert rating scales were used to ensure consistency across responses. The data collection process was kept short and the measures used were short-form, following feedback from the pre-testing survey (see below) and PPI research, to avoid fatigue and to maintain optimum attentional levels. Throughout the data collection process the participants were reminded of confidentiality and encouraged to provide honest answers that reflected their true feelings in order to reduce social desirability bias. Participants were also reminded of the aims behind the research in order to promote their motivation to complete all measures.

The order in which the questionnaires were presented to the participants was randomised to reduce any potential ordering effects.

All information obtained was stored confidentially in a locked and secure cabinet in a locked and secured office. All data was anonymised after 14 days and all questionnaires were destroyed.

4.1.1. Pre-testing Survey

The Department of Health has highlighted the importance of service user involvement in health research (Department of Health, 1999). The questionnaires were therefore administered to two residents (independent of this study) residing at one of the care centre sites. Feedback on the questionnaires, administrator instructions and the presentation of the questionnaires was obtained. The participants provided feedback on the length of the original questionnaires. The short-form versions of the questionnaires were then presented to these participants and these were identified as acceptable. No other suggestions were made.

4.1.2. The Measures

All necessary permission and approvals were obtained from the authors of the psychometric measures used within this academic research project. A number of standardised questionnaires were used to measure the SDT constructs being assessed in order to investigate the research hypotheses. The following standardised questionnaires were chosen for differing reasons. The quality of life measure was chosen because it is well validated within neurological conditions (i.e. validity and reliability within this population is well evidenced). The SDT questionnaires were chosen because they are validated SDT measures of the individual constructs, and have been widely applied within both SDT research and within clinical research focusing on improved health outcomes, wellbeing and quality of life. To ensure reliability and validation procedures of each measure, cronbach's alpha has been conducted for the following measures, and sub scales of measures where appropriate.

In order to support consistency across the measures, all measures used the same likert scale rating.

Quality of life: 'The World Health Organisation Quality of Life measure; Bref & Disabilities version (WHOQoL-BREF & DIS)' was used. The WHOQoL-BREF & DIS is a validated measure used globally to assess the quality of life in individuals with physical disabilities caused by neurological disorders (Lucas-Carrasco et al. 2010). The WHOQOL-BREF is a generic QoL measure comprising of 26 items. Twenty-four of these items are grouped into four difference domains; physical, psychological, social and environment. The remaining two global items are related to overall QoL and satisfaction with health. The WHOQOL-DIS (Disability module) is an additional module that comprises of 12 items that function as a single overall domain. There is also an additional item that assesses the overall impact of physical disability. All items in both WHOQoL versions have a 5-point likert response scale; scores ranged from 4 to 20 and the higher the score the higher the QoL. The internal consistency measured by Cronbach's alpha is good for the WHOQoL-BREF entire scale $\alpha= 0.88$ and WHOQoL-DIS $\alpha= 0.81$ and for the individual subscales; discrimination $\alpha=.53$, autonomy, $\alpha=0.79$ and inclusion $\alpha= 0.66$.

As the WHOQoL-BREF & DIS provides a QoL measure for neurological disorders it enables a consistent measure of QoL across the participants within this study, rather than using condition specific measures. This measure also considers the environment as a predictor of QoL which is also key consideration within the SDT.

The following questionnaires were used to measure the constructs of the Self-determination Theory.

Competence: The Perceived Competence Scale (PCS) is one of the most face valid instruments designed to assess the competence construct from SDT (Williams, Freedman, & Deci, 1998). The PCS is a short, 4-item questionnaire which is typically written to be specific to the relevant behaviour or domain being studied. Within this study it was written specifically for health behaviour change. The overall score is calculated by averaging the responses on the four items, the higher the score the higher the perceived competence. The PCS has good internal consistency within this study with an alpha measure of $\alpha=0.91$.).

Autonomy 1: The Perceived Choice and Awareness of Self Scale (PCASS) assesses individual differences (trait level) in perceived choice and awareness of self. The PCASS is a short, 10 item scale with two 5-item subscales. The subscales within this measures can be used separately and for the purpose of this research, the first subscale, perceived choice in one's actions, was used as a validated measure of autonomy (Elliot & McGregor, 2001). The items on the perceived choice subscale need to be reverse scored so that higher scores on each item indicate higher levels of autonomy. The internal consistency for the PCASS measure was $\alpha= 0.71$ for this study.

Autonomy 2: The Health Care Climate Questionnaire (HCCQ) is used to assess the patients' perceptions of the degree to which their treating team of healthcare professional is autonomy supportive. This is suited to the participants within this study as each individual is treated by a number of different members of the multi-disciplinary team (i.e. doctor; nurses, physiotherapists, occupational therapists, psychologists, speech and language therapists and dieticians). This is supportive of the research question for this study as it considers the healthcare climate i.e. the specialist neurorehabilitation care centre. The short form version containing 6 items was used in this study and overall scores are calculated by averaging the individual item scores. The higher the average scores, the higher the level of perceived autonomy support. The Cronbach alpha score for the HCCQ was $\alpha = 0.77$ for this study.

Relatedness: The Basic Psychological Needs Satisfaction in Relationships Scale (BPNS-R) is a SDT scale that addresses the needs satisfaction in one's particular relationships e.g. caregivers, spouse, friends, and parents (La Guardia, Ryan, Couchman & Deci, 2000). It has 9 items and the overall scores for relationships are derived by calculating the mean score. The reliability scores for the following relationships; mother, father, romantic partner, and friends are $\alpha = .92$, $\alpha = .92$, $\alpha = .92$, and $\alpha = .90$, respectively (La Guardia, Ryan, Couchman & Deci, 2000) and the reliability score for this study was $\alpha = .93$. This scale was suitable for the participants within this study as they were able to determine which relationships they were rating, allowing for flexibility rather than relationship specific scales. Questions such as ''my … accepts me and likes me as I am'' are directly linked to the relatedness construct of SDT.

4.2. Data analysis

A forward multiple regression data analysis was completed to allow for the evaluation of constructs and to establish any relationships between the constructs (Musil, Jones & Warner, 1998). It was also used to predict the value of the dependant variable (QoL) on the value of the multiple independent variables (SDT measures).

In pre-screens of data, a correlation analysis was initially ran to establish positive relationships between the SDT variables and the QoL measure. For the intended analysis, a forward multiple regression was ran, as the key analysis, to analyse all the quantitative data within this study in order to test whether the several constructs of SDT, as a whole, are related to (or are a predictor of) the quality of life of the participants.

In order to test hypothesis 2, a forward multiple regression analysis was ran to test if the autonomy measures predict quality of life. A forward multiple regression analysis was then ran to test if the competence and relatedness measures predict quality of life, this was necessary in order to establish if autonomy was the most significant predictor of quality of life.

Linear regressions were then completed to discover the effect, if any, of the individual SDT variables on the QoL measure.

A Bonferroni adjusted post hoc test was used to limit the possibility of committing a type 2 error.

4.3. Results

The final sample consisted of 54 participants, 46% were female and 54% were male. From the power analysis, 56 participants were needed for a medium effect, therefore 54 participants is close to the amount needed for a medium effect but it might be too small of a sample. The mean age of the participants was 54 years, with an age range of 37 – 68 years old. 57% of the sample identified themselves as White British; 15% as White Other, 4% as Black, 13% as Asian and 11% as mixed race. The sample included 24% of individuals with multiple sclerosis; 33% who have experienced a stroke (ischemic and/or haemorrhagic), 22% who have suffered a traumatic brain injury, 2% with spina bifida, 11% with muscular dystrophy, 4% with a spinal cord injury and 4% with multiple system atrophy. The majority of the sample had been a resident of a neurorehabilitation centre for over 5 years, with an average time of 7 years 3 months across the sample.

See Table 1 for a breakdown of sample characteristics;

Table 1 - Participant Demographics

Demographic	**Number**	**%**
Age (years)		
35 – 45	12	22
46 – 55	23	43
56 – 65	13	24
66 +	6	11
Neurological condition		
MS	13	24
Stroke (Isch/ haem)	18	33
TBI	12	22
SB	1	2
MD	6	11
SC	2	4
MSA	2	4
Sex		
Female	25	46
Male	29	54
Ethnicity		
White British	31	57
White Other	8	15
Black	2	4
Asian	7	13
Mixed	6	11
Other	0	0
Time in CFNC (years)		
0 – 3	2	4
3 – 5	7	13
5 – 7	18	33
7 +	27	50

MS (multiple sclerosis), Isch (ischemic), haem (haemorrhagic), TBI (traumatic brain injury), SB (spina bifida), MD (muscular dystrophy) SC (spinal cord), MSA (multiple system atrophy)

Regression Analysis

Table 2. Relevant descriptive statistics

	Mean	Std. Deviation	N
QoL	37.13	5.46	54
PCASS (Aut. 1)	3.72	.84	54
HCCQ (Aut. 2)	4.90	.69	54
PCS (Competence)	4.94	1.53	54
BNSR (Relatedness)	5.74	.64	54

Correlational Analysis

Using SPSS (Statistical Package for Social Sciences) statistics software, all data collected from the psychometric measures was inputted. Firstly, a test to see if the data met the assumption of collinearity were completed and indicated that multicollinearity was not a concern (PCS, Tolerance = .93, VIF = 1.07, PCASS, Tolerance = .95, VIF = 1.04, HCCQ, Tolerance = .98, VIF = 1.01, BNSR, Tolerance = .96, VIF = .96).

Secondly, a correlational analysis was computed to initially assess the relationship between the QoL measure and the individual SDT constructs. There was a positive correlation between QoL and the competence measure, r = .204, n = 54, however the relationship was not significant (p=.069). There was also a weak positive correlation between the QoL and the relatedness measure, r = .014, n = 544, however the relationship was not significant (p=.481). Therefore, the measures of competence and relatedness did not appear to be associated with improved QoL in this sample.

There was a positive correlation between the QoL and the autonomy measures. For the PCASS measure, r= .266, n = 54 and the relationship was significant (p=.026). For the HCCQ, r=.252, n= 54 and the relationship was also significant (p=.033). Therefore, the measures of autonomy did appear to be associated with improved QoL.

Multiple Regression

Hypothesis 1. A multiple regression analysis was carried out to investigate whether the self-determination theory (autonomy, competence and relatedness) could together significantly predict participants' quality of life. The results of the multiple regression indicated that the model explained 17% of the variance and that the model was not a significant predictor of quality of life, F (4, 49) = 2.506, p = 0.054.

The final predictive model was:

QoL = 12.841 + (1.361*PCASS) + (2.123*HCCQ) + (.609*PCS) + (1.012*BNSR)

Hypothesis 2. A multiple regression was then carried out to investigate whether autonomy (PCASS + HCCQ) was the most significantpredictor of quality of life amongst the participants as hypothesised (hypothesis2). The results of the regression indicated that the model explained 13.6% of the variance and that the model was a significant predictor of quality of life, F (2, 51) = 4.016, p = 0.024.

To test hypothesis 2 further, the following multiple regressions were also carried out to establish which construct was the biggest predictor of quality of life.

For the competence and relatedness measures the results of the regression indicated that the model explained 5.8% of the variance and that the model was not a significant predictor of quality of life, F (2, 51) = 1.565, p <.05.

A linear regression analysis was finally completed to establish whether individually there was a relationship between competence and quality of life, and relatedness and quality of life.

The regression analysis for competence as a predictor of quality of life was not significant, F (1, 52) = 2.268, p <.05).

The regression analysis for relatedness as a predictor of quality of life was also not significant, F (1, 52) = .509, p <.05).

4.1. A summary of the quantitative findings

Hypothesis 1; The forward multiple regression analysis found that the three constructs of SDT do not significantly predict quality of life within this sample.

Hypothesis 2; The forward multiple regression analysis for autonomy, found that the two autonomy measures did significantly predict quality of life within this sample. The forward multiple regression analysis for the competence and relatedness measures found that both measures did not significantly predict quality of life within this sample. The subsequent linear regressions completed found that competence and relatedness alone did not predict quality of life.

See table 3. Correlational analysis examining the relationship between the SDT constructs on QoL

	PCS	PCASS	HCCQ	BNSR	QoL
PCS					
Pearson Correlation	1	.215	.017	.160	**.204**
Sig. (1-tailed)		.060	.415	.124	**.069**
N	54	54	54	54	**54**
PCASS					
Pearson Correlation	.215	1	-.015	.023	**.266***
Sig. (1-tailed)	.060		.457	.433	**.026**
N	54	54	54	54	**54**
HCCQ					
Pearson Correlation	.017	-.015	1	.107	**.252***
Sig. (1-tailed)	.451	.457		.221	**.033**
N	54	54	54	54	**54**
QoL					
Pearson Correlation	.204	.266*	.252*	.014	1
Sig. (1-tailed)	.069	.026	.033	.461	
N	54	54	54	54	54
BNSR					
Pearson Correlation	.160	.023	.107	1	**.014**
Sig. (1-tailed)	.124	.433	.221		**.481**
N	54	54	54	54	**54**

*Correlation is significant at the 0.05 level (1-tailed)

See table 4. Multiple regression analysis examining the impact of SDT constructs on QoL

	R Square	Df	F	Sig.	B
QoL/SDT (all)	.170	(4, 49)	2.506	0.054	QoL; 12.84 PCS; 1.36 HCCQ; 2.12 BNSR; 1.01 PCASS; .61
QoL/PCASS/HCCQ	.136	(2, 51)	4.02	.024	QoL; 20.71 PCASS; 1.74 HCCQ; 2.03

QoL/PCASS/HCCQ/ PCS	.157	(3, 50)	3.11	.035	QoL; 18.97 PCASS; 1.54 HCCQ; 2.00 PCS; .53
QoL/PCASS/HCCQ/ BNSR	.143	(3, 50)	2.78	.050	QoL; 16.38 PCASS; 1.64 HCCQ; 2.12 BNSR; .75
QoL/PCS/BNSR	.06	(2, 51)	1.57	.219	QoL; 26.89 PCS; .79 BNSR; 1.10

4.2. Discussion

Interpretations

Hypothesis 1: Feelings of increased autonomy, competence and relatedness, predicts increased quality of life for individuals with neurological conditions in neurorehabilitation settings. As summarised above in the results section, self-determination theory, when applied to neurological conditions, is not a significant predictor of quality of life. This hypothesis has therefore been disproved.

Hypothesis 2: Feelings of increased autonomy will be the biggest predictor of quality of life for individuals with neurological conditions in neurorehabilitation settings. As hypothesised, autonomy in relation to competence and relatedness is the biggest predictor of quality of life. Both autonomy measures without the other SDT constructs significantly predicted quality of life. The competence and relatedness measures, without the autonomy measures did not significantly predict quality of life.

Implications

The SDT concept that one must experience all of the three basic psychological needs of autonomy, competence and relatedness in order to experience wellbeing and improved quality of life is not applicable to the participants within this research study. As a theory of motivation and behaviour, this research is the first to apply SDT to those with neurological conditions, residing in 24-hr care. It first seems important to note that whilst the data collection tools and measures used within this study were reliable measures of each of the SDT constructs, they do not specifically consider the social environment in terms of a neurological care home setting. SDT considers the social context and environment to be a huge influential factor to ones' motivation and wellbeing, however the specific social context and environment of a 24-hr care home is yet to be considered within SDT research. It therefore seems fair to assume that as this study contradicts the vast majority of previous SDT research around motivation and wellbeing, the influence of the social environment is pivotal in predicting ones' quality of life.

Another important factor to consider when discussing the outcome of the first hypothesis is that the specific SDT measures were generalised to health care settings and clients, but not specifically to neurological conditions, unlike the quality of life measure. As discussed in the introduction section of this research, neurological conditions undoubtedly impact on the three basic psychological needs proposed by SDT. Depending on the neurological condition, if it is degenerative there is a continual threat to the further loss of these three psychological needs. Consideration needs to be made to the 'baseline' levels of ones' autonomy and competence to physically complete tasks prior to applying SDT. If ones' physical impairment is reduced to a point that they are reliant on others to complete tasks for them, extra consideration and focus should then be on the environment and its capacity to fulfil these needs for others.

When discussing the outcome of hypothesis 2, autonomy was proven to be the biggest predictor of quality of life amongst the study sample. Interestingly the two autonomy measures and the competence measures together also significantly predicted quality of life. However, it was the integration of the relatedness measure within the multiple regression that yielded non-significant results. Ryan & Deci (2002) stated that 'people feel relatedness most typically when they are cared for by others'. There is an underlying sense of irony in this notion when applying it to this research in that all participants within this study are in fact under the care of others. As such, this poses an interesting question for phase 2 of this research for the exploration of the care givers approach.

Another consideration that can be made from these findings is that ones' relationship with the individual providing the 'care' is of great importance. The sample within this study may feel a degree of relatedness to others of whom are in a similar situation to them, or of whom are caring for them. However, the social context of the care home setting may hinder the feelings of relatedness to others such as friends and family. Moreover, it must be noted that the data collection for this phase of research was completed during the Covid-19 pandemic, at a time where CFNC had stopped all external visitors, such as friends and family, from entering the site. As the autonomy and competence measures yielded significant results together, it may be that during the Covid-19 pandemic, the autonomy and competence support such as the structure, care and daily routine of CFNC did not changed, yet the social interaction did.

SDT research has shown that relatedness-supportive techniques involve taking an interest in the person; acknowledging and accepting conflict, and authenticity and transparency in relationships (Deci & Ryan, 2008). It could be argued that as the key point of contact for the sample in this study is the caregivers, personal/professional boundaries between the caregiver and the client will need to be maintained at all times. As such, the relatedness to caregivers is limited. Firstly, it may be that the caregivers have a limited amount of time with the client which could impact on their capacity to truly take an interest in their client. Secondly, conflict between the caregiver and the client should be avoided and the caregiver will have professional standards to adhere to with regards to managing this. Which subsequently means that the relationships are not authentic or transparent. All such points will be explored further in phase 2 of this study to establish why the sample report low levels of relatedness to others.

The competence measure, without the autonomy measures, did not yield significant results for increased self-reports of quality of life. It would therefore be interesting to explore whether CFNC implement any competence-support techniques. Such techniques would include structure; identification of barriers and obstacles, setting optimal challenges (or personalised goals) and providing reinforcement and feedback to service users (Jang, Reeve & Deci, 2010; Sierens et al, 2009). It would also be interesting to explore whether ones' physical limitations as a result of their condition, or the physical limitations as a result of the environment impact on ones' sense of competence in daily life. By exploring the lived experiences of the participants, and establishing the key barriers to these basic needs, interventions can be targeted appropriately i.e. either target the environment, or the individual. As mentioned above, completing semi-structured interviews with a number of participants from this phase of data collection may provide further analysis of these queries.

As autonomy was found to the be biggest predictor of quality of life, and the highest scoring self-report measure, it would be reasonable to assume that the current support provisions and structure of CFNC are, to some extent, autonomy-supportive for its' service users. Autonomy-supportive techniques include encouraging choice and self-regulation in order to yield increased report of quality of life (Moller, Ryan & Deci, 2006); avoiding the use of controlling pressures or incentives and providing a need-supportive limit setting (Koestner et al, 2012). It will be interesting to explore the individual perceptions of volition and autonomy further in phase 2 to establish what one views as autonomy-supportive and what specific autonomy-supportive techniques are implemented within the care home setting.

Limitations

As previously discussed, the data obtained for this phase of study was collated during the Covid-19 pandemic and as such, the self-reported measures gained from the sample may not be an accurate representation of how they feel ''in general'' but rather a representation of how they felt at the time. As the key researcher is known to the sample, there is also an increased risk of social desirability bias within the data.

It also feels important to note that whilst the sample were cognitively screened, and assessed as having the mental capacity to take part, some cognitive deficits are typical amongst neurological conditions. This may therefore impact on the reliability of self-reports provided by the sample. That so, future research into neurological conditions cannot eradicate this issue and it should therefore be widely accepted amongst this sample.

Another limitation to discuss is that the sample size was just short of that required to produce a medium effect. Therefore it is important to acknowledge that the results may have been different with additional participants. However, it is also important to acknowledge the challenges around recruiting and working with such a sample. Therefore a sample size of 54 is still a considerable amount and just on the edge of an acceptable sample for a medium effect.

Future recommendations

Overall, what is promising from this research is that despite the well documented negative psychological impact that neurological conditions have on people (Kirkevold, Martinsen, Arnesveen Bronken & Kvinge, 2014; Gainotti, 2007; Knight & Godfrey, 1996), those with neurological conditions can still report high levels of quality of life and wellbeing. Further research and exploration is needed to establish the specifics of support provision, environment and the individual differences that lead to an improved quality of life. Further research should also consider using condition specific samples in order to establish more targeted interventions for future support. Finally, it would also be beneficial to gain pre (baseline) and post measures of SDT and QoL following a SDT-based intervention, in comparison to a standard intervention.

Chapter 5: Linking Statement: quantitative to qualitative analysis

Moving from the first stage of this research (quantitative data collection from questionnaires) into the second (qualitative data collection from semi-structured interviews) involved a thorough data analysis of the initial questionnaires. In doing so, key aspects from the data that held significant weighting on the overall research questions could then be explored further by modifying the interview schedule appropriately.

As discussed previously, Creswell et al (2003) and Bryman (2008) both underline the importance of being explicit in showing how methods are mixed within a mixed methods project. With this in mind, the second hypothesis that was proven from phase one of this research, highlighting that increased autonomy is the biggest predictor of quality life in relation to competence and relatedness formed the basis for the interview schedule in phase two. As such, this can allow for further exploration of this hypothesis.

The interview schedule and questions were designed specifically to explore the thoughts, feelings and lived experiences of the participants in relation to their individual perceptions of autonomy within the neurorehabilitation setting. Whilst relatedness and competence will be explored further, within the social context of the environment, the key focus remains on autonomy as this was found to be the most influential factor for quality of life amongst those with neurological conditions residing in care settings in the quantitative analysis.

Open ended questions were created to specifically explore if the environment and staff approach were autonomy-supportive. This aimed to provide an insight into the influence of social context and explores the theory of SDT further, in a way that the questionnaires are unable to do. Whilst phase 1 was able to establish the ‘what’ in relation to SDT, quality of life and neurological conditions. Phase 2 is aimed at establishing the ‘why’ and the ‘how’.

6. Data Collection Phase 2

6.1. Procedure

Participants for the data collection phase 2 of this study were identified and recruited through the researcher, following on from their participation in phase 1. Following the debriefing of participants after phase 1 of data collection, verbal information was provided regarding phase 2 of data collection. Upon expressing interest, an information sheet was provided (Appendix 6) which offered further details about the second phase of the study and included assurances of anonymity together with reassurance that participants could withdraw from the study at any point within 14 days after participation by making contact with the key researcher. This contact could be made via telephone, email or face to face meeting.

Five participants expressed a wish to participate in phase 2 of the study and all five provided informed consent (Appendix 7 & 8) to further data collection. Upon obtaining consent, the participants were informed that the researcher would make contact in one month’s time to arrange an appropriate time with the participant to complete the semi-structured interview. The interviews commenced 6 weeks after the completion of phase 1. Prior to the interview process the participants were reminded of confidentiality and encouraged to provide honest answers that reflected their true feelings in order to reduce social desirability bias. They were also reminded that the subject and focus of the discussion would be around quality of life, wellbeing and how they view their current situation.

The semi-structured interviews took approximately 30 minutes to complete. These were conducted by the key researcher who is experienced in the subject matter and is sensitive to support any issues that may have arisen. The interviews took place over video call (Teams) and, where necessary, appropriate staff on each site were contacted prior to the scheduled interviews to ensure that the participants were set up with an appropriate device ready for the video call. Following the interview process, all participants were debriefed (Appendix 9), thanked for their participation and encouraged to ask any questions.

6.1.1. Conducting an Interview

An interview guide (or script) was created that structured the course of the interview, which provided suggested questions to ask. The purpose of the interview was explained from the onset, during the recruitment process.

Interview questions

Good interview questions should contribute thematically to knowledge production and dynamically to promoting a good interview interaction (Brinkmann & Vale, 2015).

Thematically the questions relate to the 'what' of an interview and the research topic. Dynamically the questions relate to the 'how' of an interview and they should promote positive interactions to maintain the flow of conversation. To establish the 'what' appropriately, the initial researcher questions were developed with both the aims of the study and the study hypotheses in mind. For example, the key overarching aim of this research is to support the wellbeing and quality of life for those with neurological conditions. Having already established that feelings of increased autonomy predict quality of life within this sample, the main focus of the researcher questions is around understanding what autonomy means to such individuals, how it is supported and what can be done to improve it. Such questions also allow for further exploration of the second hypothesis and should help to understand why autonomy is the biggest predictor of QoL. Bearing in mind the BPNT, and to grasp a better understanding of how to satisfy the needs of relatedness within the current sample, questions have also been devised to explore the participants' feelings around their relationships both inside and outside of the care home setting and whether the setting is supportive of relationships. Similar exploratory questions have also been devised for the need of competence, to establish if this is supported appropriately (i.e. with achievable goals or activities) or whether reduced feelings of competence are heightened (i.e. with unsuitable activities) within a long-term care setting. All such questions should support another key aim of this study, to inform clinical practice and future interventions within neurorehabilitation care settings, by providing insight into the lived experiences and needs of those appropriate for such interventions.

To ensure that the questions relate to the 'how' of the interview, whilst the initial researcher questions were formulated in theoretical language, the actual interview questions to be asked were then devised into the everyday language of the interviewees**.** A basic description of 'autonomy' was also provided to the interviewees prior to the interviews to ensure an accurate understanding of the concept prior to questioning (See table 6).

Table 6. Researcher questions and interviewer questions

Researcher questions	Interviewer questions
How important is having a sense of autonomy?	1. What does "autonomy" mean to you? 2. What does it mean to you to if you are the one who makes decisions about your life?
Does the individual have autonomy over their situation?	1. To what extent do you feel that you are involved in all decisions related to your care and support?

	1a. What is it like for you when you are involved in the decision making about your care and daily living? 2. Do you feel that there are constraints to your decision making? 2a. If so, what are some of these constraints? 2b. What is it like for your living with some of these constraints? 2c. Are you support to overcome these constraints?
Does the individual have a sense of relatedness to others?	1. What does it mean to you to be connected with or separate from others? 2. Does this setting help or hinder your feelings of connectedness/separateness to others? 2a. How so?
Is the environment autonomy supportive?	1. Describe the approach of a member of staff generally supportive of your autonomy 2. Describe the approach of a staff member who is less so. What is it like being with each of these members of staff? 3. Do you engage in activities due to feeling pressure or obligation? 3a. What type of activities? 4. Are the activities within the environment appropriate to you and your needs (I.e. are you physically able to complete them?)
Is the service individualised to the needs of the client?	1. Do you have goals that you are working towards (i.e. physical, emotional, social etc.)? 1a. If yes, were these goals set by yourself or did staff set these for you? 1b. How meaningful are these goals to you? In what way are they meaningful? 1c. Are these goals achievable?
How can a neurorehabilitation service be more supportive of autonomy to improve the quality of life of service users?	1. What do you think would help to improve your own autonomy within this setting in the future? 2. What suggestions would you make to change the current service in order to promote the wellbeing and quality of life to service users?

Table 6 shows the translation of the research questions into interview questions that could provide thematic knowledge and also contribute dynamically to a natural flow of conversation.

Interviewer questions

The interview questions were brief and simple, worded in a way that they were easy to understand (academic language avoided).

The following questions were incorporated into the semi-structured interview;

- Introductory questions to encourage rich descriptions of participants lived experiences.
- Follow-up questions through either direct questioning or implicit communication such as nodding and pausing to encourage further description from the participants.
- Probing questions for further description
- Direct questions to introduce new topics
- Indirect questions
- Structuring questions in order to maintain a focus to the key topics of the interview
- Silence to allow time for reflection and encourage further conversation from the participants
- Different linguistic forms of questions to avoid a specific style of answers throughout

Whilst there were a sequence of themes to be covered within the interview, as well as some prepared questions, there was an openness to change the sequence and question forms in order to ensure conversation flow and ensure that the participants were able to tell their stories. Careful consideration was given to the social interaction between the researcher and the interviewee. Careful reactions from the researcher were given upon the answering of questions from the interviewee to ensure that no opportunity to gain information was missed.

6.1.2. Risks and Risk Management

The risk element of this data collection point was assessed as relatively low, however a risk assessment was completed to ensure safe practice (see appendix 3). The following actions were implemented by the researcher throughout the interview process:

- Participants were reminded at the beginning and during the interview that they could refuse to answer any questions and stop the interview at any time.
- The researcher monitored the participants for signs of distress such as changes in body language, pace of breathing and engagement, with an awareness that the interview could be stopped and closed down in a safe and calm manner.
- Whilst none of the participants opted to terminate the interview, if this had occurred the researcher would have offered a debriefing session or a grounding activity prior to leaving the interview to alleviate distress.

- At the end of the interview the participants were encouraged to ask questions

6.1.3. Data protection and Transcribing

The participants were informed that the interviews would be recorded using a Dictaphone. They were assured that the recording would not contain their name or any identifiable information and that it would be kept in a locked cabinet, in a locked room, only accessible to the key researcher. Participants were assured that no one else would have access to the data and if they chose to withdraw from the research, they had two weeks to do so before the data was anonymised. At the point of data analysis and transcription, all data obtained and the voice recording would be destroyed. The data would be anonymised at this point and would be analysed with interview data from other anonymised participants. All transcribing of data was completed by the key researcher.

Each interview was transcribed verbatim and analysis of data began as soon as possible to support accuracy in researcher recall. Transcribed interviews were stored on the key researchers' personal computer and were password protected. The password was complex enough to be considered secure.

6.2. Data analysis (IPA)

IPA was used to process the data collected in order to better understand the content and complexity of meanings. There is no linear 'method' for analysing data using IPA, but rather a mix of logical, creative, intuitive and academic processes (Smith, Flowers & Larkin, 2009). The following protocol, was proposed by Smith, Flowers and Larkin (2009), were followed by the researcher for data analysis:

1. Primarily engaging in one transcript at a time, reading and re-reading, to become familiar with the material.
2. Begin initial noting and commenting on significant associations, language and interpretations of the content in a separate column alongside the transcript.
3. Developing and documenting any emergent themes that captured and reflected the participant's experiences.
4. Searching for thematic connections across the data sets and emergent themes. This allows for a more analytical and theoretical ordering of themes and explores how the themes may fit together. This process is described as clustering (Smith, 2008).
5. Develop a table of themes that capture the participant's experiences and meaning. Add labels to the themes and identify superordinate themes (see Appendix 10).
6. Finalise the table of themes with superordinate and subordinate themes. Ensure that this table has been reviewed by differing members of the research team.

7. Translate the themes into a narrative explanation and illustration using extracts from the data sets. Ensure that clarity is presented between the participant's statements and the researchers' interpretations.

Throughout the above process, the key researcher ensured regular pauses from work were made to allow for reflection on thoughts and feelings about the data were completed. This supported an open-mind and enabled careful consideration about the implications of personal and epistemological assumptions about the research.

6.3. Reflexivity

IPA recognises that the exploration of participant's lived experiences cannot be easily separated from the researcher's own lived experiences and views. Therefore the nature of interaction between the researcher and the researched is also not easily separated (Willig, 2001). Therefore it is important to engage in 'personal reflexivity', which involves reflecting on ones' own prior assumptions about the research area, and ones' own motivations for completing the research in the given topic area (Wilkinson, 1988). As such, the key researcher will aim to explicitly highlight the influence of past and present life experiences that led towards this research topic and how these experiences were considered throughout the research process.

The key researcher is a trainee health psychologist working in a 'higher assistant psychologist' post within CFNC neurorehabilitation centres. Therefore, the key researcher works to support clients with neurological conditions on a daily basis and, as such, a professional rapport had already been established with a number of the participants within this study prior to participation. The key researcher accepts Heidegger's (1962) assertion that an individual can only view another individual's experience in light of their own previous experiences. The key researcher also accepts the increased risk of desirability bias upon data collection, despite preventative measures being adopted. Therefore, by making this information explicit, readers of this research can make their own judgements as to issues of quality. That so, it is important to note that the previous professional experience of neurological conditions can be helpful in terms of utilising skills, knowledge and support to ensure safe practice throughout the research process.

However, the key researcher is also aware that previous experiences of neurological conditions and the current role within CNFC is likely to have been a key motivating factor in carrying out this research. Therefore, when carrying out data collection and analysis it was imperative that the researcher continuously found the balance between being a 'higher assistant psychologist', a health psychologist and a researcher. Prior training in health psychology and research skills offered uniqueness, weight and different elements to the nature of this study, and throughout this thesis process it has been important to maintain the researcher role.

Another key point to add is that throughout the interviewing process the researcher was mindful of her own experiences. Therefore the interviews were approached with an aim to stay objective and to not ask leading questions based on previously held beliefs or assumptions. The focus of the interviews was to give the participants an open space to express their own thoughts, feelings and experiences. Being a psychologist within the care home setting the researcher ensured that participants were reassured with confidentiality, privacy and non-judgement throughout the process. Emphasis was also made on having clear boundaries between the role as a researcher, and the role as a psychologist when working with the participants and that the choice to (or not to) participate in the study held absolutely no bearing on the support provided by the psychology team. Similarly, the discussion held would not jeopardise the participants' role as resident and their position within CFNC in any way.

6.4. Analysis of qualitative findings

6.4.1. A summary of the qualitative findings

This section presents an overview of each superordinate theme, followed by a critical analysis and interpretation of meaning derived from interview transcripts.

The aim of this phase of research was to explore the lived experiences, and the influential factors to quality of life, of those with a neurological condition that require 24-hr care and support within a neurorehabilitation centre. There were 3 super-ordinate themes and eight subordinate themes that emerged from the data set following the application of IPA that appeared to chart these experiences.

The following table charts summarises these themes;

Super-ordinate theme 1: **Living with a neurological condition**	Subordinate theme 1a: **''I'm just battling with my body really''** Subordinate theme 1b: **''It's the only power I've got left''** Subordinate theme 1c: **''It's a slippery slope''**
Super-ordinate theme 2: **What autonomy means to me**	Subordinate theme 2a: differing levels **''I feel free''** Subordinate theme 2b: autonomy supportive **''What others allow or enable you to do''** Subordinate theme 2c: changing **''it's a thing that changes constantly because of my condition''**
Super-ordinate theme 3: **Life as a permanent resident**	Subordinate theme 3a: **''You've got to avoid the institutionalisation of centres''** Subordinate theme 3b:

	“I'm the king of the castle, listen to me, this is how it should be done” Subordinate theme 3c: **“We are all pains in the ass sometimes”**

Table 9. - Participant Demographics

Participant number	Age	Sex	Ethnicity	Neurological condition	Degenerative condition	Age of onset of condition	Time in CFNC (years)
Participant 1	51	Female	White British	MS	Yes	33	+ 10
Participant 2	56	Male	White British	MS	Yes	39	1
Participant 3	35	Male	White British	SB	No	Since birth	4
Participant 4	47	Male	White British	Stroke (haem)	No	34	+ 10
Participant 5	61	Male	White British	TBI	No	59	2

**MS (multiple sclerosis), Isch (ischemic), haem (haemorrhagic), TBI (traumatic brain injury), SB (spina bifida)*

6.4.2. Living with a neurological condition

Super-ordinate theme 1; Living with a neurological condition

This super-ordinate theme addresses those times that the participants talked about living with a neurological condition either directly or indirectly in response to situational questions. Each of the five participants have a neurological condition that has impacted their ability to physically perform activities of daily living to the point where they all require permanent 24-hour care and support. Whilst there are individual differences to each of their situations, they all share a lot situationally in common, most notably their home environment.

It seems to be worth nothing the different ways in which the participants talk about their condition, or do not talk about their condition, when asked questions about their lives during the interviewprocess. This will be explored further throughout the sub-themes. However, overall there is a distinct lackof focus in discussions about one’s condition, with only one resident talking directly about the physical changes he has endured as a result of his degenerative condition. This focus on external factors, rather than one’s condition also gives an indication early on in this analysis that the satisfaction of the three basic psychological needs is heavily reliant on one’s environment and external influences. This may be interpreted as a coping mechanism for the participants whereby they shift their focus onto controllable things. However, at times throughout the interview process it can also feel like an avoidance. This ambiguity around the lack of focus, or acknowledgement of one's condition could be viewed in two ways, as an acceptance or an avoidance. The following statement seems to reflect this ambiguity;

Participant 2: You not only realize when you start to lose those things. So when like you-- you know there's good and healthy and that's in your head, because you're indestructible. You don't consider it much. Once you are stuck with something chronic then you don't want to dwell on things too much because then it'll ruin your past a bit.

In this statement Participant 2 acknowledges his 'chronic' condition and by using the term 'stuck' he communicates a lack of control over a condition that he does not want, but cannot get rid of. In an attempt to gain control over ones situation, Participant 2 is making an active choice to not 'dwell' on this. By using the term 'dwell' an indication of negative thought processes can be linked to his condition. The conscious limiting of such thought processes could be seen as an avoidance of the unpleasant emotions, memories and thoughts associated with one's condition. Alternatively, acceptance is described as an active choice to allow unpleasant experiences to exist, without trying to deny or change them, this too could be interpreted from the statement. Participant 2 acknowledges the negativity around his condition, but chooses not to focus on this. Such ambiguity around ones' coping is also echoed in the following statement made by Participant 3 when asked about any restrictions he experiences in daily living;

Participant 3: I don't feel like I'm restricted, if I wanted someone to come around or whatever. They are not restricting me at all.

Here is an example of how the participants do not talk about their condition. Participant 3 is linking any restrictions in living with a neurological condition to external, controllable factors that are influenced by others rather than the physical limitations of his condition. Again, this can be interpreted as an avoidance of ones' condition whereby he avoids discussion about how his condition has restricted him. Or, this can be interpreted as an acceptance of ones' condition whereby Participant 3 is aware that he is physically restricted, and that this is not changeable, so instead he focuses on the changeable factors within his life that he is still able to assert control over. In doing do, one is increasing a sense of autonomy and choice over the situation. The fact that this statement is generally a positive statement gives a sense that this participant, overall, could be more accepting of his condition. It seems important to note that Participant 3 was born with his neurological condition, and as such, he has always lived with a neurological condition. Whilst he has undoubtedly has needed to adapt to life within a care home, he hasn’t experienced a sudden loss of in ability that he once had and throughout this theme he seems the most ‘content’ with his lived experiences.

Conversely, Participant 4 suffered a sudden stroke, experienced significant change and seems to hold a lot of anger and frustration around his current life. For example;

Participant 4: I don't need to change. The people in this place need to change.
Participant 4: They need to stop treating me like a child and give me…give me choice.

Again, different perspectives can be drawn from this statement. Has Participant 4 accepted his physical limitations to the point where he genuinely feels that he does not need to change, and instead others around him need to change? Or is Participant 4 avoiding and denying the changes that he has endured as a result of his neurological condition and is he externalising his negative thoughts onto those around him as a way of coping? Either way, what is clear is that there is no motivation for this individual to want to change anything about his behaviour in order to support his situation. An underlying sense of anger can be drawn from this text, and many other statements made by Participant 4, and such negativity would infer that living with a neurological condition is extremely challenging. As this theme develops, it becomes more apparent that expressing anger is a way in which Participant 4 copes.

Discussion

Arguably, either perspective of avoidance and acceptance can be viewed as a means of coping and adapting to life with a neurological condition. This ambiguity of ones’ ability to cope with their condition remains a theme throughout the entirety of this analysis and whilst negative and positive emotions can make assumptions clearer, life with a neurological condition is a very contrasting theme. The type of neurological condition, the onset and the trajectory of the condition all seem be key influential factors of this.

Sub-theme 1a; ‘’It’s my body’s decision really, whether I’m going to handle it or not.’’

This sub-theme addresses the times where the participants inadvertently talk about their condition as though it is a separate entity to them. Across a number of the transcripts a theme has emerged of a sense of ‘compartmentalization’ between the ‘self’ and the ‘condition’. As though the ‘self’ is one entity that is able to make certain choices and decisions and the ‘condition’ is another entity. This is highlighted below, when participant 3 was asked about his constraints to decision making:

Participant 3: I’m just battling with my body really. It’s my body’s decision really, whether I’m going to handle it or not.

There are several important points to note within this brief extract. Firstly, Participant 3 uses a 'battle metaphor' to infer that he is at war with his body. The use of 'battle metaphors' is a way of expressing emotions and has been found to help individuals suffering from chronic conditions make sense of their experiences, explore different perspectives and articulate coping strategies (Gustafsson, Hommerberg & Sandgren, 2020). This statement infers an ongoing battle between 'self' and 'body' and emphasises the distinction of intentions between the two entities. It would seem that whilst the 'self' is able to make decisions, these decisions are limited by what the 'body' can do. This inference of a battle with the body is quickly ended when Participant 3 then follows this statement with ''it's my body's decision really…''. Implying that the body always wins the battle. This infers that the body is not competent to complete tasks that the mind would like to complete. The impact of this on ones' sense of self could be catastrophic, with both needs of autonomy and competence are threatened here, and Participant 3 seems to deal with this loss of control by externalising the body in his statements. By doing so, he compartmentalises himself from his body and he is able to retain his sense of self and self-image (Granek et al, 2016). Further compartmentalisation of 'self' and 'body' can be found in another statement made by Participant 3, on the same topic of limitations to decision making;

Participant 3: Sometimes, if it's to do with my pressure sore. If it's physical health, sometimes, yes. Mentally, no.

Firstly, Participant 3 is again making reference to the distinction between the barriers he experiences with his physical health, in comparison to no barriers he experiences with his mental health. He then chooses to provide an example of his ''pressure sore'' when discussing his physical health, rather than his neurological condition (which arguably resulted in the presence of a pressure sore). This would infer that his limitations to decision making are temporary and will reduce in line with his pressure sore. Participant 3 is focusing on a more controllable aspect of his physical health which may be a way of him taking control back over his situation. Rather than focusing on something he cannot change (his neurological condition). As previously discussed, this could be viewed as both avoidance of his neurological condition or it could be viewed as acceptance. Likewise, the notion that Participant 3 compartmentalises himself from his body could also be viewed as either a coping mechanism or a defence mechanism (Gustafsson, Hommerberg & Sandgren, 2020). A similar response to the same question can be observed by Participant 1;

Participant 1: I mean I'm limited at the moment because of my pressure sore. But once it's…once it's all healed then I'd be able to do more for myself because especially now that I can drive my chair and myself, that's given me a lot of independence.

Here, Participant 1 also refers to her ''pressure sore'' as being the key limiting factor to her independence again, not her neurological condition. By choosing not to directly acknowledge her neurological condition, a degree of compartmentalisation could also be inferred from this statement. However, what is different in this statement to Participant 3's statements is that Participant 1 doesn't seem to separate herself from her condition intentionally. She provides an example of what she is able to do, without the pressure sore present, and this example clearly indicates the extent to some of her physical limitations as a result of her neurological condition. What Participant 1 is actually highlighting here is that she is 'more' limited at the moment because of her pressure sore. Interestingly, by not using the word 'more' you could argue that Participant 1 has either accepted, to some degree, the physical limitations of her neurological condition or she is avoiding this. Another point to make from this statement is that Participant 1 refers to the act of driving her wheelchair as giving her ''a lot of independence''. This suggests an adaptiveness to ones' condition, as well as highlighting how feelings of autonomy can change in line with ones' abilities. This will be discussed further in the superordinate theme 2.

Discussion

The overarching message within this theme seems to be that the participants separate themselves from their condition in order to preserve a sense of self. In doing so, they are not letting their condition define them and they are portraying a message that they are not their condition. As previously discussed, this could be a way of coping with their condition in order to promote their quality of life.

Sub-ordinate theme 1b; ''It's the only power I've got left''

This sub-ordinate theme addresses those times where the participants spoke about their mental capabilities in the face of their physical condition. Whilst the extremity in comments does vary, the message behind the statements holds a similar focus on the importance of the mind. For Participant 3, in-line with the above mentioned theme, a belief of mind-body dualism (Descartes, 1441/1984) can be interpreted from the following statement;

Participant 3: I'm working on my mental health, that's a continual thing. Then my mental health, in turn, will help me with physical health, with my pressure sore so that I'll actually leave.

A number of points can be drawn from this extract. Firstly, Participant 3 places an emphasis on how he is working on his mental health to subsequently support his physical health, which he refers to as being his pressure sore. By using the physical example of a pressure sore, the mind-body dualism belief is assumed whereby the mind has the power to heal the body. In previous statements already discussed, Participant 3 eludes to an ongoing battle between himself and his body, whereby his body always wins. Mind-body dualism as a belief generally values the mind over the body and views the body as a tool that helps the mind interact with the physical world (Gray, Knickman & Wegner, 2011). This stance of ‘lessening’ the body and promoting the power of the mind could be viewed as a way of preserving a sense of self. By ‘lessening’ the body that one has limited control over, the impact of this lack of control can be minimised, one’s sense of autonomy can be preserved and one’s sense of competence is satisfied. Another interesting point in this statement is that Participant 3 talks about being able to leave CFNC once his sore is healed. This would indicate that Participant 3 views his residency at CFNC as temporary and dependant on his pressure sore, not his neurological condition. Again, the focus of physical health has been shifted away from the chronic condition and onto a more transient, controllable issue. Similarly, Participant 3 may be focusing on his mental health as he is able to assert some control over this, in the sense that this could be changeable, rather than his physical health which leaves him feeling restricted.

An emphasis on the importance of the mind can also be found in the following statements made by Participant 1 when asked about decision making:

Participant 1: Extremely important because I'm to make to those decisions. It's the only power I've got left.

Participant 1: I love doing word games, scrabble and crosswords because you only need your brain to do these.

In this extract Participant 1 uses the word ‘power’ to describe her mental capability to make decisions. Without directly discussing her physical condition, it could be assumed from this statement that Participant 1 views her body as powerless. The emphasis in this statement is that her mind is what gives her a sense of control over her life, hence why she describes enjoying challenges that only require her thinking skills as she achieves a sense of mastery over such tasks. Having the ability to make decisions is clearly meaningful to this participant and an assertiveness over decision making can be seen in the language used ‘’I’m to make…’’. The need for assertiveness could be indicative of a feeling of an underlying threat to ones’ decision making, which could be indicative of a controlling environment or a paternalistic model of care approach. This may also be linked to an awareness of her degenerative condition. Further statements made by Participant 1 carry a similar tone, for example;

Participant 1: I can speak for myself and get things done that I want and not what others want.

Self-assurance, dominance and a need for control can be drawn from this statement. It would seem that for as long as Participant 1 has the mental capability to make decisions, she feels as though she has control over her situation. This notion can also be drawn from comments made by Participant 2, when asked the same question about decision making:

Participant 2: You try to make decisions to the best degree you're capable of and as long as I can think clearly, which I can, I want clarity in my head. What I feel is certain people get stuck and that's what I worry about. So think clearly.

In line with above, Participant 2 infers control over decision making for ‘as long as I can think clearly’, emphasising the power he holds on his ability to make decisions in order to assert control over his situation and retain a sense of autonomy. The repetition of ‘think clearly’, emphasises the importance of this but also indicates a concern around losing the ability to think clearly. It would appear that mental capabilities within this statement are referring to cognitive ability rather than mental health. Participant 2 has a degenerative condition that will eventually lead to altered thought processes and impaired decision making. The threat of losing this ability emphasises the importance of wanting to retain that ability, as ones’ ability shrinks, it becomes more valuable. By then going on to state ‘I want clarity in my head’, rather than stating ‘I have clarity...’ could imply that there may be times where Participant 2 has difficulties with his thought processes.

This threat of changing abilities is clearly anxiety provoking for Participant 2 and he voices his concerns about becoming ‘stuck’. He is honest about his concerns of how his condition will change him in the future and interestingly, he is the only participant to openly discuss his anxieties in relation to his condition. This non-avoidance to the acknowledgement of his situation could be argued as an acceptance that things will change, and by having a degree of acceptance of his condition he is bringing himself a willingness to tolerate the difficult situation he finds himself in. By doing so, he is maintaining a quality of life.

Discussion

When the physical ability to take control of a situation has gone, the emphasis on ones’ mental ability to take control of a situation takes precedent. The shifting perspectives model of chronic illness (Paterson, 2001) describes living with a chronic illness as an ongoing, continually shifting process. As a condition changes, the perspective of the person continually shifts from illness-in-the-foreground to wellness-in-the-foreground. With neurological conditions, a loss of competency can bring illness-in-the-foreground. In order to shift back to wellness-in-the-foreground, the individual needs to shift the focus from what they have lost, to what they still have. A focus on the condition and the losses can temporarily serve as a protective function with illness-in-the-foreground but the shifting of focus to what one is still able to do bring wellness-in-the-foreground and this also serves as a protective function. This model highlights the variability in ones’ coping style, and how one way of coping is not definitive. This model also provides an explanation for why the participants are focusing so intently on their mental capabilities (what they can do – competence) rather than their physical difficulties (what they cannot do).

Sub-ordinate theme 1c; ''It's a slippery slope''

This subordinate theme addresses the times where a couple of the participants directly and indirectly make reference to the impact that their neurological condition has had on their lives, and the changing picture of their situation. The majority of text analysed within this theme has been derived from the two participants' with degenerative conditions. Interestingly, these participants seem to give a more direct and honest representation of their situation than those with 'stable' conditions. For example when discussing his current situation Participant 2 made the following statements;

Participant 2: It's like a slippery slope…

Participant 2: You not only realize when you start to lose those things. So when like you-- you know there's good and healthy and that's in your head, because you're indestructible. You don't consider it much. Once you are stuck with something chronic then you don't want to dwell on things too much because then it'll ruin your past a bit. I'm knackered, so I'm here.

The first statement is a powerful description of his condition which implies a downward trajectory that will inevitably lead to a worsening situation. A real sense of a loss of control, autonomy and competence can be interpreted from this description as Participant 2 acknowledges the degenerative nature of his condition. His use of the term ''knackered'' to describe how he is feeling also emphasises the impact that his condition has on his life, almost as though he has been defeated by his condition and now accepts the need for care. Participant 2 appears to be a realist and throughout his interview, there are no times were it feels as though Participant 2 is trying to 'sugar-coat' his situation or portray it in a light that makes it seem better than it is. In further discussions about his condition Participant 2 goes on to say;

Participant 2: When you realize there's really nowhere to go and the next thing you lose control over something else. Well obviously, it's the things that you can take control of yourself.

Again, Participant 2 is honest about discussing the changing nature of his situation. In this text, he talks about having nowhere to go, which could be interpreted in a number of ways. For example, Participant 2 could mean that he feels that he has nowhere further to go with regards to physical changes and losses incurred from his condition, he may already feel that he has lost so much that he cannot envisage further loss. This text could also be a reference to situational aspects such as he feels as though he has nowhere to go now that he is in a 24-hr care home. Either way, the realization of both these interpretations would have brought his ''illness-in-the-foreground'', even only if this was temporarily. Participant 2's ability to then bring ''wellness-in-the-foreground'' and shift his focus on to what he can still take control of highlights a person's ability to adapt to their health condition. This ability to shift focus on what one is able to take control of enables an individual to live with a degenerative condition and still retain a sense autonomy and a quality of life.

This ability to shift focus and maintain a ‘’wellness-in-the-foreground’’ stance can be seen in a less direct way in comments made by Participant 1;

Participant 1: ‘’… they give me the computer and sort it for me so that I’ve got my independence.’’ and ‘’This improves my independence and autonomy massively.’’

Here, Participant 1 is making references to her Access Control Technology (ACT), which is an environmental aid (computer) controlled by her eyes that enables her to access the internet, as well as control devices within her room. Participant 1 is clearly physically limited by her condition which is why she now uses ACT. However, instead of focusing on this loss she focuses on her sense of independence and autonomy that she has maintained. She has adapted to use of the ACT equipment which has increased her need for competence and mastery over tasks and as such, has enabled her to maintain control over her situation. This ability to adapt, and maintain a focus on what can be done is more evident in Participant 1 and 2 than in any of the other transcripts.
What also becomes increasingly more evident from working through these themes is the subjectivity of what autonomy and independence is.

Discussion

Living with a degenerative condition seems to be a very different experience to those living with a ‘stable’ neurological condition. It seems that as ones’ abilities shrink, the importance of the things that one is able to do, such as being able to make a choice, become much more valuable. The focus on such abilities almost makes the individual grateful for what they are still able to do at that time. A sense of anxiety has been noted within this theme, however the participants do not appear angry or frustrated at their situation unlike other participants who have experienced a sudden stroke or TBI. One explanation behind this may be that the change in ones’ abilities with a degenerative condition is gradual rather than sudden. The individuals are aware of the changes before they happen which allows them more time to adjust to their situation. The process of change is slower and the significant changes often occur years after a primary diagnosis, allowing the individuals with time to adjust.

Another theory as to why the two participants with degenerative conditions are more open about discussing the impact of their condition than those with ‘stable’ conditions may be explained by the shifting perspectives of chronic illness model (Paterson, 2001). For example, when a condition is changing, the changes bring the illness to the forefront, as such, discussions about the condition may seem more relevant and recent. As oppose to those with a long-standing condition that has not changed.

6.4.3. What autonomy means to me

Super-ordinate theme 2; What autonomy means to me

This theme addresses those times that the participants talked about their own perspectives of autonomy. Despite all of the participants having physical impairment that impacts on their daily functioning, all reported feeling a sense of autonomy and some level of control over their situations at times. However these levels are variable and hard to compare across the participants because the meaning of autonomy is different for each participant. This is highlighted across the participants within this study who possess differing perspectives of autonomy, differing levels of perceived autonomy and differences in what being autonomous means to them.

What became very apparent during the interviews was the uniqueness of the concept of autonomy as well as the fluidity and subjectivity of what we individuals view autonomy to be. It seems that autonomy changes, in line with the changes one experiences within their lives.

Participant 2: Well no your, you know, your condition affects you and your body changes, circumstances, the parameters you stick them under the name of autonomy are just moveable stuff.

Here, Participant 2 talks about how autonomy changes with his abilities. As his abilities reduce, his perspectives of what autonomy is changes. As he loses the ability or competency to complete certain tasks, his views shift in order to adapt to what he is still able to do. There is a need here to continually adapt to ones' changing situation in order to preserve ones' sense of control and maintain a quality of life. This statement would infer that to Participant 2, autonomy is what he is able to do, as highlighted in the below statement.

It also seems to be that as ones' autonomy reduces or shrinks the value of autonomy increases significantly. For example;

Participant 2: You not only realize when you start to lose those things. So when like you-- you know there's good and healthy and that's in your head, because you're indestructible. You don't consider it much.

Here Participant 2 is talking about autonomy and inferring that he only realised the importance of autonomy as he begun to 'lose those things'. He indicates that autonomy was a not a significant consideration prior to his diagnosis, when the threat of losing it wasn't so prevalent, when he was ''indestructible''. However, now that his competence and physical ability is changing, as he physically loses control over things, it has become a more apparent factor within his life. As Participant 2 has a degenerative condition, there is a continual threat to the loss of ability and this may explain why he focuses a lot on his changing abilities and the changing perspectives throughout his interview. This is in contrast to answers provided by other participants, for example, when Participant 5 was asked about what autonomy meant to him, he gave the following answer;

Participant 5: Different dinner menu options and, you know, being able to, you know, have a shower when I want and eat when I want, so those sort of things.

Here, Participant 5 focuses on the concrete decision making of external/situational factors, rather than basing his views of autonomy on his physical abilities. It would seem as though Participant 5 views autonomy as choice and freedom around basic day to day decisions. Whilst there is a sense of institutionalisation here, for example, being able to choose when to eat would seem like a basic and reasonable choice, this will be explored further in later themes. The element of choice around these decisions is limited to Participant 5's situation, indicating a controlling environment and what he values seems to have adjusted to this environment. Therefore, within this context, having some choice would be enough to make him feel a sense of autonomy.

Discussion

Autonomy is subjective, and what it means to one individual is very different to what it might mean to another. As we explore the notion of autonomy further within this theme, there seems to be two key focuses for autonomy; ones' physical abilities and ones' ability to make choices. Both of which are influenced significantly by, and are to some extent reliant on, the external factors and social context.

Sub-ordinate theme 2a; ''I feel free''

As highlighted above, some participants focus on their physical abilities and denote what they can physically do as having a sense of autonomy, whereas others view having freedom of thought and the mental capacity to make decisions as autonomous. The focus within this sub-theme is that individuals can possess a high sense of autonomy if they are given freedom and choice, irrespective of their physical capabilities. For example, Participant made the following statement when discussing his current situation;

Participant 3: I feel free.

Participant 3: That's what I've always been used to. I've always been used to being independent, to be able to choose how things go for me. It's massive for me. It's a massive thing.

Autonomy is defined as ''freedom from external control or influence'' (Oxford English Dictionary). Therefore this statement of feeling free made by Participant 3 could be viewed as having reached the highest sense of autonomy. This highlights how subjective autonomy is to each individual and how adaptable individuals can be to chronic conditions. Situationally, Participant 3 is not ‘free’ particularly as the timing of his interview was during the first peak of the COVID-19 pandemic and the care home he was residing in had gone into an extended period of isolation. However, ones’ mind cannot be restricted by anything situational and therefore freedom in this statement can be linked to the assumption that Participant 3 still has freedom and choice over ones’ thoughts and the second statement emphasises his sense of autonomy. Similar to this assumption, when asked what autonomy means to you, Participant 1 and 5 answered;

Participant 1: It means that I can speak for myself and get things done that I want and not what others want.

Participant 5: It means having my own-own independence and being able to make my own choices about what I want to do.

Here, both Participant 1 and 5 view autonomy as being able to communicate and make their own decisions, rather than following the decisions of others. There is a sense of assertiveness within this statement with the ‘not what others want’ reference. This could indicate that at times Participant 1 may feel or notice situational pressures to ‘conform’ to others wants and needs, this will be explored in more detail later on in the analysis. Autonomy can be viewed here as having choice and being able to make these choices, even when they aren’t aligned with external factors. This requires a degree of self-confidence and self-esteem in order to assert oneself and such confidence can be linked to feelings of increased competence. This particularly can be derived from many comments made by Participant 1 and 5 throughout their interviews when compared with other participant comments. For example, Participant 4 also makes reference to decision making when discussing autonomy;

Participant 4: I should be the one making my decisions about my life shouldn't I?

Like Participant 1 and 5, decision making over physical ability has been prioritised here with regards to having a sense of autonomy. However by turning this statement into a question the meaning behind it completely changes. The uncertainty of this statement can be indicative of apprehension around ones’ ability and competence to make decisions and validation to his answer is then sought. This could stem from reduced levels of self-esteem or a certain level of ‘conformity’ to ones’ situation (as discussed above) whereby decisions have regularly been made by others, this sense of ‘institutionalisation’ could be indicative of a paternalistic model of care with decisions being made in best interest. However, it is interesting to note here that within this sub-theme autonomy is linked to choice and decision making, which can be influenced by both physical abilities and ones’ situational factors.

Discussion

Four out of the five participants within this study denote a sense of autonomy to freedom around decision making and choice. The final participant links his autonomy to his physical capabilities. It could be assumed that a lack of competence to complete a task reduces one's sense of autonomy. It also seems that the environment could be a more influential factor to ones' sense of autonomy. Highlighting the importance of autonomy-supportive approaches, settings and supporting the assumptions of the BPNT that the needs play interlinking roles and all need to be satisfied to support wellbeing.

Subordinate theme 2b; 'What others allow or enable you to do…''

This subordinate theme addresses the times where the participants were able to identify what enables their sense of autonomy. Examples of enablement tend to stem from either environmental aids and adaptations or an 'autonomy supportive' approach of staff members. The perceptions of what the participants believe is 'autonomy supportive' about the approach of some staff members will be discussed first.

Participant 2: What others allow or enable you to do, rather than take that control away from you and do the things for you.

Here, Participant 2 infers that his sense of autonomy can either be enabled or disabled by others. In this text Participant 2 is inferring that he cannot complete certain tasks himself without support and as such, he requires the support of others to satisfy his feelings of competence. If he is supported to complete these tasks his perceived competence increases which leads to increased feelings of autonomy, however if he is not supported to complete these tasks and the staff complete them on his behalf, he feels disabled. In such circumstances staff would be adopting a controlling approach to care. It seems fair to assume that enabling a disabled individual to complete a task for themselves would take longer than a staff member completing it for them. Another common theme across all participants' is the importance of being listened to (the needs for relatedness). Whilst both of these factors may be influenced by time constraints, they may also be dependent on staff skill set. Both factors play a significant role in delivering individualised care, enabling participants and improving quality of life. For example, when asked what makes a staff member 'autonomy supportive', Participant 1 and 4 stated;

Participant 1: I can't do an awful lot with the activities and they do help, but I do feel like not participating a lot… especially when it's crafts. And they try and encourage me. I do, do it sometimes because they're really nice. 'When you can't do it yourself, but you can tell us what you want'. You know, ' we can do it for you.'.

Participant 4; They listen to me and help me.

Both participants acknowledge the need for support, which could be viewed as having reduced competence which could threaten their sense of autonomy, but instead in this context both are talking positively about the staff approach which they view to be ‘autonomy-supportive’, and helps them to feel enabled. Within this context the staff approach is vital to protecting and supporting their needs. Evidently staff need to listen and provide adequate support to enable the participants to do things for themselves, as such, increasing their sense of competency. This approach is vital, particularly for the example Participant 1 has provided because without the support, activities that aren’t suitable for the physical abilities of an individual could easily have a negative impact on the wellbeing of an individual. When asked the same question, Participant 5 makes a similar statement;

Participant 5: Somebody who asked me what I wanna do or how I like things done and gives me their time.

Here, Participant 5 wants to be asked questions about his preferences, given the time to be listened to which subsequently leads to feeling cared for. This statement is a bit more directive than Participant 4’s statement, with a higher need for having increased control over ones’ situation in order to feel enabled. There could also be a potential underlying unmet need of relatedness here with a need for more interaction with staff (or people in general) whereby Participant 4 states ‘’gives me their time’’. He seems to be wanting more time with staff which could indicate feelings of loneliness, or could emphasis his reliance on staff to facilitate his need for competence and autonomy. Conversely, whilst Participant 2 also talks about the importance of being listened to, his emphasis is not on increased interactions;

Participant 2: Obviously you're not going to be best friends with everybody but if they listen and remember that really helps.

Participant 2: I understand that, they’re busy, I understand all of that, they’re all great people, they’re doing a fantastic job, but there are a few of them that they’ll tailor every day. You feel like they are happy to be here. The follow what you said yesterday, last week, and the week before.

Here, what is enabling for Participant 2 is that staff listen and then remember his needs (personalised care). This may actually reduce the interactions between himself and the staff, as conversations will not be repeated, but it would be meaningful to him. Inadvertently, Participant 2 is acknowledging the personal/professional barriers between staff and resident (patient) and makes it clear that he doesn’t expect a friendship, but he does expect a certain level of relatedness and person centred care. Such care would come from staff familiarity, consistency and the adoption of a self-deterministic model of care. Similarly to this, Participant 1 also places emphasis on staff remembering her needs;

Participant 1: They know my routine, they know…they're very keen to give me the computer and sort it for me so that I've got my independence. And ask me if I want the door open.

Here, Participant 1 refers to having a routine which she feels is important for staff to know. Having a routine could be seen as a way of taking control or direction over day to day life and it may be a way of enabling her own sense of autonomy. By describing the staff as 'very keen' Participant 1 is emphasising the 'want' that staff have to support her. This sense of 'wanting to support' might provide a level of comfort to Participant 1. Which, alongside staff asking questions (and the use of ACT equipment) is enabling enough for Participant 1 to feel a sense of relatedness and a view that staff are supportive of her autonomy. These assumptions are supported in a further statement;

Participant 1: They understand and they know where things go. And they're always very concerned to make sure things are right.

Again, Participant 1 emphasises the importance of staff familiarity as a way of feeling enabled. Interestingly, Participant 1 uses the term ''very concerned'' when referring to staff wanting to support her needs. This statement and the above mentioned statement give a sense that as long as Participant 1 feels as though the staff member supporting her genuinely cares about her needs then she will feel properly supported. As discussed previously regarding statements made by Participant 4, this too could be indicative of an unmet need for personal, human interaction and a desire to feel cared about. Alternatively, this statement could also indicate that Participant 1 is quite particular about how she likes things to be done, and the concern that staff possess is due to a worry that they cannot complete the tasks to the standards that Participant 1 would like. This could then be linked back to control whereby Participant 1 has a loss of control over her condition, she therefore asserts some control back over her caregivers which is then viewed as enabling. Similarly, Participant 3 appears to assert control over his caregivers for enablement;

Participant 3: They advise me but they will support me in my decisions at the end of the day.

Participant 3: They will advise me if they think it's not advisable, but they will support me if I decide to. I'm quite strong-minded.

In this text, Participant 3 is inferring that he gains advice from staff but regardless of the advice, he makes his own decisions and continues to gain support for this. This is indicative of a self-deterministic model of care which Participant 3 finds enabling and this too could link back to having the autonomy (or control) to do this.

As previously discussed, environmental aids and adaptations are also a key source of enablement for some of the participants and increases their competence to complete tasks.

Participant 1: There's only so much you can talk to carers about. So with my computer I can actually be more personal with my friends and family.

Here, Participant 1 is acknowledging the boundaries in relationships between staff and residents (patients) and uses her adaptive technology to maintain personal relationships. This could indicate that the social context of a care home is limiting to the need for relatedness and in order to satisfy this need, relationship are sought with others outside of the care environment. Having this equipment has enabled Participant 1's autonomy over relationships outside of the care home setting. The impact of this technology on Participant 1 can be seen in further comments;

Participant 1: They improve my independence and autonomy massively.

Participant 1: And my computer, where I can speak my mind and email people if I'm not happy.

The technology is also used as a key source of communication for needs other than personal relations and to support with managing difficult situations within the home, as well as an outlet for her to vent her frustrations. The fact that Participant 1 uses her technology to deal with complaints, rather than verbal discussions, could be indicative of both the nature of the complaint (i.e. needing a formalised process) or the approach expected from the staff (i.e. defensiveness). The tone of this statement is interesting and it feels quite passive aggressive, indicating that there are times where Participant 1 experiences difficulties of some sort within the centre. From this statement it is unclear as to what difficulties she may have experienced, however later themes may help to shed some light on this.

Discussion

This theme highlights the influence of situational and environmental factors on feelings of autonomy and the importance of the staff approach. The participants need to feel enabled and supported to make their own decisions. It seems that for the majority of these participants, having a restricted environment is more impactful on ones' sense of autonomy than having physical restrictions as a result of their condition. This highlights how adaptive humans can be to their physical conditions. This also emphasises the impact of external factors on ones' quality of life and wellbeing.

Subordinate theme 2c: ''it's a thing that changes constantly because of my condition''

This theme explores the notion that humans exist in relation to autonomy and autonomy is constantly changing, in line with ones' life changes. The adaptiveness of the concept of autonomy is highlighted in comments made by Participant 2;

Participant 2: Really it's the things you can do at that time.

Again, Participant 2 seems to be focusing more on physical abilities and his competence to complete tasks, rather than choice and decision making. Similar to the above theme, Participant 2 also makes reference to environmental aids as being autonomy-supportive as they increase his competence to master a task;

Participant 2: As long as I can use my hands, there are all kinds of devices and things to help you communicate and have some independence.

From this comment and comments previously discussed, Participant 2 views autonomy as changing in line with his condition progression and degree of competence to physically complete tasks. Here, it seems as though Participant 2 has mentally set himself a milestone of retaining hand function, if he can retain hand function he is able to utilise environmental aids to support his independence. As long as Participant 2 is able to continually shift his ‘milestones’, and adapt as his condition deteriorates, he will be able to preserve his sense of autonomy and quality of life. Conversely, Participant 2 also made the following comments;

Participant 2: I would've said, six months ago and beforehand, the infection has now stopped me standing. If I could be able to stand I would be autonomous. I've now foregone all sense of autonomy because I can't stand.

There are two ways in which this statement can be interpreted. The first interpretation is that Participant 2 was able to stand six months ago and that being able to stand made him feel autonomous. Now that he has lost the ability to stand, he views himself as no longer autonomous. The second interpretation is that if Participant 2 was asked six months ago, when he could stand, what he viewed autonomy as he would’ve said it was being able to stand. However now that he has lost the ability to stand, what he perceives as autonomous has changed. As mentioned above, Participant 2 also talks about how retaining the function of his hands, will maintain his sense of autonomy. In his comments Participant 2 has shifted from viewing standing as autonomy to now having the ability to use his hands, highlighting his shifting perspectives, in line with his shifting condition. What is also apparent in this text is that Participant 2 has experienced a significant decline in his condition over a six month period which has undoubtedly brought his illness to the forefront and threatened his basic psychological needs.

When looking at other statements made by Participant 2, it would seem that the second interpretation of this text is more accurate. For example in further discussions about autonomy, Participant 2 states;

Participant 2: Well it's that, it's a thing that changes constantly because of my condition.

Here he denotes that what he views as autonomous changes as his condition changes, again linked to his deteriorating physical abilities. To Participant 2 autonomy is fluid, indicating a need for constant adaptability to change in line with one's competence. To Participant 2, autonomy is also a dynamic thing, with differing levels.

Participant 2: There comes different levels of autonomy, you know, based on what you are physically able to do and what others allow or enable you to do.

Firstly, Participant 2 confirms the influence that others have on ones' ability to be autonomous (see above theme). Secondly, he talks about different levels of autonomy rather than the more concrete view held by Participant 1, 4 and 5 around decision making within the environment. This indicates that there is a significant threat to Participant 2's wellbeing and psychological need for autonomy, as his condition and his levels of physical competence deteriorate. To highlight the difference in views as to what satisfies the need for autonomy, when asked what would improve his sense of autonomy, Participant 5 answered;

Participant 5: I'd like just to be able to, you know, have a lie-in one day a week or, you know, a few days a week where I'm not having to get up at a set time each day.

To Participant 2, the concept of autonomy is complex, multifaceted and influenced by a number of different factors. To Participant 5, feelings of autonomy seem to be a lot more concrete and very much dependent on his environment. This may be because Participant 5's condition is not degenerative, it is not changing with his condition but rather is has changed because of his condition. As such, his focus is not on his 'changing condition' but rather on his basic day to day choices.

Discussion

It seems fair to assume that because Participant 2 has a degenerative condition, his autonomy is changing as his condition progresses and this may be why he choose to focus his discussions on the adaptive nature of autonomy. Other participants have provided much more concrete answers to what they perceive as autonomous and this may be because their condition and their situation is stable. It is not expected to change therefore this is not the focus of their discussions and it is influenced solely on the impact of external factors.

6.4.4. Super-ordinate theme 3; Life as a permanent resident

This super-ordinate theme addresses those times where the participants directly and indirectly made references to their lives as a permanent resident of a care home. There are two key themes that can be derived as influential factors to living in a care home, the first being environmental factors and context, and the other being the collaborative care approach adopted by each of the participants in their day to day care.

Within the previous super-ordinate theme, enablement and what makes an ‘autonomy-supportive’ environment has been explored. This current theme will explore the counter argument to these points and discuss what further disables the participants’. This current theme will also explore the relationships between the participants and staff further.

Whilst this super-ordinate theme will focus a lot on the negatives to ‘life as a permanent resident’, it is important to note that the participants, at times, also speak very highly of the support that they receive. For example;

Participant 2: You, this place, are doing a pretty good job of going over all the crap that I have to live on a day by day basis. You make it bearable.

Participant 2: it makes a big difference. When you see in the morning who's there and who isn't it does make a huge difference... Sometimes you just with you were, you know, living at home with a private and full-time nurse that you'd handpicked.

Here, Participant 2 recognises the challenges of his daily life and praises the staff and the centre for the support he receives that makes his situation ‘bearable’. Previously, it was discussed that Participant 2 stated that ‘’I’m knackered, so I’m here…’’. This is a stark reminder that none of the participants would have chosen to become a permanent resident at CNFC, were it not for the physical limitations of their condition. This statement emphasises the importance of external factors such as the staff and setting for making life more manageable. Participant 5 is fully reliant on others to meet his basic psychological needs. The second statement also reiterates the importance of staff approach, and the impact that different staff can have on the quality of life and wellbeing of others. This lack of control over one’s situation will be explored in the following sub-theme and should be considered when interpreting the comments made about the environment.

Participant 1 also makes supportive comments;

Participant 1: It helps, because we’d always be on the same table with the same friends. And we’d talk with each other… And laugh and talking. So it was really good before lockdown.

Here, Participant 1 is referring to relationships within CFNC and how the centre helps her maintain these relationships. Interestingly, this comment could be interpreted in the next sub-theme as an institutionalised environment, whereby individuals sit at the same table each day, however in the context and view of Participant 1, this is seen as a positive and beneficial. As previously mentioned, the interviews were conducted during the C-19 pandemic and all the participants were in isolation. Therefore, Participant 1 refers to the 'normal' environment of CFNC being ''really good before lockdown''. This is a positive interpretation of life as a permanent resident and Participant 1 seems to value the set up and structure, as well as others, within the care home setting and indicates needs for relatedness can be met via socialising with other service users.

Discussion

Life as a permanent resident is a decision, not made out of choice. Despite this, some of the residents can draw upon positives of their situation and can see how they benefit from living where they do and from the support they receive. It is evident that staff are an integral part of their daily life. There is also an acknowledgement of the need to reside in full time care and evidence that some basic needs can be satisfied within this environment.

Subordinate theme 3a: ''You've got to avoid the institutionalisation of centres''

This sub-theme addresses those times where the participants made comments about their situation and residency at CFNC that really highlighted their role as a resident or service user. There is a sense of frustration at ones' situation that can be drawn from some of the participant's statements within this theme. Participants were able to identify what disables their sense of autonomy and independence, and the key disabling factor, is the environment, its rigid structure and the approach of some of the staff. Not the neurological condition itself.

Participant 4: This place doesn't feel like my home. It feels like a hospital or a psychiatric unit.

There are a few key points that can be discussed from this statement. Firstly, the use of 'doesn't' and 'my' instead of 'isn't and 'a' is interesting in the first sentence. This could indicate an underlying acknowledgement from Participant 4, in that he knows CFNC is his home despite him not wanting it to be. The references then made to a hospital would indicate that the setting feels very clinical (quite medical model) and could emphasise the amount of medical and care input this individual receives on a day to day basis. The reference to a psychiatric unit could have a number of meanings. Participant 4 may feel as though others around him are suffering from serious mental health problems. This opinion may have been formed from previous observations or experiences of others that Participant 4 may have found unsettling. Conversely, this reference could indicate that Participant 4 himself feels that he has serious mental health problems and that is why he feels as though he is in a psychiatric unit. Another assumption could also be that Participant 4 is confusing cognitive impairment and the symptoms of this with mental health. Regardless of the specific intended meaning behind these references, this statement highlights how unsettled Participant 4 is feeling within the setting and how challenging life in a permanent care facility can be. This is evidenced further in the following statement;

Participant 4: Well I think this place is more like a…a barracks.

Here the reference to the environment shifts from a clinical setting to a regimented, dormitory type setting. Again, this reference has negative connotations and could be viewed in a number of ways. Firstly, Participant 4 could be referring to the physical structure and set up of CFNC. In that, the bedrooms feel like dormitories with a sense of encampment and basic living conditions. Alternatively, Participant 4 could be referring to the structure and routine within the care home giving a sense of a regimented lifestyle. Both assumptions infer that the environment of CFNC is disabling for Participant 4 and indicate significant feelings of a lack of control, a threat to autonomy and increased feelings of being controlled. This is evident in further comments;

Participant 4: Barracks is like a..a sergeant major out the army… This place is like the barracks. It means you get told what to do and when to do it, and if we don't do it then there's gonna be consequences.

Here, the sergeant major reference is linked to staff approach. This whole statement infers that the staff approach Participant 4 is referring to is extremely disabling. All sense of control and autonomy seem to have been lost within the text with staff reportedly adopting an authoritative, almost dictatorship style approach. Interestingly, this text is contradictory to previous statements made by Participant 4 whereby he claims that he is able to make all his own decisions. Albeit, this text shows a very negative, black and white style of thinking for Participant 4. And again, a sense of institutionalisation within the centre can be perceived from this text and potential feelings of entrapment which would significantly impact on quality of life. There are also feelings of anger and resentment towards ones' situation, and this anger may work as a protective mechanism for Participant 4 to help him cope with his situation. Further comments regarding the disablement of the environment can be seen in other participants' comments;

Participant 2: You've got to avoid the institutionalization of centres.

Participant 2: When you need an explanation there's always something that can't be done, in every particular one, it seems sometimes it's all very illogical, to me anyway… and hide behind being busy, they're all busy.

This first answer was given when Participant 2 was asked to give suggestions to support the wellbeing of individuals within CFNC. This statement also implies a degree of institutionalisation within CFNC. The second answer was given when asked about staff approach and emphasises the point of institutionalisation and inflexibility within the centre. This would undoubtedly threaten one's autonomy and lead to a loss of control for the individuals residing there as it highlights an inflexibility in routine and a lack of individualised, person-centred care.

Similar comments of this nature were also made by Participant 5 and Participant 1 when asked the same question;

Participant 5: I'd like just to be able to, you know, have a lie-in one day a week or, you know, a few days a week where I'm not having to get up at a set time each day.

Participant 1: We used to have the…you know, the country days like we have Mexican day, Chinese day... I mean doing the, it just gives us a different thing to think about than the same activity and the same menu.

A lack of control and flexibility over ones' day to day decisions is evident within both these texts and the 'regimented' reference made by Participant 4 earlier can be interpreted to some extent here. It would seem that the routine Participant 5 currently has, is not one that he has chosen and is disabling to him. Understandably, when you are fully reliant on others to meet your daily needs there will need to be some compromise between when you want to do something and when it can be physically done however this text would imply that even a basic decisions or choice is limited and aspects of the environment feel controlling and lack flexibility.

Discussion

From the above statements it seems as though there is a set routine or structure with CFNC that adopts a 'one-size' fits all model which is disabling for those who have needs outside of this structure. A real sense of anger and helplessness can be drawn from some of the comments made above and the setting threatens one's basic human needs which would undoubtedly impact on the wellbeing of its' service users. More flexibility within both the environment and the staff approach seems necessary and sought after by all the participants.

Subordinate theme 3b: ''I'm the king of the castle, listen to me, this is how it should be done''

This theme is similar to the above theme as it continues to explore the institutionalisation of CFNC, however it focuses on the staff approach, rather than the structures within the environment. From some of the comments made it is evident that the interactions experienced by the participants with staff are different to 'normal' social interactions because the participants are seen as 'residents' or service users and the approach seems to take on a paternalistic model of care where the views and values of the participants are not considered. This seems to depersonalise the expectations for ‘normal’ interactions between staff and residents. For example when discussing the approach of staff members, Participant 5 states the following;

Participant 5: Somebody who, you know, doesn't want to talk or rushes things with me, it's frustrating. It makes me feel like a number on a list of jobs rather than actually a person.

Participant 1: We need more time with carers.

There are a number of points to drawn from this text. Firstly, Participant 5 highlights that there are times where staff do not want to talk to him. To talk to someone when you are in the company of them would be considered a normal expectation for human behaviour. What is more important here is that we have previously already acknowledged a need for more human interaction amongst some of the participants, therefore a care routine may be a key opportunity for the participants to get this interaction and satisfy his need for relatedness. For Participant 5 there is a frustration that comes from not being spoken to which could stem for a need for positive interactions. He also states that being rushed is another frustration. Again, this could link back to previous comments about time constraints within healthcare settings (as evidenced by Participant 1), as well as the sense of institutionalisation within the centre. The reference made to feeling like a number on a list is a strong example of how meaningless Participant 5 can feel, inferring that he feels more like a statistic than a human. This is really powerful statement and which could be linked to reduced feelings of relatedness and a lack of personalised human interaction. This may be influenced by the personal/professional boundaries that should be adhered to by staff within the care setting and it may be that Participant 5 is seeking interactions on a less superficial level. Similar points have also been raised by Participant 2 when discussing his experiences of interactions with certain staff;

Participant 2: I know they won’t talk to me or listen to me. They don’t ask me if things hurt or if I am comfortable, they rush – like in and out as quick as they can.

Participant 2 has used the same example of not being spoken to, as well as being rushed. A loss of control over ones’ care can be felt from this statement, along with a lack of consideration or care for the individual needs of the Participant. It can be assumed that such interactions highlight a sort of barrier and/or differences in levels between the staff and the residents. Almost giving a sense of hierarchical interactions, or a power imbalance between staff and resident, that the expectations of human interaction changes because of the differing roles. This is highlight further in comments made by participant 4;

Participant 4: I'm the king of the castle, listen to me, this is how it should be done. That's how you do it, now do it.

Participant 4: They need to stop treating me like a child and give me…give me choice.

Here, Participant 4 uses a metaphor to describe his interactions with some staff which is also indicative of hierarchical perceptions between staff and resident, particularly as in the second statement he makes reference to being treated like a child. Like previous comments made by Participant 4, an emphasis is placed on authoritative and dictator-like interactions with staff. Again, this is a very rigid statement made by Participant 4 which appears to be more emotive than comments made by the other participants. This may be influenced by his feelings of anger and resentment towards his situation and his need to blame others to protect himself. However, what can be interpreted from this statement is that Participant 4 feels as though he is spoken down to and told what to do. There appears to be no element of relatedness during interactions, control, choice or autonomy over ones' actions from this text a sense of helplessness can be drawn from this. To Participant 4, the role of being a resident frustrates his basic psychological needs and he feels as though he is restricted by others and his environment. To him, the power imbalance between himself and the staff members is massive.

In line with the above comments, Participant 3 is the only participant eludes to being treated differently when discussing his interactions with staff.

Participant 3: I'm close to some people that can be in different groups as well. You're sometimes treated differently because you're closer with other people. That's just human nature to me, that's just normal.

Here, Participant 3 was probed to give further explanation around the meaning of this statement however he began giving short and closed answers, indicating that he did not want to discuss this matter further. Whilst it is not overly clear, the assumption from this statement is that Participant 3 is referring to being treated differently as a resident who has formed closer relationships with some staff members. This assumption is because there seems to be an issue around Participant 3 being closer with 'other people', which would only really be seen as problematic within the health care setting if this blurs the lines between personal/professional relationships with staff. It seems fair to assume that boundaries can become blurred at times when a service user has resided in a care setting for years and built up rapport with staff over that time. The reference to 'human nature' is Participant 3 acknowledging that it is normal to form closer bonds with certain individuals, and being a resident in a care home doesn't change this. From the majority of his comments, Participant 3 does not seem to view himself as reliant on others and he therefore may have a lack of appreciation for relationship boundaries within the setting.

Discussion

For some of the participants it can be perceived that staff can adopt a depersonalised approach to their care. The negative impact that this approach has on the wellbeing of the participants is evident in the above comments and the basics of human interaction seem to be lost at times. Time constraints of staff could again be an influential factor to this, so too could the importance of maintaining personal/professional boundaries between staff and residents. This could be challenging for the residents as their main interaction may be with the staff members, of whom they may have formed bonds with. Moreover, due to the Covid-19 pandemic, the only face to face human interaction these participants were receiving at the time of these interviews was with the staff supporting them.

Subordinate theme 3c: ‘’We are all pains in the ass sometimes’’

This subordinate theme addresses those times where the participants inadvertently spoke about the collaborative ‘working’ relationships that they have with their care givers. There seemed to be an unexpected role reversal observed in some of the transcripts and an underlying sense that some of the participants felt as though they were burdening their care givers. An acknowledgement is made for the challenging role that the care givers have when supporting the participants and a conscious effort is made by some of the participants to act as the ‘’collaborator’’ within the relationship by adapting, and changing their behaviours or requests, in order to support the care givers. For example;

Participant 1: There are sometimes when I feel like I'm asking too much or they've got a time constraint. And I alter it, work with them to actually change it a bit.

Here, Participant 1 indicates that she feels she asks for too much, which may mean that she feels as though she is a burden on her care givers. This could stem from reduced feelings of self-worth or self-esteem whereby Participant 1 does not view her needs as being above those of her care givers. As such, this could stem from unmet needs of relatedness. This may also stem from previous learnt experiences whereby she has been told that she is asking for too much, or that her expectations of care are set too high. An acknowledgement to time constraints also appears here again, and this supports previous discussions. Participant 1 is conscientious of her requests for support and actually alters her behaviour to suit the care givers. She talks about working with them, as though they are part of the same team and as though she is required to work too in order to input into the delivery of her own care. This conscientiousness and awareness of others shows an empathetic and caring nature to Participant 1. It could also be indicative of previous negative experiences with staff whereby the ‘working’ relationship may have broken down and this is something that Participant 1 is now actively trying to avoid. It may also mean that being more flexible in her approach leads to a more positive interaction and care experience with the staff which Participant 1 prefers. From previously discussed comments made by Participant 1, an underlying sense of seeking validation, a need for interpersonal interactions and a need to feel part of a team has been assumed and this may also be another reason as to why she changes her behaviours to suit the needs of others. More comments of a similar nature can be found in Participant 1’s transcript;

Participant 1: I know that the carers are under a certain amount of pressure especially at the moment. So I try and work with them instead of trying to put more pressure on them.

Participant 1: Well, they tend to be very pushed. So I don't think we do have enough time with them. They do seem to be very pushed. And I mean they seem to be…have a lot of people to help. And…but I don't seem to have much time being with any one person.

The conscientiousness of staff needs echoes in this statement too. Again, Participant 1 talks about working with the staff and a need for ‘inclusion’ can be assumed from this. This may come from unmet needs and feelings of isolation and loneliness, which is evidence in comments made about a lack of time being spend with any one person. Participant 1 is conscious as to not put additional pressure on staff and acknowledges staffing pressures which have led to her to adapt her behaviours. As discussed, this ‘people pleasing’ approach could be an attempt to avoid conflict or rejection, or it could stem from previous experiences whereby Participant 1 has felt under pressure. Either way, Participant 1’s role here is to very much be the collaborator, with a need to work collaboratively with her caregivers. Similar conscientiousness of carers needs can be observed in Participant 2 when discussing his care needs;

Participant 2: We are all pains in the ass sometimes.

Here, Participant 2 uses humour when acknowledging the potential burden he may have on his care givers. This statement has been generalised to infer that everyone can cause a burden to others some of the time. What is different here to Participant 1’s comments is that Participant 2 is not discussing changing his behaviour to suit others, he is just acknowledging that at times he may be a pain. He may beusing humour to make light of the situation and to potentially deflect from his acknowledgment of own behaviours. Conversely, a similar comment was made by Participant 1 when discussing her care interactions;

Participant 1: It makes you feel like a pain.

This text was derived from comments Participant 1 made about asking for support from staff. Like Participant 2, Participant 1 is referring to herself as being a pain. However, what is different in this statement is that Participant 1 seems to have internalised the message to some degree whereby she now sees herself, and her requests as genuinely burdening on others. Whilst Participant 2 seems to have the confidence and self-esteem to acknowledge that he may be a burden, he makes light of the issue with humour, Participant 1 does not. Instead, seeing herself as a burden to others appears to be a much bigger issue, and she would rather support their needs. It may also be that Participant 2's need for relatedness is met by means external to staff support.

In a similar context, Participant 3 also inadvertently talks about supporting the needs of staff, and again, working collaboratively with them.

Participant 3: I'll just get on with it. It's professional at the end of the day.

Here, Participant 3 is making reference to working with staff during his personal care routines. The reference to being 'professional', expresses a need for a collaborative relationship with his care givers and again, this could imply that Participant 3 is changing his behaviour to suit this relationship. Another assumption could be that this is too a learnt behaviour from previous negative experiences with staff and the need for professionalism may have been enforced by staff on the care situation in general. It may also be that Participant 3 feels a sense of responsibility over his behaviours and, like participant 1, he feels part of the team. The ''I'll just get on with it'' statement could indicate that the care routines aren't an overly positive experience for Participant 3. As previously discussed, Participant 3 describes himself as an extremely independent individual with a high sense of autonomy. During discussions he also places emphasis on the power of the mind and mental health, over his body. It may be that the act of personal care, whereby Participant 3 is reliant on the support of others, is a reminder of the limitations he faces physically.

Discussion

Within this theme, it seems clear that some of the participants' value the collaborative relationship that they have with their caregivers. They try to adapt to the needs of the caregiver, in order to not over burden them. They seem to adopt the role as the collaborator within this relationship and there is a sense that there is a higher need for them to make this relationship work, than there is for the caregivers. This may stem from reduced feelings of relatedness to others within the care home setting.

6.5. Discussion

Super-ordinate theme 1; Living with a neurological condition

Interpretations

Living with a neurological condition and the way in which one copes with their neurological condition seems to differ depending on a number of factors. Firstly, the type of neurological condition itself seems to be an influential factor in how one copes. Those with a degenerative condition seem to discuss their condition more openly and they seem more realistic in their views when discussing the future. They talk more about adapting to their difficulties and modifying the environment to suit their needs. It also seems that the concept of autonomy and competence appear to grow in importance as their abilities shrink. Whereas those with stable conditions appeared to talk less about their condition, if at all, and did not engage in discussions around adaptations to their difficulties. Rather, instead they spoke about structure and routine within the care home and how this needs to change to suit their needs.

The onset of the neurological condition may be an influential factor into how the participants differ in discussions. For example, a degenerative condition is typically a slow process of deterioration over time whereas an acquired brain injury can cause instant damage. It would also seem that those who are born with a neurological condition could be the most accepting of their situation, and do not view their condition as having an impact on their autonomy.

The notion of compartmentalisation is also apparent within the first theme, with nearly all the participants' separating themselves from their condition. This was queried as a coping mechanism and it seems as though there has been some emotional detachment of all participants from their condition.

Super-ordinate theme 2; What autonomy means to me

Interpretations

What the participants perceived or interpreted autonomy as fell into two categories; ones' own physical abilities and ones' own mental ability to make meaningful choices. Both of which are influenced significantly by ones' environment, highlighting the importance of autonomy-supportive approaches within 24-hr care settings. It seems fair to denote that from this theme, having a restricted environment is more detrimental to ones' sense of autonomy and wellbeing, than having physical limitations as a result of ones' condition. As mentioned before, it was again apparent within this theme that as ones' sense of autonomy shrinks, its value grows.

What else became apparent within this theme was the interlinking of the basic psychological needs. For example, one participant frequently referred to his autonomy as being what he is physically capable of doing at that time (competence), therefore as his competence reduced so too did his autonomy. The need for competence can be met and satisfied through appropriate staff support (relatedness) and the use ACT equipment within the environment which subsequently increases a sense of autonomy.

Super-ordinate theme 3; Life as a permanent resident

Interpretations

Whilst there is a general acceptance from some of the participants that they require the support of a 24-hr care home, there seems to be a sense of institutionalisation within the care home. For example, fixed daily routines and inflexibility around this appear to trigger a negative emotional response from some of the participants. A shortage in staff time also seems to be a common factor across the transcripts, this could lead to a depersonalised approach to care which subsequently impacts on all three basic psychological needs proposed by SDT (Deci & Ryan, 2008). The need to maintain personal/professional boundaries with staff also seems to be a trigger for the participants, in some respects it seems as though the participants are wanting more from their relationships than the caregivers can provide. This unmet need may explain the participants behaviour in trying to maintain such relationships and work ‘’collaboratively’’ with the care givers when receiving support.

The long-term care environment needs to adopt a self-deterministic model of care to ensure the wellbeing and wellness of its service users. The negative impact that a controlling environment, without freedom of choice and flexibility can have on an individuals’ quality of life was evident within this theme. The significant focus that each participant held on the environment and the staff support, over discussions about their own physical conditions, is a strong indicator for where health behaviour change interventions should target in the future for this sample.

Implications

Throughout all the themes, it was apparent that the participants’ viewed themselves as separate to their condition and they did not let their condition define who they are. In doing so, this may provide an increased a sense of control over ones’ life. Which subsequently increases’ ones’ sense of autonomy and competence, leading to a greater sense of wellbeing. In order to do this, the participants tended to focus intently on what they could do, rather than what they couldn’t. They valued having the ability to make decisions and choices and this ability was meaningful to each of them. They also valued the ability to communicate with others and it was clear that this was also very meaningful. All of the participants expressed feelings of autonomy within their lives.

That being said, what was also apparent throughout the themes was the impact that the environment has on the individual. The lack of flexibility in routine, the time constraints with staff and the impact that the environment has on the participants with friends and relatives outside of the home appeared to be the most influential factors for reduced wellbeing and quality of life. All of the participants felt that the environment of the care home hindered their feelings of relatedness to others.

The approach of the staff members was also another key topic of discussion for the participants. It would seem that the approach used by the caregivers is not a consistent approach, in that some staff are autonomy and competence supportive, whereas others aren’t. The participants viewed staff who took their time; listened to their requests, showed empathy towards them and remembered specifics about their care routine as being autonomy-supportive. They viewed those who rushed, did not engage in conversation and did not listen as non-autonomy-supportive. All reported to receive both differing approaches on a regular basis.

The participants felt that more psychological support (or a bigger psychology team) was required within the care home setting. This may well be appropriate for support of the underlying sense of anger derived from some of the transcripts. Targeted support around acceptance and commitment may also be beneficial for this sample. Participants also stated that more trips into the community, different menu options and different daily activities would improve the general wellbeing of all those that reside within the home.

Limitations

Although this study has produced a variety of rich and detailed material concerning the experiences of those with neurological conditions, acknowledgement is required in regards to the limitations of the study.

Firstly, the semi-structured interviews were completed via video calls during the Covid-19 pandemic. As such, the ‘daily life’ within CFNC at that time was different to its usual routine. Video calls are less personal than face to face interviews and key nonverbal cues may have been lost via this method. The participants were all isolated in their own bedrooms, they were only receiving face to face human interactions with staff and they were all deemed to fall within the ‘’highly vulnerable’’ risk category for Covid. Therefore, the way in which the participants answered the questions may not be a wholly reliable representation of life with a neurological condition residing in 24-hr care, but rather a representation of how they felt at that time. Moreover, the uncertainty of the ongoing restrictions and the unknown about future lockdowns within the UK at the time of this research will have undoubtedly impacted on the outcome of the self-reported measures for the basic psychological needs. This can be assumed as evidence collated by the Office of National Statistics (ONS) reviewing coronavirus and the social impacts on Great Britain (16 April 2020) has shown that 4 in 5 adults in the general population were very worried during the pandemic; just over half of adults (53.1%) reported effects on wellbeing and staying in touch with family and friends was said to be the most common action that supported coping (76.9%). Unfortunately for this sample, residing in a care home during this time meant that the only contact with friends and family was via telephone or video calls. That being said, the fact that the participants within this study still reported feeling a sense of autonomy and quality of life, at such a time, is a promising find for the current provisions of support that are in place for this sample.

Secondly, the research could be criticised methodologically due to a lack of homogeneity in the research sample (i.e. only one female participant) which is an important aspect of IPA research. Although all the participants within this study had been diagnosed with a neurological condition there were significant variances in the personal characteristics, clinical history and type of neurological condition. That so, this problem reflects the lack of homogeneity recognised and criticised within the clinical problem itself (Gostemeyer & Levey, 2018) and this sample is reflective of this phenomenon.

Thirdly, the researcher entered this research with significant theoretical knowledge and practice experience within this patient group. This bias must be acknowledged and its possible effects recognised within the findings. As the participants' also knew the interviewer this may have also caused some bias responses.

Future Recommendations

This phase of research attempted to explore the lived experiences of having a diagnosis of a neurological condition and required 24-hr specialist care and support. Given the very limited existing research in this area, it would appear that further research focusing on any similarities and differences in the challenges that may present themselves in those with neurological conditions is required.

This research has highlighted particular experiences of living with a neurological condition for this sample and has shed some light into what is required to promote and maintain a quality of life for such individuals. Future research would benefit from trialling specific SDT-based interventions within the neurological population, inside neurological settings. Interventions specifically targeted at increasing feelings of relatedness to others for this population may be of greatest benefit. It may also be useful to investigate the efficacy of SDT-based interventions against more traditional interventions.

Another important factor worth consideration would be to research common factors that would be necessary to optimise the 24-hr care home environment, to promote the three basic psychological needs of SDT. From the qualitative analysis, whilst the participants all desired a sense of autonomy, there were key barriers within the environment that frustrated this need. For example, rigid routines; an inflexibility in day to day care, time constraints with support staff, a lack of variety in menus and daily activities (or activities not suitable for client) and a sense of feeling like a burden. Despite all of these external barriers within the long-term care setting, it could be argued that targeting the approach of the caregiver would be of most benefit to this sample. Whilst there is no doubt that interventions to challenge the above examples would improve autonomy within the setting, there is a limit to the facilitation of autonomy, irrespective of one's condition. For example, the care setting itself is limited to rules, regulations and policies that staff and service users must adhere to. Therefore a targeted self-deterministic model of care approach adopted by staff can also help to satisfy the needs of relatedness and competence, when autonomy is limited, which during this study it was due to the Covid-19 pandemic. If staff are trained to deliver such a supportive approach, wellbeing and wellness can be maintained adequately at such times.

7. Overall discussion

This chapter draws on the findings from the two data collection points undertaken within this research to summarise the applicability of the self-determination theory in predicting quality of life in those with neurological conditions, residing in neurorehabilitation care homes. This section will begin a brief overview on how the Covid-19 pandemic has impacted on this research. This will be followed by a summary of the findings from both phases and a reflection on the methodology. Clinical implications from the research are then discussed, relating to support and guidance for those working within health care settings on how to promote an autonomy support. The chapter ends with a consideration of the strengths and limitations of the current research and suggestions for future research.

7.1. The impact of Covid-19

This research was conducted and completed during the Covid-19 pandemic. As previously discussed, recruitment and data collection approaches were adapted to meet necessary Covid-19 requirements to manage risk and ensure safety. It is hard to determine whether completing this research during a pandemic has weakened the generalisations of the findings or not. When reflecting on health care services and long-term care settings pre-pandemic (early 2019), during the height of the peak pandemic (2020-2021) and now (2022) much of the health and safety measures implemented within health care settings at the start of the pandemic remain in place now. It could therefore be argued that generalisability of setting has not been limited due to Covid-19. Conversely, it could also be argued that the data collected from those who participated within this research was collated at a time of general angst, unknown and isolation. This would therefore limit the generalisability of findings somewhat to 'normal' life of those with neurological conditions residing in long-term care. However at present it is unclear as to what 'normal' life will look like post-pandemic. It therefore seems too early to state if this research has been weakened or strengthened by the Covid-19 pandemic and whether this research is a 'snap shot' of a certain sample within a certain context at a certain time, or in general. It is therefore important to consider this impact when considering the overall generalisation of the findings within this study.

7.2. Summary of findings

The findings from the quantitative research challenges the theory of SDT in that the three basic psychological needs; autonomy, competence and relatedness, are all required to achieve wellbeing and quality of life. When applied to a sample with neurological conditions, feelings of autonomy and competency together significantly predicted improved quality of life, however relatedness did not. These findings were explored further in more depth in data collection phase 2 of this study.

During the second phase, it became apparent that reduced feelings of relatedness to others was influenced significantly by external factors such as the environment and restrictions within it. In line with the findings in phase 1, all participants reported to feel a sense of autonomy and some competence within their daily life. Again, the support from the environment was a big influential factor in this. Drawing upon the initial findings in phase 1 via the interview process in phase 2 enabled insight into the lived experiences of the participants and shifted the initial assumptions of the researcher. It was assumed that the neurological condition, its symptoms and limitations would be the key focus of the discussions with the participants and that this would also be the key influential factor to ones' sense of autonomy, competence and relatedness to others. However, it came to light that the key influence to these basic psychological needs are in fact the environment and support structure surrounding the individual. It is not ones' own physical ability to complete a task independently that is important, it is that one is enabled to do as much as he can do through the support of others, the environment or adaptive aids. Likewise, if one is able to make choices, no matter how basic, about their needs then one perceives themselves as autonomous. What is important is that the opportunity to make a choice is there.

Autonomy, competence and relatedness to others are all very subjective themes and the way in which they are perceived depends on the circumstances of those perceiving. What one person views as autonomy is different to another person and this changes in line with ones' abilities. For example, having flexibility around meal times is only important when that flexibility is taken away. These such reflections would not have been possible without qualitative data collection. As human beings it is insightful to know that we have the ability to adapt to many given situations in order to achieve a sense of wellness and quality of life.

7.3. Reflection on Methodology

In order to demonstrate a critical understanding of the methodology of enquiry within this study, and to critically reflect on this approach, a reflection on the methodological approach adopted is necessary.

A pragmatic, mixed methods approach was used for this research in order to answer the research questions appropriately (Johnson & Onwuegbuzie, 2004). It has been suggested that mixed methods can offer a range of benefits (Doyle, Brady & Byrne, 2009) including completeness (combining approaches to provide a more comprehensive representation of the phenomenon studied), and an explanation of findings (using one approach to explain the findings from the other). However, there is a great deal of debate within research regarding the suitability of mixed methods, with a number of criticisms being levelled at the approach. One of the main concerns towards mixed methods research related to a perceived incompatibility between quantitative and qualitative techniques. This is because the approaches differ significantly in terms of ontological, epistemological and methodological assumptions. This lack of clearly defined epistemology and ontology has been viewed as reducing the value of both methods together (Sale, Lohfeld & Brazil, 2002). That so, rather than being viewed as opposites, epistemological and ontological considerations belong on a continuum, with mixed methods falling between positivism and constructivism as pragmatism.

Quantitative research (or positivist) is considered by many to be the ‘gold standard’ (Doyle, Brady & Byrne 2009), suggesting that there is a ‘single truth’ in the world which can be established by objective measures (Johnson & Onwuegbuzie, 2004). While quantitative techniques are extremely effective for a number of research questions, for example comparing scores on outcome measures and establishing relationships, they may also be considered limiting when used in isolation within psychosocial research such as that of this thesis. By incorporating qualitative methods into this study, the researchers’ interaction with the participants has enabled a truer understanding of the social and cultural contexts within the research questions (Creswell, 1994).

This research was therefore approached with a degree of intersubjectivity, in that whilst there may be a ‘single truth’, individuals are still unique and they differ greatly in terms of their perceptions of that truth. For example, whilst the questionnaires provided a clear, measurable effect of SDT and the basic psychological needs on quality of life, the interviews were aimed at gaining a deeper level understanding of the way in which the participants interpreted their experiences.

Adopting this pragmatic approach may lend itself to answering 'real world' questions in a practical, applicable way by reducing the restrictions imposed from positivism or constructivism approaches alone (Feilzer, 2010).

Employing a mixed methods approach is timely and challenging and as such, requires careful planning and time management skills of the researcher. Whilst a definite pragmatic technique for conducting mixed methods research is yet to be established (Johnson & Onwuegbuzie, 2004), it can be viewed as a way of combining approaches to ensure the most effective way of answering specific research questions (Doyle, Brady & Byrne 2009).

Triangulation of findings requires the researcher to compare the quantitative and qualitative findings in order to establish convergence (agreement), or dissonance (disagreement) between the two techniques (O'Cathain, Murphy & Nicholl, 2010). Within this study convergence between the two techniques occurred, with the qualitative findings expanding on what the quantitative findings concluded. As such, this gives greater credibility to the findings within this study (Fetters, Curry & Creswell, 2013). That so, inconsistencies amongst findings is common amongst mixed methods research and is expected with objective outcome measures and subjective views (Nevo & Nevo, 2009).

Whilst dissonance did not occur within this research, potential for it to occur is acknowledged particularly, as previously discussed, some of the outcome measures used were not specifically designed for the study sample. As such, if discrepancies in findings did occur, it may be assumed that these were linked to the generic nature of the outcome measures (Gaskell, 2007). Moreover, social desirability bias can occur with the participants given the answers they feel the researcher wants (Helitzer-Allen & Kendall, 1992). If dissonance had occurred within this study, a number of strategies could have been implemented to address this, for example conducting follow-up interviews (Helitzer-Allen & Kendall, 1992) to explore the inconsistencies.

Whist triangulation of findings is one way to increase the credibility and validity of the qualitative findings, other validation procedures were also considered. For example, in order to make reliable thematic connections across the transcripts, a thorough process of code-recode took place with the transcripts ensuring short periods of time (days) in between to allow researcher breaks in between analysis. Regular supervisions also allowed opportunities to discuss research reasoning and one of the participants (participant 3) also reviewed the overall results and interpretations from the qualitative analysis to increase confirmability of this study.

Overall, it seems fair to state that the use of mixed methods worked well within this study in answering the research questions. Convergence was found between the quantitative and qualitative techniques, lending strength to the findings. It is recommended that future psychosocial research into neurological conditions continue to employ a mixed methods approach where appropriate in order to address specific research questions.

7.4. Clinical implications

Current research to ensure new initiatives for improving patient care are used in clinical practice is limited and, and the small amount of research that has been conducted to explore the area is largely atheoretical (Eccles et al, 2009). Based on the assumption that clinical practice is a behaviour, we can draw on the use of theories from health psychology, such as SDT that predict and explain health behaviour outcomes (Eccles et al, 2005).

This research has developed an independent judgment of issues experienced by those with neurological conditions residing in long-term care and there are important implications for health psychology as a result of this study. The current research highlights the importance of autonomy-supportive approaches and a consideration for how these approaches are delivered when supporting the wellbeing and quality of life in those with neurological conditions residing in neurorehabilitation settings. What is apparent within this study, and across research within the neurological domain is that there if a lack of appreciation of social and psychological processes underpinning support for neurological conditions which has led to different agendas for patients and professionals (paternalisticmodel of care), a lack of recognition of power relationships, and an insufficient management for emotional responses. This was interpreted from the anger observed in one participants within the qualitative analysis. Specialist support can be provided by health psychologists to target such issues and to support those with neurological conditions. For example, education could be provided to support staff on the biopsychosocial perspective to facilitate a patient-centred approach (Kusnanto, Agustian & Hilmanto, 2018; Ellis-Hill, Payne & Ward, 2008) and support can be provided around effective communication. Psychoeducation can be provided around the importance of the self-deterministic model of care, effective SMART goals can be set and targeted interventions can be delivered (i.e. cognitive behavioural therapy, mindfulness and pacing programmes). What is key within Health psychology is that it is reliant on a good understanding of the unique perspectives of the individual which provides the foundations for effective clinical work to support engagement in therapy, adaptation and to overall improve the quality of life of others.

Another key implication of this study is the application of the shifting perspectives model of chronic illness (Paterson, 2001) to neurological conditions. This theory provides guidance for health psychologists and other clinical practitioners as to when additional support and intervention might be needed. It also provides insight into the ongoing, shifting coping process inwhich an individual with a chronic illness endures.

This study also provides an insight into which psychological needs are threatened for those with neurological conditions. By recognising that feelings of competence and relatedness are at risk of becoming reduced and unmet, practitioners can tailor their support and interventions appropriately in order to support the fulfilment of this need.

A key aim of this study was to broaden the scope of practice for health psychologists when supporting those with chronic conditions. Typically health psychology as discipline is well established with supporting chronic conditions such as cardiovascular disease; chronic obstructive pulmonary disease, chronic fatigue, irritable bowel syndrome, diabetes, obesity and chronic pain. However, neurological conditions also satisfy the criteria of a chronic condition and the need for this specialist support has been evidenced within this study.

7.3.1. Strengths

This is the first study to apply the theory of Self-Determination to a sample of neurological conditions residing in a neurological care home. Interesting insights have been gained from this research which can be used to shape future research and interventions. Convergence established in the mixed methods approach gives weighting to the findings and has provided an answer to the research question that a quantitative or qualitative approach alone could not achieve. The participants within this study were given the opportunity to discuss their lived experiences openly with the hope to support others in similar situations in the future.

Key points have already been established within this research that can inform clinical practice within the neurological field and future research should aim to build upon this.

7.3.2. Limitations

This research has been generalised across a broad range of neurological conditions, therefore specific differences amongst conditions have not be established. The research has been conducted with a sample that are all at a point in their ‘treatment’ where they required 24-hr care and support. For some, this has occurred suddenly with the onset of an acquired injury and for others this is a result of this deteriorating condition. Either way, it must be acknowledged that for the sample used in this study their physical needs are considered too high for them to live independently or with a care package at home. They are therefore classed by the National Health Service (NHS) as some of the most dependant individuals in the country. This therefore limits the generalisation of the findings to the neurological population as not all individuals with neurological conditions will require such an intensity of support.

7.5. Future recommendations

Future research should consider condition specific samples in order to establish individual differences amongst the conditions and develop more individualised treatment pathway. Interventions for those with neurological conditions residing in 24-hr care should focus on supporting the all three basic psychological needs, however the needs of competence and relatedness for the participants within this sample were not met statistically and therefore research should prioritise establishing adequate support of these needs in the first instance. The environment is a pivotal factor in supporting quality of life, as is the approach of the staff and the need for autonomy support. A self-deterministic model of care should be considered over a paternalistic model of care within such settings to support wellness and positive healthoutcomes. Further research should look into targeted interventions that utilise such approaches and trial the applicability of these on the neurological population.

A review of funding should be considered for specialist neurorehabilitation care centres to ensure that staffing levels are optimal and that staff are able to invest time in the service users.

SDT research should consider the impact of the social context of those who live in a care home environment and test the generalisability of the theory across such populations further.

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9. Appendix

Appendix 1 – Study Information Sheets (Quantitative phase 1)

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

Participant information sheet

FAO potential research participants

You are invited to take part in research taking place at Castel Froma Neuro Care; Lillington House and Helen Ley House sites. It is funded independently by the researcher. Before you decide whether to take part, it is important for you to understand why the study is being conducted and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact [redacted] or EXT 231.

Research team

This research is being conducted by Katie McCourt, currently studying a professional doctorate in Health Psychology at University of the West of England (UWE) Bristol. Supervised by Tim Moss, [redacted] (Director of Studies) and James Byron-Daniel, [redacted] (second supervisor).

The aim of the research

The research is looking at how a theory of motivation and behaviour can predict quality of life and wellbeing in neurological conditions in neurorehabilitation settings. As this theory is recognised as a good predictor of wellbeing for other health conditions and other settings, we want to know if it can be applied to neurological conditions within a neurorehabilitation setting. To help us answer these questions we will be conducting self-reported questionnaires.

Any data collected will be made anonymous and there will be way of tracing the data back to participants.

The results of our study will be analysed and used in a report made available to the University of the West of England's open-access repository and will fulfil the research component of the above mentioned professional doctorate.

The anonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

As a resident of Castel Froma Neuro care, we are interested in gaining information about your quality of life and wellbeing. Therefore you will be asked for information specific to this. We will not be asking any questions relating to anyone else, or that are specific to your neurological condition.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form. If you do decide to take part, you are able to withdraw from the research without giving a reason until the point at which your data is anonymised and can therefore no longer be traced back to you. This point will take place 14 days from the date you signed your consent form. If you want to withdraw from the study within this period, please write [redacted] at [redacted] telephone internally EXT 213 or request a face to face meeting. Deciding not to take part or to withdrawal from the study does not have any penalty, it will not affect the standard of care that you receive at Castel Froma or anything related to your current situation.

What will happen to me if I take part and what do I have to do?

If you agree to take part you will be asked to complete 6 self-reported questionnaires that use closed questions with either a yes/no answer of a likert scale rating (0-6) to answer questions. All questionnaires will be conducted by [redacted]. The data collection will take place at either [redacted] [redacted] (depending on which one you reside at), [redacted] will come to you to facilitate everything.

The subject and focus of the discussion will be around quality of life, wellbeing and how you view your current situation. Your personal data and answers will be fully anonymised.

What are the benefits of taking part?

This research is designed to address a major deficit in knowledge regarding the support of wellbeing and quality of life for those with neurological conditions residing in neurorehabilitation care homes. If you take part, you will be helping us to gain a better understanding of how to support those with neurological conditions in long-term or permanent care settings.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for questionnaire to stop. If you need any support during or after the questionnaire then the researcher will be able to put you in touch with suitable support agencies. The research team is experienced in conducting questionnaires and are sensitive to the subject area. All data collection methods have been designed with these considerations in mind.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and anonymised two weeks after formal consent and participation of questionnaires. The only circumstance where we may not be able to keep your information confidential is that should, during any time that we work with you there becomes any concern for immediate risk of harm to yourself or anyone else. Information relevant to the concerns of harm will need to be passed onto [redacted] Hard copy research material will be kept in a locked and secure cabinet in a locked and secured office. [redacted] will have access to the

keys, in accordance with UWE's and Castel Froma Neuro Care's and the Data Protection Act 2018 and General Data Protection Regulation requirements. Questionnaires will be destroyed securely immediately after anonymised data. Your anonymised data will be analysed together with other and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Where will the results of the research study be published?

A Report will be written containing our research findings. This Report will be available on the University of the West of England's open-access Research Repository. The project funder is [redacted]

A hard copy of the Report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by the Faculty/University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

Direct contact will be made to Director of Studies in the first instance.

What if I have more questions or do not understand something?

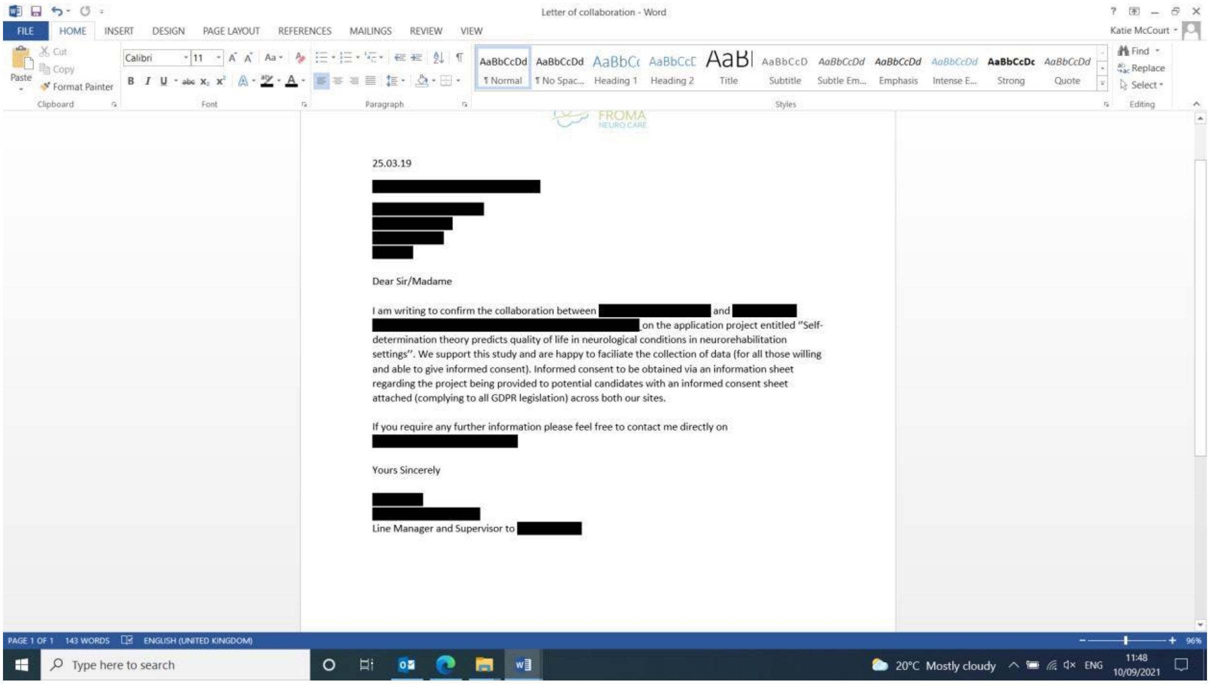
If you would like any further information about the research please contact in the first instance:

[redacted]

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Appendix 2 – Letter of collaboration



FROMA
NEURO CARE

25.03.19

[redacted]

[redacted]

Dear Sir/Madame

I am writing to confirm the collaboration between [redacted] and [redacted] [redacted] on the application project entitled "Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings". We support this study and are happy to faciliate the collection of data (for all those willing and able to give informed consent). Informed consent to be obtained via an information sheet regarding the project being provided to potential candidates with an informed consent sheet attached (complying to all GDPR legislation) across both our sites.

If you require any further information please feel free to contact me directly on [redacted]

Yours Sincerely

[redacted]
Line Manager and Supervisor to [redacted]

Appendix 3 – Risk assessment for data collection

RISK ASSESSMENT FORM

Name: **DOB:**	N/A	Area or activity assessed	One to one sessions to collect quantitative and qualitative data, independently from residents at Lillington House/Helen Ley for research projects.
Assessment Date	12.07.2019		
Review Date			
Persons who might be affected by the activity (i.e. are at risk)	Katie McCourt, residents, residents relatives, staff of Castel Froma		

Risk Controls

Hazard No.	**Hazard Description**	**Existing controls to reduce risk**	**Risk Level**	**Further action needed to reduce risks** ***(provide timescales and initials of person responsible)***
			High **Med** **Low**	
1.	Fire at HL/LH	• All staff and residents aware of fire safety procedure, training regularly received • Fire exits are readily available and one to ones will be held within close proximity of fire exit doors • Katie to ensure fire safety training is up to date before data collection • Katie to always make line manager aware of whereabouts, and clearly communicate the whereabouts of residents	Low	• Re-read fire safety policy before data collection
2.	Lone working with residents	• Lone working policy in situ. • Castel Froma did not accept "challenging behaviours" i.e. verbal and physical aggression – this therefore significantly reduces risk of harm • Katie already familiar with residents as has been currently working at Castel Froma for over two years	Low	• Re-read lone working policy before data collection • Always inform line manager of whereabouts
3.	Increased fatigue / tiredness to residents	• Discussions with care staff, MDT, nursing team, resident and relative to ensure that the best time for the resident is chosen for data collection • Support from SALT team to facilitate most effective way of communicating to some complex residents	Low	• Katie to ensure flexibility with data collection times (whilst still setting an end date to stop collecting data) to allow for unexpected hospital visits, illness etc.

Additional notes and information	
Review dates	

Appendix 4 – Consent form – written (Quantitative phase 1)

Consent Form

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a [redacted] whose details are set out on the Participant Information Sheet.

If you are happy to take part in the completion of six brief self-reported questionnaires, sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed)…………………………………………………………………………….

Signature…………………………………………………. Date…………………….

Appendix 5 – Consent form – veral (Quantitative phase 1)

Consent Form

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact [redacted] whose details are set out on the Participant Information Sheet.

If you are happy to take part in the completion of six brief self-reported questionnaires verbally state your consent and the date. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed)………………………………………………………………………….

Verbal consent (recorded)…………………………………………………….

Date…………………….

Appendix 6 – Participant information sheet (Qualitative data collection phase 2)

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

Participant information sheet

FAO potential research participants

You are invited to take part in research taking place at [redacted] sites. It is funded independently by the researcher. Before you decide whether to take part, it is important for you to understand why the study is being conducted and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact [redacted] or EXT 231.

Research team

This research is being conducted by Katie McCourt, currently studying a professional doctorate in Health Psychology at University of the West of England (UWE) Bristol. Supervised by Tim Moss, [redacted]Director of Studies) and James Byron-Daniel, [redacted] (second supervisor).

The aim of the research

The research is looking at how a theory of motivation and behaviour can predict quality of life and wellbeing in neurological conditions in neurorehabilitation settings. As this theory is recognised as a good predictor of wellbeing for other health conditions and other settings, we want to know if it can be applied to neurological conditions within a neurorehabilitation setting. To help us answer these questions we will be conducting a semi-structured interview.

Any data collected will be made anonymous and there will be way of tracing the data back to participants.

The results of our study will be analysed and used in a report made available to the University of the West of England's open-access repository and will fulfil the research component of the above mentioned professional doctorate.

The anonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

As a resident of Castel Froma Neuro care, we are interested in gaining information about your quality of life and wellbeing. Therefore you will be asked for information specific to this. We will not be asking any questions relating to anyone else, or that are specific to your neurological condition.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form. If you do decide to take part, you are able to withdraw from the research without giving a reason until the point at which your data is anonymised and can therefore no longer be traced back to you. This point will take place 14 days from the date you signed your consent form. If you want to withdraw from the study within this period, please write to [redacted] at [redacted] telephone internally EXT 213 or request a face to face meeting. Deciding not to take part or to withdrawal from the study does not have any penalty, it will not affect the standard of care that you receive at Castel Froma or anything related to your current situation.

What will happen to me if I take part and what do I have to do?

If you agree to take part you will be asked to complete a semi-structured interview. This will be conducted by [redacted] who is experienced in the subject matter and is sensitive to issues it may raise. The semi-structured interview will take approximately 30 minutes. The data collection will take place at either [redacted] (depending on which one you reside at), [redacted] will come to you to facilitate everything.

The subject and focus of the discussion will be around quality of life, wellbeing and how you view your current situation. Your answers will be fully anonymised.

The semi-structured interview this will be recorded using a dictaphone. The recording will not contain your name or any identifiable information, it will be kept in locked cabinet alongside the data collected from the questionnaires that [redacted] will hold the key for. No one else will have access to this data. If you choose to withdraw from the research, you have two weeks from the date you give consent and a unique identifier will be used to re-identify you. Once the data is anonymised we cannot identify your data to then remove it.

At the point of data analysis and transcription, all data obtained and your voice recording will be destroyed. Your data will be anonymised at this point and will be analysed with interview data from other anonymised participants.

What are the benefits of taking part?

This research is designed to address a major deficit in knowledge regarding the support of wellbeing and quality of life for those with neurological conditions residing in neurorehabilitation care homes. If you take part, you will be helping us to gain a better understanding of how to support those with neurological conditions in long-term or permanent care settings.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the interview to stop. If you need any support during or after the interview then the researcher will be able to put you in touch with suitable support agencies. The research team is experienced in conducting semi-structured interviews and are sensitive to the subject area. All data collection methods have been designed with these considerations in mind.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information from the semi-structured questionnaires will be anonymised at the point of transcription. The only circumstance where we may not be able to keep your information confidential is that should, during any time that we work with you there becomes any concern for immediate risk of harm to yourself or anyone else. Information relevant to the concerns of harm will need to be passed onto [redacted] Hard copy research material will be kept in a locked and secure cabinet in a locked and secured office. Only [redacted] will have access to the keys, in accordance with UWE's and Castel Froma Neuro Care's and the Data Protection Act 2018 and General Data Protection Regulation requirements. Voice recordings will be destroyed securely immediately after anonymised data and transcription. Your anonymised data will be analysed together with other interviews and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Where will the results of the research study be published?

A Report will be written containing our research findings. This Report will be available on the University of the West of England's open-access Research Repository. The project funder is [redacted].

A hard copy of the Report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by the Faculty/University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the [redacted]

[redacted]

What if something goes wrong?

Direct contact will be made to Director of Studies in the first instance.

What if I have more questions or do not understand something?

If you would like any further information about the research please contact in the first instance:

[redacted]

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Appendix 7 – Consent form - written (Qualitative data collection phase 2)

Consent Form

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a [redacted] whose details are set out on the Participant Information Sheet.

If you are happy to take part in the completion of a semi-structured interview, sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed)……………………………………………………………………………….

Signature………………………………………………………. Date…………………….

Appendix 8 – Consent form – verbal (Qualitative data collection phase 2)

Consent Form

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a [redacted] whose details are set out on the Participant Information Sheet.

If you are happy to take part in the completion of a semi-structured interview, verbally state your consent and the date. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed)………………………………………………………………………….

Verbal consent (recorded)…………………………………………………….

Date…………………….

UWE Bristol University of the West of England

CASTEL FROMA NEURO CARE

Appendix 9 – Debriefing form

Debriefing Form

Self-determination theory predicts quality of life in neurological conditions in neurorehabilitation settings

If you have any queries about the study or have any further questions please do not hesitate to contact me using the details provided below.

Contact Details:

[redacted]

Tel: [redacted]

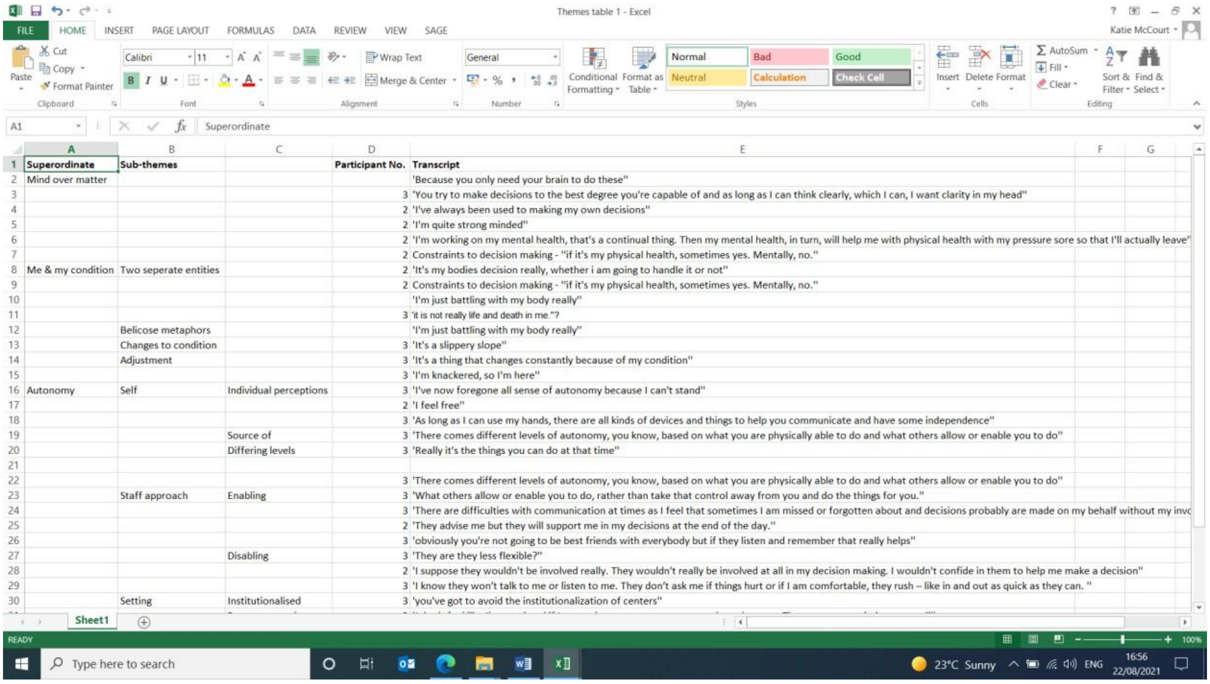
E-mail: [redacted]

I'd like to take this opportunity to thank you for your contribution to the current study and a sample copy of the findings will be available to you if you choose.

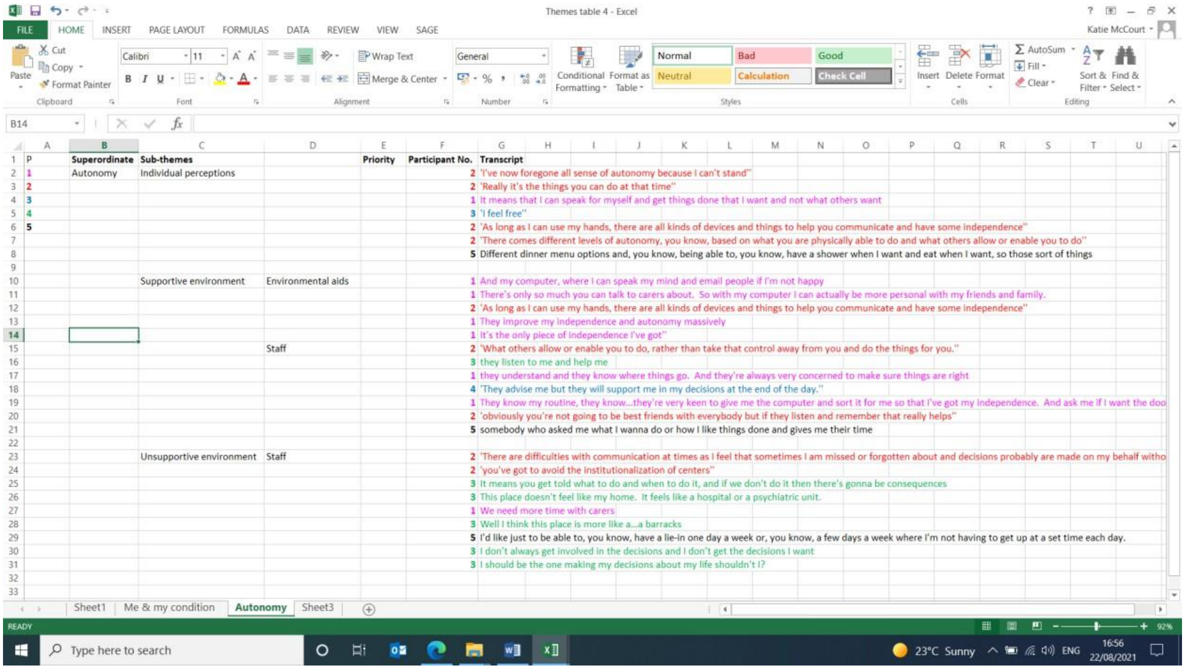
If you do feel you wish to withdraw from the study at any time before the write up of the study is complete, please email me, stating your personal ID number.

Some of the subjects within the study may have been of a sensitive nature to you or you may have further questions. If so, please do not hesitate to contact any of the services below, who will be more than happy to offer you support and guidance.

Appendix 10 – Example of table of themes



	Superordinate	Sub-themes		Participant No.	Transcript
2	Mind over matter				'Because you only need your brain to do these"
3				3	'You try to make decisions to the best degree you're capable of and as long as I can think clearly, which I can, I want clarity in my head"
4				2	'I've always been used to making my own decisions"
5				2	'I'm quite strong minded"
6				2	'I'm working on my mental health, that's a continual thing. Then my mental health, in turn, will help me with physical health with my pressure sore so that I'll actually leave"
7				2	Constraints to decision making - "if it's my physical health, sometimes yes. Mentally, no."
8	Me & my condition	Two seperate entities		2	'It's my bodies decision really, whether i am going to handle it or not"
9				2	Constraints to decision making - "if it's my physical health, sometimes yes. Mentally, no."
10					'I'm just battling with my body really"
11				3	'it is not really life and death in me."?
12		Belicose metaphors			'I'm just battling with my body really"
13		Changes to condition		3	'It's a slippery slope"
14		Adjustment		3	'It's a thing that changes constantly because of my condition"
15				3	'I'm knackered, so I'm here"
16	Autonomy	Self	Individual perceptions	3	'I've now foregone all sense of autonomy because I can't stand"
17				2	'I feel free"
18				3	'As long as I can use my hands, there are all kinds of devices and things to help you communicate and have some independence"
19			Source of	3	'There comes different levels of autonomy, you know, based on what you are physically able to do and what others allow or enable you to do"
20			Differing levels	3	'Really it's the things you can do at that time"
21					
22				3	'There comes different levels of autonomy, you know, based on what you are physically able to do and what others allow or enable you to do"
23		Staff approach	Enabling	3	'What others allow or enable you to do, rather than take that control away from you and do the things for you."
24				3	'There are difficulties with communication at times as I feel that sometimes I am missed or forgotten about and decisions probably are made on my behalf without my invc
25				2	'They advise me but they will support me in my decisions at the end of the day."
26				3	'obviously you're not going to be best friends with everybody but if they listen and remember that really helps"
27			Disabling	3	'They are they less flexible?"
28				2	'I suppose they wouldn't be involved really. They wouldn't really be involved at all in my decision making. I wouldn't confide in them to help me make a decision"
29				3	'I know they won't talk to me or listen to me. They don't ask me if things hurt or if I am comfortable, they rush – like in and out as quick as they can. "
30		Setting	Institutionalised	3	'you've got to avoid the institutionalization of centers"



	P	Superordinate	Sub-themes		Priority	Participant No.	Transcript
2	1	Autonomy	Individual perceptions			2	'I've now foregone all sense of autonomy because I can't stand"
3	2					2	'Really it's the things you can do at that time"
4	3					1	It means that I can speak for myself and get things done that I want and not what others want
5	4					3	'I feel free"
6	5					2	'As long as I can use my hands, there are all kinds of devices and things to help you communicate and have some independence"
7						2	'There comes different levels of autonomy, you know, based on what you are physically able to do and what others allow or enable you to do"
8						5	Different dinner menu options and, you know, being able to, you know, have a shower when I want and eat when I want, so those sort of things
9							
10			Supportive environment	Environmental aids		1	And my computer, where I can speak my mind and email people if I'm not happy
11						1	There's only so much you can talk to carers about. So with my computer I can actually be more personal with my friends and family.
12						2	'As long as I can use my hands, there are all kinds of devices and things to help you communicate and have some independence"
13						1	They improve my independence and autonomy massively
14						1	It's the only piece of independence I've got"
15				Staff		2	'What others allow or enable you to do, rather than take that control away from you and do the things for you."
16						3	they listen to me and help me
17						1	they understand and they know where things go. And they're always very concerned to make sure things are right
18						4	'They advise me but they will support me in my decisions at the end of the day."
19						1	They know my routine, they know...they're very keen to give me the computer and sort it for me so that I've got my independence. And ask me if I want the doo
20						2	'obviously you're not going to be best friends with everybody but if they listen and remember that really helps"
21						5	somebody who asked me what I wanna do or how I like things done and gives me their time
22							
23			Unsupportive environment	Staff		2	'There are difficulties with communication at times as I feel that sometimes I am missed or forgotten about and decisions probably are made on my behalf witho
24						2	'you've got to avoid the institutionalization of centers"
25						3	It means you get told what to do and when to do it, and if we don't do it then there's gonna be consequences
26						3	This place doesn't feel like my home. It feels like a hospital or a psychiatric unit.
27						1	We need more time with carers
28						3	Well I think this place is more like a...a barracks
29						5	I'd like just to be able to, you know, have a lie-in one day a week or, you know, a few days a week where I'm not having to get up at a set time each day.
30						3	I don't always get involved in the decisions and I don't get the decisions I want
31						3	I should be the one making my decisions about my life shouldn't I?

Appendix 11 – Systematic Review – ‘’The effectiveness of psychosocial interventions for post-stroke fatigue’

The Effectiveness of Psychosocial Interventions in Reducing Post-Stroke Fatigue. A Systematic Review.

5967 words

Katie McCourt

Abstract

The effectiveness of psychosocial interventions in reducing post-stroke fatigue. A systematic review.

Background. Fatigue is a prevalent and debilitating symptom of stroke, to date no intervention has been recommended as an effective treatment of post-stroke fatigue. The majority of available research focuses on the effectiveness of pharmacological studies. Therefore, is it important to establish if any psychosocial intervention could support the reduction of fatigue in stroke survivors.

Methods. Study inclusion criteria consisted of any psychosocial intervention reporting measures of fatigue as a primary and/or secondary outcome of therapy using post-stroke cohorts. The following databases were searched electronically from the year 2000 to present: MEDLINE, PUBMED, PsychINFO and CINAHL along with grey literature and hand searching. The methodological quality of the included studies was evaluated using the Effective Public Health Practice Project (EPHPP) tool.

Key results. Eight studies implementing psychosocial interventions with 341 post-stroke individuals were included. Five studies were primarily intended to treat post-stroke fatigue, the other three studies included post-stroke fatigue as a secondary outcome measure. To date, there is insufficient evidence to support the use of psychosocial interventions as an effective treatment for post-stroke fatigue, due to the lack of reliable evidence presented.

Quality of evidence. Overall the general quality of included studies is low to moderate. Study designs were poor and the majority of samples were small and ungeneralizable to the target population. The feasibility of psychosocial interventions for post-stroke fatigue is evident therefore more robust randomised controlled trials are required for future research.

Introduction

Stroke is the second-ranked cause of mortality in the world [1]. It causes physical disabilities; cognitive difficulties, psychological issues and behavioural impairments [2]. Whether ischemic or haemorrhagic, stroke is increasingly prevalent and both types can leave a myriad of debilitating symptoms for its survivors. A predominant disabling symptom is fatigue, affecting up to 72% of stroke survivors [3]. Research shows that even years after stroke, fatigue does not diminish [4].

Up until recently, fatigue has always been considered a symptom of post-stroke depression [5]. However antidepressants as a treatment of post-stroke fatigue have not been effective [6] and the fact that depression free stroke survivors suffer from fatigue has prompted the consideration of ''post-stroke fatigue'' (PSF) as a specific syndrome [7].

There is no consensual definition of PSF. The aetiology of PSF is unknown and a multitude of psychosocial, behavioural and biological factors might be associated with it [8]. It has been described as a disease state that is characterised by a chronic and persistent tiredness; excessive lack of energy [6,9] and a weakness or exhaustion after stroke [10] which can present itself both mentally and or physically [11]. It is also unrelated to previous exertion levels [12]. It significantly impedes on an individuals' daily life; limiting participation in rehabilitation, functional independence and overall quality of life[13]. It affects both the psychological and physical function as well as being a predictor of death following stroke [14].

To date, the United Kingdom's National Clinical Guidelines for Stroke [15] provides no clear definition or evidence for PSF treatment and the literature on interventions for PSF is still nascent. The Australian National Clinical Guidelines for Stroke briefly mentions fatigue [16] highlighting that information and education about fatigue, along with potential self-management strategies should be provided to stroke survivors, family members and caregivers [16]. The Canadian guidelines also recommend education and 'energy conservation strategies' [17]. Despite this, little guidance has been provided on what specific strategies would be effective and there is still no routine treatment for PSF.

The limited research that is available has placed emphasis on researching pharmacological interventions as seen in a recent Cochrane review [8]. This review subsequently highlighted limited evidence of pharmacological treatments as effective PSF treatments. Thus, emphasising that the management of severe conditions and symptoms, such as PSF, should not be subjective to medication. Particularly when PSF has been conceptualised as a complex multi-dimensional symptom [18].

Further consideration should be taken into psychosocial interventions by considering the complex interplay of not just biological, but psychological and social factors that may influence levels of PSF.

The review of literature currently available regarding the treatment of fatigue prevalence in other chronic diseases, for example cancer, multiple sclerosis and chronic fatigue syndrome, has found cognitive therapy [19-22]; fatigue education programmes [18], the application of behaviour change techniques [23, 24] and increased physical activity [25,26] effective in alleviating symptoms of fatigue.

Therefore psychosocial interventions specifically aimed at improving symptoms of fatigue in chronic conditions are promising approaches that may be effective in reducing PSF.

Why it is important to do this review

The purpose of this systematic review is to explore the significant gap in literature regarding the potential for psychosocial interventions for treating the highly prevalent and debilitating symptoms of post-stroke fatigue.

Objectives

To determine whether psychosocial interventions among individuals with stroke are effective at alleviating symptoms of fatigue.

2.0 Method

In June 2018, this review was submitted and accepted for registration by PROSPERO (https://www.crd.york.ac.uk/PROSPERO/).

2.1 Search Strategy

Searches were conducted on the following electronic databases: MEDLINE, PUBMED, PsychINFO and CINAHL. Four further databases were searched to identify any grey literature: PsychBITE, Trials Central, Stroke Trials Registry, and Health Service Research Projects in Progress. Furthermore, the reference lists of all included articles were screened manually. Searches were conducted in June 2018. MEDLINE search strategy was developed using a combination of population, intervention and outcome search terms and MESH terms were adapted where necessary. The terms included: ‘’stroke’’, ‘’post stroke’’, ‘’brain haemorrhage’’, ‘’ischemic stroke’’, ‘’cerebral infarction’’ and ‘’brain aneurysm’’. Intervention search terms included: ‘’behavior therapy’’, ‘’behaviour interventions’’ ‘’cognitive therapy’’, ‘’cognitive behavioural therapy’’, ‘’CBT’’, ‘’psychotherapy’’, ‘’mind-body therapies’’, ‘’psychotherapy’’, ‘’meditation’’, ‘’mindfulness’’, ‘’relaxation therapy’’, ‘’psychosocial’’, ‘’psychoeducation’’. Outcome search terms included: ‘’fatigue’’, ‘’mental fatigue’’, ‘’muscle fatigue’’, ‘’chronic fatigue’’. See appendix 2. for example of search strategy.

2.2 Eligibility Criteria

In order to identify relevant non-pharmacological, psychosocial interventions that target post-stroke fatigue the following set of inclusion criteria was developed. The articles had to be published in English from 2000 to 2018 in order to provide a current review of literature.

Inclusion criteria;

- Post-stroke cohort
- Studies including fatigue as primary and/or secondary outcome
- Fatigue symptoms reported as continuous variables on a fatigue scale
- Interventions could include a psychosocial, psychotherapeutic, psychoeducational or physical activity approach
- Individual or group-based interventions, any method of delivery
- Pre and post-intervention measure of fatigue

No differentiation between blinded and non-blinded procedures and random allocation was not considered a necessity, as this might have limited the number of studies included.

Exclusion criteria;

- Mixed methods and qualitative studies
- Participants with any other neurological condition other than stroke as this may influence outcomes
- Medical or pharmacological interventions

Identified abstracts were initially read and reviewed in relation to the eligibility criteria by the first author. Abstracts potentially relevant to this review were then screened by another reviewer. An additional third reviewer was then included to review full-text articles and screen against inclusion criteria.

2.3 Data extraction

All relevant data was extracted from the final articles using a standardised data extraction protocol. The extracted data included; methods (design, location, setting, allocation), participants (number per condition, mean age, stroke criteria, fatigue criteria, time since stroke onset), intervention (treatment, control, duration, method of delivery), outcomes (measures, reliability, validity, timing, administration), and data analysis (withdrawals/non completers, baseline group comparison, findings). Where necessary authors were contacted for separate information regarding just stroke participants. For example some studies included samples of mixed neurological conditions [27-29]. See table 1. for data extracted characteristics of included studies.

2.4 Appraisal of Study Quality

The methodological quality of the included studies was evaluated using the Effective Public Health Practice Project (EPHPP) tool as it is designed to suit quantitative studies. The tool was applied independently by the author and second reviewer. Any discrepancies among the two reviewers were discussed collectively with the third reviewer and final decisions were made in agreement. This tool will be applied to the narrative synthesis to support the evaluation of strength and evidence for the included studies. See table 3. For EPHPP assessment outcomes.

2.5 Data Synthesis

Studies were assessed for methodological and clinical heterogeneity. Due to the vast differences in the included studies a meta-analysis was deemed inappropriate for this review as this may produce misleading results. Instead a narrative synthesis will be conducted to evaluate interventions.

3.0 Results

See figure 1. (PRISMA flow diagram) for the process and outcome of the search.

The key characteristics of included studies will be highlighted. A narrative synthesis will then be provided discussing the reported effects and evidence for the effectiveness of psychosocial interventions on PSF.

3.1 Included studies

Among the eight included studies (341 participants), five studies (141 participants) were primarily intended to treat PSF [16, 18, 28, 29, 30,].

Three studies (200 participants) did not primarily target the treatment of PSF, however reported fatigue as an outcome post treatment [31, 32, 27]. See table 1. for summary of included studies characteristics.

3.2 Participant characteristics

Age and sex. All eight studies (341 participants) recruited female and male adults, with the male proportion ranging from 15% [29] to 73% [16]. The mean age ranged from 48 years [29] to 72 years [18], except for two trials that recruited populations with mixed conditions, and therefore did not report these demographics separately for the stroke samples [27, 28].

Stroke criteria. Seven studies recruited participants with ischaemic or haemorrhagic stroke [16, 18, 27-30, 32] and one trial recruited participants with single unilateral stroke [31].

Recruitment. Seven studies recruited community dwelling participants with stroke [16, 18, 27-31] and one study recruited in-patients of a stroke neurorehabilitation centre [32].

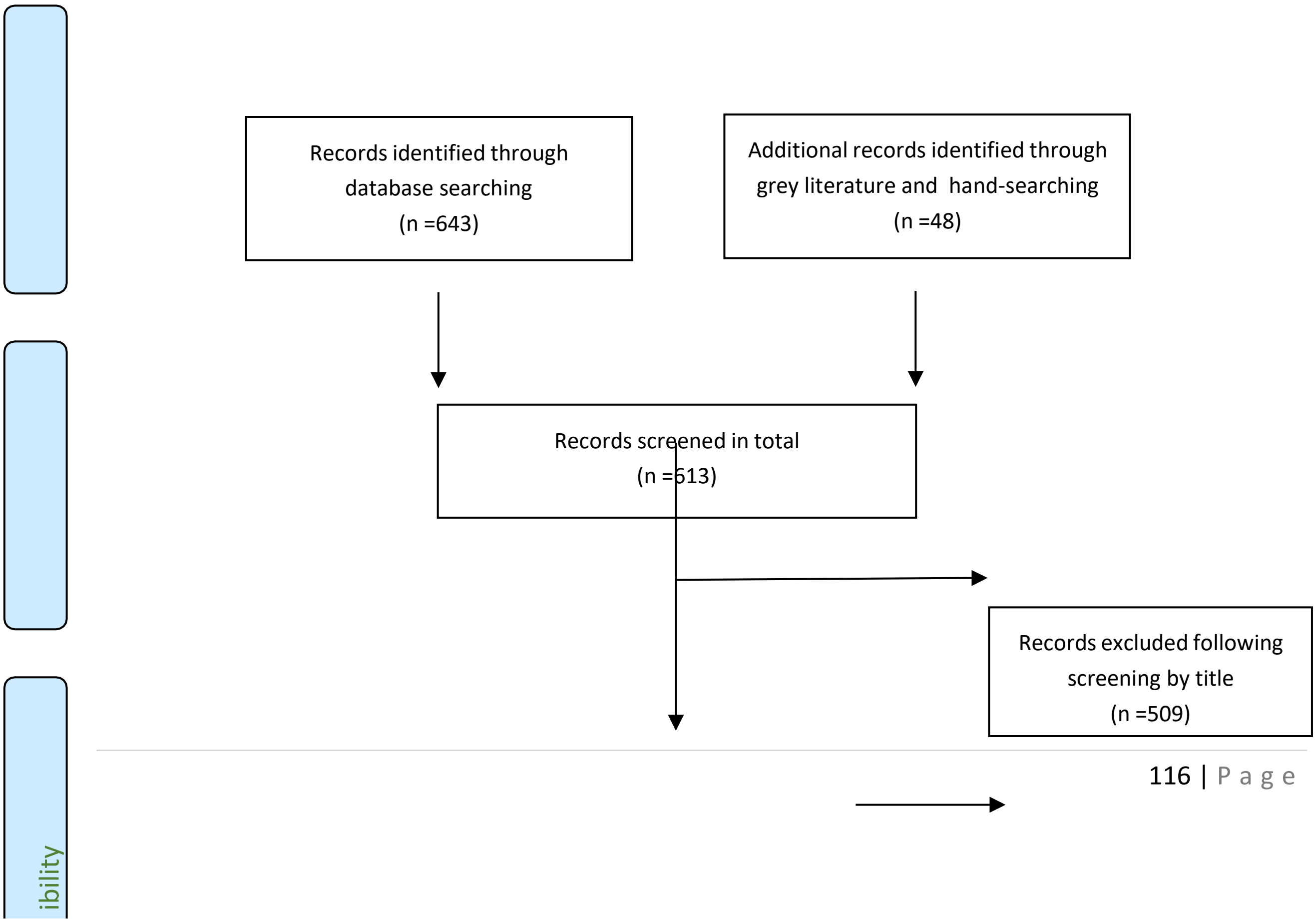
Time since stroke onset. One study recruited participants within forty days of stroke [32]; one study recruited participants at least three months after stroke onset [18], one study more than four months post-stroke [30] and two studies more than one year after stroke [28, 29]. Three studies did not specify this criteria, therefore the mean time since stroke onset was two and half years [16] and four and a half years [31]. One study did not report these demographics [27].

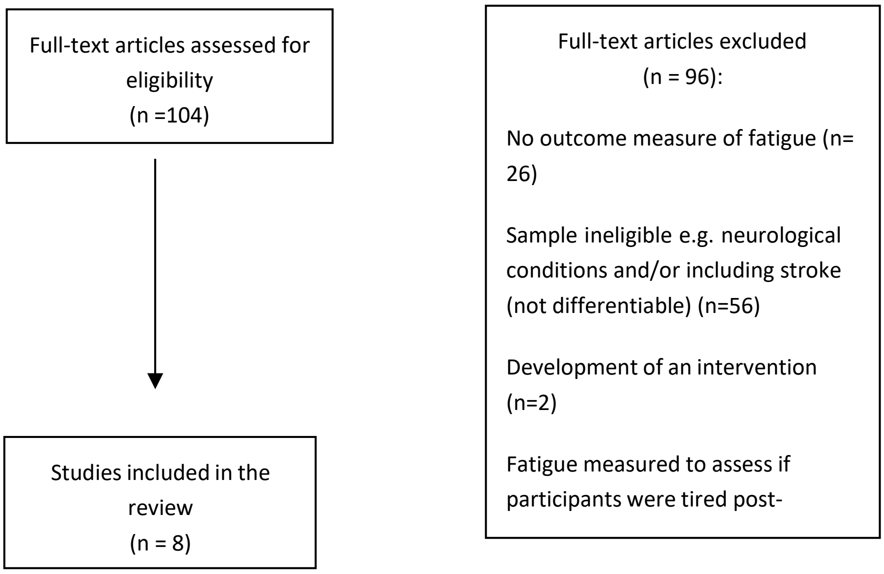
Fatigue criteria. Varied diagnostic criteria of fatigue were implemented at recruitment. Including a mean score of the Fatigue Severity Scale (FSS) of 3.9 or more [16, 18], or a score of less than 5 on the Pittsburgh Sleep Quality Index [16], a total score of the Mental Fatigue Scale (MFS) of 10 or more [28, 29], a score of 40 or more on the Checklist Individual Strength-fatigue scale (CIS-f) [30]. This criteria was not reported for the studies not primarily intended to treat PSF.

3.3 Outcome measures

See table 2. for summary of outcome measures.

Figure 1. PRISMA flow diagram of search and study selection





3.4 Intervention characteristics

Of the eight studies included in this review, five studies compared intervention with control (treatment as usual or waitlist) [16, 18, 27, 28, 31]. One study compared two interventions with a ‘walking group’ control [29].

Two studies did not have a control arm, instead these studies compared two interventions [30, 32].

3.5 Studies primarily intended to treat post-stroke fatigue based on intervention approach

See appendix 1. for further details of characteristics of interventions.

Cognitive Therapy

Two studies evaluated cognitive therapy based interventions [30, 16].

- Zedlitz *et al.* (2012) evaluated cognitive therapy (CO) compared with cognitive and graded physical therapy (COGRAT), in alleviating PSF. Cognitive therapy treatment focused on relaxation and emphasising pacing in day to day life. In addition to the CO, a graded physical therapy (GRAT) involving walking on a treadmill and strength training was incorporated for the COGRAT group. Additional homework assignments were set in both trials to maximise the therapeutic objectives.
- Nguyen *et al.* (2017) evaluated cognitive behavioural therapy (CBT) compared with treatment as usual (TAU) control group. Six modules were delivered over the duration of the CBT treatment addressing fatigue and sleep with the focus of implementing cognitive strategies (i.e. memory aids, routine planning, stress management strategies etc.). Moderate exercise three to five times a week was also recommended.

Mindfulness

Two studies evaluated mindfulness based stress reduction (MBSR) treatment [28, 29].

- Johansson *et al.* (2012b) assessed the feasibility of MBSR treatment compared with a 'wait-list' control. The MBSR treatment was based on Kabat Zinns' MBSR programme [33], focusing on body scanning, deep breathing exercises and sitting meditation. The programme incorporated a silent led retreat and provided guided instructions and CDs for home practice.
- Johansson *et al.* (2015) evaluated MBSR (face to face) treatment compared with MBSR (online) treatment and a 'walking group' control. Both MBSR groups followed the same structure and curriculum as Johansson *et al.,* 2012b. In addition, they incorporated two extra short sitting meditation sessions respectively. Information was also provided on the silent retreat which involved difference types of meditation i.e. walking, loving kindness and mountain meditation.

Psychoeducation

Two studies evaluated psychoeducation programmes [18, 27].

- Clarke *et al.* (2012) evaluated a fatigue management group (FMG) relative to a stroke education group. All sessions in the FMG treatment group were aimed at alleviating fatigue symptoms, for example; 'intro to fatigue', 'fatigue management' and 'sleep-relaxation'. As well as focusing on exercise, nutrition and mood. Homework and a fatigue diary were administered throughout and handouts summarising session content were provided at the end of each session. The control group followed the same structure as FMG however focused primarily on stroke education, not fatigue.

Studies not primarily intended to treat post-stroke fatigue

- Lorig *et al.* (2001) evaluated a Chronic Disease Self-Management Programme (CDSMP) focusing on self-efficacy, health status and healthcare use of individuals that had suffered from stroke, heart and/or lung disease or arthritis. Those allocated to the CDSMP group immediately received seven peer-led sessions focused on exercise programmes; cognitive symptom management, nutrition, fatigue, medication, emotions, assessing the community, communication, problem solving and decision making. A manual handout of programme content was also provided. The control group were offered the treatment programme six months after randomisation.

Physical Activity

Two studies evaluated physical activity interventions [31, 32].

- Paul *et al.* (2016) assessed the efficacy of increasing physical activity in stroke using 'STARFISH', an interactive mobile phone application, compared to a TAU group. The treatment group were provided with a mobile phone with 'STARFISH' already downloaded on to it and told that each person represented a coloured fish in the app. This fish moves when a person is active and individual activity could be viewed by all those in the group. Gradually increasing step targets were applied based on potential ability of the participant, and positive reinforcement via ''rewards'' were attained when target was achieved.
- Renner *et al.* (2016) evaluated group therapy task training versus individual therapy task training for increasing physical activity and fitness during inpatient stroke rehabilitation. The group therapy consisted of four stages; warm up, task training, sports and games and cool down. The individual therapy was tailored to the abilities of the participant, using a graded progression approach focusing on balance, physical condition and walking competency.

3.6 Effectiveness of Interventions

The methodological quality of the eight studies included are summarized in table 3. The EPHPP quality assessment tool has been applied to establish study quality and effect evidence.

Table 1. Characteristics of included studies

	Participants						Dose (sessions)		Format		Facilitator			Outcome measures (f)	Outcome Results: Post	Follow-up	Effect size
Author (date); Country	M Age (SD), stroke criteria	Stroke onset	Fatigue criteria	Intervention	Control	Follow-up	No.	Mins	Face/Remote	Group/Ind	Trained	Role	n				(d)
Studies primarily intended to treat PSF																	
Nguyen et al. (2017); Australia	N = 15, 49 yrs, isc / hea	U	FSS >4, PSQI >5	CBT	TAU	4 mnth	8	U	Face	Ind	Y	Psych	3	FSS-7; BFI, PSQI, ISI, ESS	Y (95% CI: 0.70 to 2.77), N (-1.07 to 3.84), Y (0.71 to 3.82), Y (0.65 to 7.14), N (-1.60 to 2.67)	Y (95% CI:0.24 to 3.60), N (-1.80 to 3.30), Y (0.39 to 4.64), N (-0.08 to 11.30), N (-3.73 to 2.80)	CIS-f (0.48), SOL-f (0.12)
Zedlitz et al. (2012); Netherlands	N = 73, 55 yrs, isc / hea	>4 mnth	CIS-f >40	Cog. & Physio	Cog. therapy	6 mnth	12	120	Face, Face	Group, Ind	Y	Psych; Physio	U	CIS-f; SOL-f, SOL-s	Y(<0.001), Y(0.007), Y (0.007)	Y (<0.01), Y(<0.01), Y (<0.01)	PI (0.52), Follow-up (0.36)
Clarke et al. (2012); New Zealand	N = 19, 72 yrs, isc / hea	3 to 18 mnth	FSS >3.9	Psy ed. (f)	Psy ed. (non-f)	3 mnth	6	60	Face	Group	Y	Psych	1	FSS; CIS, VAS-f, VAS-v	Y (0.020); N (0.343), N (0.956),	N (0.692); N (0.381), N (0.243)	U

															N (0.494)	, N (0.616)	
Johansson et al. (2012b); Sweden	N = 16, U yrs, isc / hea	>12 mnth	MFS >10, >12 mnth	MBSR	Wait-list		8 (+1 day)	150	Face	Group	U	U	U	MFS	Y (0.004)		U
Johansson et al. (2015); Sweden	N = 18, 48 yrs, isc / hea	>12 mnth	MFS > 10 >6 mnth	MBSR (1), (2)	Walking group		8 (+ 1 day), (1), (2)	150	Face (1), Remote (2)	Group (1), group (2)	Y	Psych	1	MFS	(1) N(0.12), (2) Y(<0.001)		U
Studies not primarily intended to treat PSF																	
Lorig et al. (2001); USA	N = 104, U yrs, U	U	U	CDSMP	N/A		7	150	Face	Group	Y	Peer leaders	2	MOS (energy/fatigue)	Yr 1 N(0.165) Yr 2 Y(0.054)		U
Renner et al. (2016); Germany	N = 73, 56 yrs, isc / hea	<40 days	U	Group task training	Individual task training	5 mnth	30	90	Face, Face	Group, Ind	Y	Fitness Inst	1	FSS	N (0.30)	N (0.28)	U
Paul et al. (2016); Scotland	N = 23, 56 yrs, Single unilateral	U	U	Starfish' app	TAU		2	N/A	Remote	Ind	U	U	U	FSS	Y (0.031)		Group (0.205), group/time (0.349)

Notes: PSF = post-stroke fatigue. EPHPP = quality assessment tool. Participants: N = number, Isc = iscehmic, Hea = heamorrhagic. Intervention: CBT = Cognitive behavioural therapy, Cog. = cognitive, psychoed. (f) = psychoeducation fatigue, psy ed. (non-f) = psychoeducation non-fatigue, MBSR - mindfulness based stress reduction, CDSMP = Chronic disease self-management programme, TAU = treatment as usual. Dose: presented in terms of the number of sessions (No.) and length of each session (minutes). Format: Ind = individual. Facilitator: details of the facilitator running the intervention; were they trained Y/N/U = yes/no/unclear. The role of facilitator presented in terms of profession. n = number of facilitators, psych = psychologist. (U) was used when information was unclear throughout, N/A was used when information was not applicable throughout. Outcome measures: FSS = Fatigue Severity Scale, MOS = Medical Outcomes Study, MFS = Mental Fatigue Scale, CIS-f = Clinically Isolated Syndrome- fatigue, SOL-f = Self Observation List fatigue. Results: Sig. improvements in outcome measures were indicated by Y/N = yes/no. Effect size: PI = post intervention, group = group interaction, group/time = group and time interaction

Table 2. Outcome measures used to determine fatigue

Measure	Assessment Type	Areas of Assessment
FSS-9; fatigue severity scale	Self-reported questionnaire	Activities of daily living; Life participation, Sleep
FSS-7	Self-reported questionnaire	Activities of daily living; Life participation, Sleep
MFS; mental fatigue scale	Self-reported questionnaire	Fatigue; lack of initiation, mental fatigue, mental recovery, concentration, memory, slowness of thinking, stress, emotions, irritability, external variables i.e. light, noise, sleep
MOS; medical outcomes study(energy/fatigue)	Self-reported questionnaire	Physical symptoms of fatigue; mental symptoms of fatigue
CIS-f; clinically isolated syndrome- fatigue	Self-reported questionnaire	Fatigue difficulties, concentration difficulties, reduced motivation, reduced activity
SOL-f; self observation list - fatigue	Self-reported questionnaire	Quality of sleep, sleep pattern, daily rest periods
SOL-s; self observation list - sleep	Self-reported questionnaire	Average amount of sleep disturbances
VAS-f; Visual analogue scale - fatigue	Visual analogue scale (VAS range 0-10)	Patient reported satisfaction re. fatigue
VAS-s; Visual analogue scale - sleep	Visual analogue scale (VAS range 0-10)	Patient reported satisfaction re. sleep
BFI; Brief fatigue inventory	Self-reported questionnaire	Fatigue levels; usually, now and past 24 hours. General activity; mood, walking ability, work, relationships, enjoyment
PSQI; Pittsburgh sleep quality index	Self-reported questionnaire	Quality of sleep; sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleeping meds, daytime dysfunction over the last month
ISI; Insomnia severity index	Self-reported questionnaire	Difficulty falling asleep, staying asleep, waking too early
ESS; Epworth sleepiness scale	Self-reported questionnaire	Daytime sleepiness

Table 3. Quality Assessment EPHPP

STUDY ID	SELECTION BIAS	STUDY DESIGN	CONFOUNDERS	BLINDING	DATA COLLECTION METHODS	WITHDRAWALS AND DROP-OUTS	GLOBAL RATING
Clarke (2012)	3	1	3	3	1	1	3
Lorig (2001)	2	2	3	3	2	2	3
Johansson (2012b)	2	1	2	3	2	1	3
Johansson (2015)	2	1	2	3	2	1	3
Zedlitz (2012)	2	1	1	2	1	1	2
Nguyen (2017)	2	1	1	1	1	1	2
Renner (2016)	2	1	3	1	1	2	2
Paul (2016)	2	2	1	3	2	1	3

Notes: Ratings; 3 = Weak, 2 = Moderate, 1 = Strong

Effectiveness of studies primarily intended to treat post-stroke fatigue

Cognitive Therapy;

Zedlitz *et al.* (2012) reported main effects of time for primary outcomes, CIS-f and SOL-f, post-intervention and showed sustained effects at follow-up for both the CO and COGRAT groups (CIS p<0.001; Sol-f p=0.007). Effect sizes were substantial for CIS-f (d = 0.48) and less SOL-f (d=0.12). At follow up, CIS-f score improved for COGRAT (<35) and marginally increased for CO. Those allocated to the COGRAT group also showed an increased clinically relevant improvement compared to those in CO group when outcomes were reviewed at an individual level (p=0.002). SOL-f remained stable for COGRAT at follow-up but slightly increased for CO. Therefore, participants in COGRAT group had a significantly higher reduction in fatigue outcome than those in the CO group, indicating that cognitive therapy combined with graded exercise is more effective than cognitive therapy alone.

Nguyen *et al.* (2017) also reported main effects of primary outcome FFS-7, with treatment group reporting significantly lower levels of fatigue compared to control group at post-treatment (95% CI: 0.70 to 2.77) and at follow up (95% CI: 0.24 to 3.60). Large treatment effects sizes were found at post-intervention (d=0.52) and maintained at follow-up (d=0.36) which are within similar range to Zedlitz *et al.* (2012) COGRAT group. Five out of the eight participants in the CBT group achieved statistically reliable reductions of at least 0.47 or more on the FSS-7 compared to one out of six in the TAU group. Therefore, CBT as an intervention is significantly more effective that TAU for reducing levels of PSF.

Evidence of effects;

Nguyen *et al.* (2017) supports findings from Zedlitz *et al.* (2012) that cognitive therapy is efficacious in treating PSF and due to both studies having large effect sizes this is promising for future treatment. In addition, it is reported that COGRAT is more effective than cognitive therapy alone [30] however we cannot conclude that this is not prerequisite for the effects of cognitive therapy, therefore were do not know if this is a result of physical training or a combination effect of physical and cognitive therapy. Moreover, the CBT treatment also incorporated physical activity into its curriculum [16]. As neither studies reported which components of the treatments were most effective further research would be required to draw upon the above conclusions.

Due to a number of methodological flaws across both studies, the global rating for both when applying the quality assessment tool EPHPP is ‘moderate’, therefore findings should be considered tentatively.

Firstly, the effects observed from the CBT study can only be considered as preliminary as the study is a pilot RCT [16]. As this was a preliminary study, the sample size was small (n=15) compared with n=72 [30]. The mean age of both samples were relatively young for a stroke cohort, 49 years [16] and 55 years [30] considering two thirds of the stroke population are over the age of 65 [15]. Strict inclusion criteria for both regarding ambulation and cognition also limits the generalizability of effects and thus increases the risk of selection bias.

However, both RCTs did employ appropriate randomisation methods; block randomisation per treatment centre [30] and group allocation by an online random number sequence [16].

A strength of design in the COGRAT study is the implementation of a 3-month qualification period without treatment prior intervention to limit confounding variables [30]. Whilst in the CBT study no important differences between groups at baseline were reported for the CBT and TAU group, the TAU control group is undefined [16]. Therefore, it is unclear as to whether participants in the control group were undertaking active treatments and thus increasing the potential of confounding variables.

A strength of the CBT study is the double-blinding of assessor and participants, controlling for response and social desirability bias [16]. However, there is an increased risk of response bias, despite describing ‘’assessor-blind’’ methods with the COGRAT study as the interventions used in the two groups were visibly different therefore participants and staff would be aware of this [30].

Both studies used validated and reliable outcome measures, however these differed across studies therefore comparisons of self-reported fatigue outcomes are not applicable. Both studies also used self-reported questionnaires which may be subject to individual bias and unreliable memory when applied to the stroke population.

A strength of both studies is that treatment appears to be well tolerated with 80% [30] and 100% adherence [16]. The duration of studies varied between eight weeks [16] and twelve weeks [30], which may explain reduced attrition rates for CBT [16]. Follow-up of results varied in time with a four month follow-up [16] and a six month follow-up 30. Whilst we know sustainability of effects were established at these points, longer-term effects are still unclear.

Therefore the evidence of effectiveness of cognitive therapy based treatment in reducing PSF is moderate, the feasibility of treatment is evident however further research requires more robust RCT designs.

Mindfulness

In Johansson *et al.* (2012b) the MBSR group and 'wait-list' control group differed significantly in the primary outcome measure MFS immediately after intervention (p=0.008). The MBSR group showed a decline in MFS (p=0.004), whilst the control group MFS was unchanged post treatment. The control group later completed MBSR treatment and showed similar decline in MFS post-intervention (p=0.002). This suggests that MBSR significantly reduced fatigue compared with 'wait-list' control.

Johansson *et al.* (2015) also reported a significant interaction between treatment and MFS rating (p=0.028). Improvements in the MFS self-assessment were observed in the online MBSR group for pre to post intervention (p<0.001). In the face-to-face MBSR group, the MFS rating decreased from 18.4 to 15.1, however this was not significant (p=0.126). Ratings in the control group stayed at a similar level. Therefore, results suggest that MBSR online had a significantly higher reduction in fatigue than MBSR face-to-face, both MBSR treatments were more effective in reducing fatigue compared with the 'walking' group.

Evidence of effects;

Johansson *et al.* (2015) supports the findings in Johansson *et al.* (2012b) that MBSR treatment is effective in reducing PSF. Some direct comparisons can be made between studies due to the consistencies in MBSR treatment and measures. Despite this, the overall evidence for MBSR effect is weak when applying the EPHPP quality tool.

Firstly, both study stroke samples are weak due to size (n=16) [28] (n=18) [29] and significantly limited in terms of male representation therefore limiting generalizability of effects. Furthermore, only 75% of individuals eligible for recruitment agreed to participate in one study [29].

Secondly, study designs were flawed. Despite one study being described as an RCT, no information was provided regarding randomisation methods [28]. The second study was described as a quasi-RCT as some individuals (n=5) opted for the MBSR face-to-face group for 'personal' reasons therefore increasing risks of bias [29]. Allocation of the remaining participants was described as randomised however insufficient information again regarding this.

Sufficient control for confounding variables in both studies is not described and a lack of consideration has been made for the potential impact of travel time to MBSR face-to-face compared to MBSR online, accessed at home, on fatigue levels [29]. It is also important to note that a 'walking group' control group for PSF may have negative effects on fatigue and therefore would not seem like a fair comparator to MBSR. Particular as 'energy-conservation strategies' have been recommended for post-stroke treatment [17].

Blinding methods were unclear in both studies which increases potential response and social desirability bias effects.

However, data collection methods are reliable and valid for long term conditions. Despite this, sustainability of effects is also unclear due to a lack of follow-up.

A strength of both studies is the high treatment adherence, 90% [28] and 89% [29]. Indicating that MBSR is a tolerable treatment for post-stroke sufferers. This is also positive as engagement in rehabilitation treatments post-stroke can be limited [13].

Nevertheless, the overall effectiveness of MBSR as an intervention to reducing PSF is unclear. Due to poor methodological quality and a high risk of bias, further research is required in this field.

Psychoeducation

Clarke *et al.* (2012) reported significant reductions in the primary outcome measure FSS in both the experimental and control group post intervention that were sustained at follow-up (p=0.020). The FMG reported a greater decrease in the self-reported assessment than the control group, however this was not significant (p=0.086). As both education groups reported significant reductions in FSS post-intervention this would suggest that educational programmes are initially effective in reducing fatigue, however effects are not sustainable.

Lorig *et al.* (2001) did not publish results separately however data for the stroke sample was provided for the differences in the scores of self-rated energy/fatigue levels from baseline to after treatment. No significant differences in scores were observed in the first-year assessment (p=0.165) and marginal (non-significant) improvements post-intervention were observed in the second-year assessment (p=0.054).

Evidence of effects;

Both studies indicate some potential for psychoeducation programmes in reducing levels of PSF. However, the EPHPP global ratings for both these studies is ‘weak’ therefore evidence of effects is minimal.

Direct comparisons cannot be made between the FMG and CDSMP groups due to a number of methodological differences and differing primary aims of the studies. Firstly, stroke sample sizes and strength vary significantly from weak (n=19) [18] to strong (n=125) [27].

Secondly, treatment in one study was designed for stroke [18], whereas treatment was designed for a number of chronic diseases, including heart disease, stroke and arthritis in the other [27]. A possible reason why the FMG study may have been more successful in reducing FSS is that symptoms across chronic diseases differ significantly and therefore information should be modified to support the potential cognitive deficits experienced with stroke. For example, stroke needs would differ substantially to arthritic needs, therefore a broad ‘chronic disease’ treatment does not target condition specific deficits [27].

Despite this, limitations in design can still be observed in the FMG study, with no information provided around randomisation and blinding methods, thus making it a high risk of bias [18]. The study did not also effectively control for the bias of confounding variables, for example those in the FMG averaged at 7-yrs younger than the stroke education group and differed in time since stroke. Whilst the CDSMP study did offer treatment to its whole cohort, consideration was not taken into the potential effect of participants engaging in other therapies throughout the study [27].

Multiple valid and reliable measures of fatigue where implemented across one study [18], unlike the majority of included studies in this review that only implemented one or two measures. Therefore allowing examination of concurrent validity. Whereas the validity and reliability of data collection tools implemented in the CDSMP study are questionable due to modifications made specific to this intervention[27]. However, both studies did have high levels of treatment adherence was also high (80%) [27] and (86%) [18].

The effects of FMG were not sustainable at 3-month follow up and no follow-up was completed for the CDSMP group. Therefore sustainability of psychoeducation interventions is unknown and the overall evidence for the effectiveness of psychoeducation in treating fatigue is poor.

Physical Activity

Paul *et al.* (2016) applied the FSS as a secondary outcome measure. They reported significant reductions in FSS in the treatment group post-intervention in comparison to an increase FSS in the TAU group. There was a significant group interaction (p=0.031), effect size (d = 0.203) and group/time interaction (p=0.003), effect size (d = 0.349). Therefore indicating that increased physical activity significantly reduced PSF with a relatively large effect size.

Renner *et al.* (2016) also used the FSS as a secondary outcome measure to monitor fatigue at baseline, post-intervention and follow-up. There was no significant difference in self-reported FSS observed between groups at baseline to six weeks (p=0.26). The treatment group saw a decrease in FSS post-intervention however this was not significant. The individual treatment group reported adverse effects in treatment on FSS, however this was not statistically significant. Therefore increased physical activity did not significantly improve self-rated levels of fatigue in stroke survivors.

Evidence of effects;

Whilst large effect sizes for increased physical activity on reducing FSS where reported [31], converse evidence for this effect can also be observed [32].

The overall evidence of effect for physical activity in reducing FSS is weak [31] to moderate [32] when applying the EPHPP quality tool.

The studies differed significantly in their methodological approach. One was a feasibility study therefore the cohort of stroke survivors was small (n=23) and relatively heterogeneous between groups in terms of physical activity [31]. Whereas the other had a reasonably large stroke sample (N=73) [32], however the sample was also heterogeneous with baseline differences in participants in favour of the group therapy task training for FSS. This was not controlled for and therefore the reported differences in groups could be misleading.

Both studies differed in intervention setting and recruitment with one set remotely [31] and the other at an in-patient rehabilitation centre [32]. Strengths of the remote treatment include the intervention of a mobile phone app being relatively low cost, compared with the other included studies, and easily integrated into the daily routine of participants. Moreover, treatment access did not require transport to sessions which led to attrition in other studies included in this review [29]. This was also a strength of in-patient treatment [31].

The intensive in-patient treatment [32] would be relatively high in cost in comparison to a mobile phone app[32]. Moreover the intensive nature of the in-patient treatment, which involved thirty, ninety minute sessions (in comparison to the average eight sessions in this review) may explain why significant reductions in FSS were not observed and adverse effects were apparent. Such intensity of treatment may also be a reason why attrition levels were highest in this study compared with all the other included studies (21%). In addition, there is a high risk of selection bias as identified eligible participants only agreed to treatment if they felt confident to engage in targeted, group training sessions. Which, arguably in the early stages of post-stroke (>40 days) individuals are adjusting to deficits which may have a knock on effect on confidence levels. In contrast, the STARFISH intervention involved participants that were up to 10-yrs post-stroke with high treatment tolerance (96%) [31].

Other differences in approach between the two treatments include the implementation of a theoretical behaviour change approach to increasing physical activity [31]. This may explain the increased effects on FSS [31] in comparison to the non-theoretical approach [32].

That so, there were clear strengths observed in the in-patient therapy training study [32] with a robust study design, providing detailed and appropriate methods of randomisation and double-blind procedures. These strengths were not observed in the STARFISH study which allocated participants to groups and included assessors that were aware of the group allocation [31] thus increasing the risk of researcher bias.

Overall, there is currently insufficient evidence to indicate that increasing physical activity is effective in reducing PSF. In addition, sustainability of the positive effects observed is unknown due to a lack of follow-up [31]. Further research on physical activity and PSF would be beneficial to establish if primarily targeting fatigue is more effective.

4.0 Discussion

This systematic review was conducted on psychosocial interventions delivered to post-stroke individuals, with the purpose of identifying interventions there were effective in improving levels of post-stroke fatigue. The general findings from the eight studies are of weak to moderate quality providing insufficient evidence to draw upon any firm conclusions regarding whether these interventions are effective in reducing PSF. Therefore, higher quality robust studies are required to ensure more reliable evidence of effectiveness of interventions.

Summary of main results;

Cognitive therapy

PSF has been described as a mixture of biological, physical, psychological and behavioural factors [8]. Therefore as treatments involving a cognitive approach, such as CBT, have already been found to be successful in treating fatigue in other chronic conditions [34, 35] it seems promising to assume its applicability to treating PSF. Particularly when interventions include physical factors too, as seen in Nguyen *et al.,* (2017) who reported promising results with a CBT approach incorporating physical activity. Zedlitz *et al.,* (2012) also found optimal fatigue outcomes in its COGRAT group. Whilst findings may be promising, neither studies demonstrated whether or not these interventions were effective due to study limitations. Therefore future research should involve more robust RCTs with adequate sample sizes and comparator groups. For example, studies that compare cognitive therapy with physical training.

Mindfulness

Research suggests that cognitive activities such as stress require more neurological resources than normal [36]. This therefore increases mental activity which can lead to increased fatigue [37]. Mindfulness promotes relaxation and stress management techniques to help manage this. Previous systematic reviews and meta-analyses highlight the potential of mindfulness-based interventions in supporting individuals suffering from long-term conditions to cope better with symptoms of anxiety and depression [38, 39]. In this review two studies investigating mindfulness for PSF were identified [28, 29]. Overall the quality of these studies was weak from a methodological point of view with poor sample generalizability. Efficacy of these interventions should be investigated in future studies with larger sample sizes, including more male individuals, and more robust study designs. More consideration of confounding variables between experimental group and controls is also required.

Psychoeducation

Educational fatigue management programmes have shown success in reducing fatigue in conditions such as cancer, multiple sclerosis [40] and acquired brain injury [19]. In this review we identified one study [18] primarily intended to treat PSF that adopted a fatigue management programme. However lowered fatigue effects were not sustained at follow-up. Due to weak quality of this study a more robust RCT is required with larger stroke sample and an adequate control comparison. Effects were observed in both educational groups therefore it is unclear as to whether fatigue specific education improved fatigue at post-intervention or stroke education in general did. Another study [27] did not primarily target PSF and was unable to demonstrate if intervention was effective due multiple limitations of the study design and a lack of consideration for stroke specific deficits.

Physical activity

Previous research associated PSF with an overall reduced physical fitness and lower levels of physical activity [25, 26]. In this review we found two studies investigating physical activity in stroke survivors reporting fatigue as a secondary outcome measure [31, 32]. When loosely comparing the two studies, one had more success with reducing PSF [31] than the other [32]. One argument to this is the inclusion of behavioural change techniques associated with control theory [31] (i.e. setting goals, planning, monitoring progress, comparing with others and positive feedback) which have been found to be more effective with increasing physical activity than interventions that don't include these techniques [23, 24]. This approach could be promising for future research, however we cannot conclude on the effectiveness of increasing physical activity due to the weak to moderate quality of these two studies and the fact that neither of these interventions were specifically designed for PSF. In addition, high risk of attrition bias [32] and selection bias [31] were observed.

Common methodological flaws

Common limitations that have appeared within this review involve small sample size and generalizability to target population. Study design methods are lacking in appropriate randomisation methods and only two studies reported double-blinding measures [16, 32]. Only one study acknowledged the potential implications that participants engaging in rehabilitation leading up to treatment might have on intervention effects [30], and an overall lack of control for confounding variables has been observed across studies. A lack of follow-up in half of the included studies [27-29, 31] means sustainability of treatment effects is also unclear. Nearly all reported outcome measures are self-reported questionnaires which may also be subject to individual bias and unreliable memory when applied to the stroke population. The one study to use a different outcome measure to a questionnaire employed a visual analogue scale [18] which also has limitations to stroke population and should be employed with caution due to the potential of visual disturbances in stroke sufferers**.**

Overall applicability of evidence

The inclusion criteria of this systematic review was kept broad with the overarching aim to support and inform future research within this area. Included studies measured fatigue as either a primary or secondary outcome to treatment. It was also not a requirement for participants to have been diagnosed with fatigue prior to interventions. This is to enable research with the prevention, as well as the treatment of PSF.

Generally, psychosocial interventions targeting cognition and behaviour do seem feasible as promising treatments for PSF in the future. However the poor methodological quality observed in this review means that future research requires more robust designs and larger study samples to detect a clinically significant therapeutic effect.

Due to the heterogeneity in the study design and sample characteristics included in this review overall generalisability of findings is limited. Samples varied significantly in age and time since stroke onset. Stroke type also differed with one study limiting its inclusion criteria to a single unilateral stroke [31] which will vary in severity compared to individuals who may have suffered multiple ischaemic or haemorrhagic strokes.

In addition, no study included participants with severe cognitive deficits and all studies included samples with fewer verbal and physical impairments i.e. milder deficits of stroke. Post-stroke cognitive impairment is very high according to data therefore future research needs to consider stroke samples with severe cognitive difficulties.

Adverse effects were observed marginally in one study [32]. Two studies reported medical issues as a reason for participant drop-out [18, 31]. One study reported drop out due to participants finding the treatment to heavy [32] and four studies reported drop out but did not provide [27-30]. One study did not experience participant drop out [16].

Conclusions

Due overall study quality there was insufficient evidence of any psychosocial intervention for the treatment of PSF. Adequate sample sizes are essential for future research as the majority of samples in this review are small, heterogeneous and have a high risk of selection bias. A consistent methodological approach is required to enable reliable, comparable and replicable studies which would also allow for the completion of a meta-analysis. Whilst the majority of included studies used valid outcome measures, these differed across studies and were all self-reported questionnaires which can be limiting and risk bias. Therefore an agreed combination of well-validated fatigue measures would be beneficial in progressing research further.

Implications for research

Given that PSF is a common and persisting outcome of stoke which debilitating effects on rehabilitation; functional independence, quality of life, mental health, social interaction and mortality [12], further research is urgently required to identify effective PSF treatments. There is a varied range of interventions in this review that have primarily targeted treatment for PSF, this reflects the complexities and ongoing uncertainties of PSF. Psychosocial interventions have shown feasibility in post-stroke individuals and future research needs to investigate their efficacy in stronger RCT designs.

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Appendices

Appendix 1.

Characteristics of included studies

Clarke 2012

Methods	RCT Randomisation: Block Blinding: Single-blind (Participants)
Participants	Location: New Zealand

	Setting: Stroke clinic or local community Number: 19 at randomisation, 16 completed study (62% male, mean age 72 years) Treatment group: 9 (62% male, mean age 69 years) Control group: 7 (57% male, mean age 76 years) Stroke criteria: ischaemic or haemorrhagic Stroke onset: 3 to 18 months Fatigue criteria: FFS >4
Interventions	Treatment: 6 group psychoeducation sessions (targeting alleviating fatigue), 60 mins weekly Control: 6 group psychoeducation sessions (general education without targeting fatigue), 60 mins weekly Duration: 6 weeks Facilitators: Clinical Psychologist
Outcomes	Primary outcome: FSS Secondary outcome: CIS-f, VAS-f, VAS-s

Johansson 2012b

Methods	RCT Randomisation: Unclear Blinding: wait-list controlled, no blinding
Participants	Location: Sweden Setting: Community Number: 29 participants; 16 of these stroke Treatment group: 7 stroke (age & sex unclear) Control group: 9 stroke (age & sex unclear) Stroke criteria: ischemic or haemorrhagic Stroke onset: >1 year post stroke Fatigue criteria: MFS >10
Interventions	Treatment: Mindfulness-based stress reduction (8 weekly group sessions, 2.5 hours sessions, 1 silent led retreat between 6 and 7 sessions, and 45 mins home practice for 6 days a week for 8 weeks) Control: Wait-list

	Duration: 8 weeks Facilitators: Unclear
Outcomes	Primary outcome: MFS Secondary outcome:

Johansson 2015

Methods	Quasi-RCT Randomisation: unclear Blinding: single-blind (participants)
Participants	Location: Sweden Setting: Community Number: 38; 18 of these stroke Treatment group: 12, stroke n=5 (mean age 48 years, 11 F, 1 M) Control group: 13, stroke n=7 (mean age 46.3 years, 11 F, 2 M) Stroke criteria: Ischemic or haemorrhagic Stroke onset: 1 year > post stroke Fatigue criteria: MFS > 10
Interventions	Treatment: (1)Mindfulness-based stress reduction Face-to-Face (8 weekly group, 2.5 hour sessions, 1 full day 7.5 between 6 and 7 sessions, and 45 mins home practice for 6 days a week for 8 weeks). (2) MDSR online – exactly as above Face-to-Face however all online instead Control: Walking group (8 weeks, 1.5 hr walking per week) Duration: 8 weeks Facilitators: Clinical psychologist
Outcomes	Primary outcome: MFS Secondary outcome:

Lorig 2001

Methods	Longitudinal Randomisation: unclear Blinding: unclear

Participants	Location: USA Setting: Community Number: 1140 participants, 125 were stroke sample, 104 completed 6-month assessment Treatment group: 58 (age & sex unclear) Control group: 46 (age & sex unclear) Stroke criteria: Ischemic or haemorrhagic Stroke onset: unclear Fatigue criteria: not required
Interventions	Treatment: 7 weekly group sessions lasting 2.5 hours in community centres where Ps were taught CDSMP by peer leaders. This included teaching about exercise programmes; the use of cognitive symptom management techniques; nutritional change; fatigue and sleep management; use of community resources; use of medications; dealing with emotions of fear, anger and depression; communication with others; problem solving and decision making. Control: Wait-list, offered CDSMP after 6-months Duration: 7 weeks Facilitators: 2 peer leaders who had received 20 hours of training
Outcomes	Primary outcome: MOS (energy/fatigue) Secondary outcome:

Nguyen 2017

Methods	RCT Randomisation: group allocation by online random number sequence by independent researcher Blinding: double-blind
Participants	Location: Australia Setting: community Number: 15 Treatment group: 9 (3 F, mean age 47 years) Control group: 6 (1 F, mean age 51 years)

	Stroke criteria: Ischemic or haemorrhagic Stroke onset: unclear Fatigue criteria: FFS >3.9
Interventions	Treatment: CBT treatment group: cognitive behavioural therapy individual sessions (6 modules addressing fatigue & sleep) over 8 weekly sessions. Timing of CBT sessions not defined, 30 mins of moderate exercise three to five times a week recommended. Control: TAU Duration: 8 weeks Facilitators: Clinical psychologists
Outcomes	Primary outcome: FSS Secondary outcome: BFI, PSQI, ISI, ESS

Paul 2016

Methods	Parallel controlled trial Randomisation: no Blinding: no
Participants	Location: Scotland Setting: Community Number: 23 Treatment group: 15 (mean age 56.3 years, 7 M, 8 F) Control group: 8 (mean age 55.3yrs, 4 M, 4 F) Stroke criteria: Single unilateral Stroke onset: unclear Fatigue criteria: not required
Interventions	Treatment: The Starfish App: Used step goals for Ps, ‘’rewards’’ in app for motivation when goal achieved. 1 week pre intervention with phone, Information session (30mins on app) 6 weeks with phone At week three attendance at the CRF to discuss progress Control: TAU Duration: 6 weeks

	Facilitators: Unclear
Outcomes	Primary outcome: Secondary outcome: FSS

Renner 2016

Methods	RCT Randomisation: by person independent from the study using an ‘’online’’ minimization procedure. Blinding: single-blind (participants)
Participants	Location: Germany Setting: In-patient rehabilitation centre Number: 73 Treatment group: 34 (Mean age 56 years, 22 M, 12 F) Control group: 39 (Mean age 55 years, 29 M, 10 F) Stroke criteria: Ischemic or haemorrhagic Stroke onset: <40 days Fatigue criteria: not required
Interventions	Treatment: Group therapy task training: *(methodology of the FIT-Stroke)* Group training program included four stages: warming up, task training, sports and games, and cooling down. 90-minute, structured progressive task training program 5 times a week over a 6 week period (30 sessions) Control: Individual task training: The training was tailored to the deficits of the patient and aimed to improve balance, physical condition and walking competency. 90-minute, structured progressive task training program 5 times a week over a 6 week period (30 sessions) Duration: 6 weeks Facilitators: physiotherapist or sports therapist
Outcomes	Primary outcome: Secondary outcome: FSS

Zedlitz 2012

Methods	RCT Randomisation: block per treatment centre Blinding: assessor blind
Participants	Location: Netherlands Setting: Community Number: 83, 73 completed and 68 completed follow-up Treatment group: 38 (55% M, mean age 55 years) Control group: 45 (49% M, mean age 55 years) Stroke criteria: Ischemic or haemorrhagic Stroke onset: >4months post stroke Fatigue criteria: CIS-f >40
Interventions	Treatment: Treatment (1) (CO): group cognitive therapy (emphasising pacing and relaxation), 2 hours each session, once a week, 12 weeks Control: Treatment (2) (COGRAT): CO plus GRAT – physical training (walking on treadmill, strength training and homework assignment), 2 hours each session, twice a week, 12 weeks Duration: 12 weeks Facilitators: CO delivered by neuro-psychologists GRAT delivered by physiotherapists
Outcomes	Primary outcome: CIS-f Secondary outcome: SOL-f, SOL-s

Appendix 2.

Medline search strategy (example)

1. (stroke or poststroke or SAH or cerebrovasc$ or cerebral vasc$ or CVA).tw.
2. ((brain$ or cerebr$ or cerebell$) adj5 (haemorrhage$ or bleed$)).tw.
3. ((brain$ or cerebr$) adj5 (isch?emi$ or infarcts$ or aneurysm)).tw.
4. Behavior Therapy/
5. [(behavio?r$ adj3 (intervention$ or therap$)].tw.

6. Cognitive Therapy/
7. [(cognitive-behav$ or cognitive or cognition) adj3 (intervention$ or therap$ or treatment$)].tw.
8. CBT.tw.
9. Psychotherapy/ Mind-Body Therapies/
10. (psycho$ therap$ or psychotherapy$).tw.
11. (meditation or mindfulness or mind training).tw.
12. (Relax$ adj3 (treatment$ or therap$)].tw.
13. [(psychosocial or psycho-socail or psychoeducation$) adj3 (intervention$ or treatment$)]
14. Fatigue/ or fatigue syndrome, chronic/ or mental fatigue / or muscle fatigue