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Psychology**

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Doctoral Thesis

A qualitative exploration of the movement disorder experience

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Prepared in accordance with Instructions for Authors for ‘Psychology & Health’

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Thesis Abstract

The thesis entitled 'A qualitative exploration of the movement disorder experience' explores both the experience of diagnosis of several, and the lived experience of one specific, common movement disorders.

Section One presents a meta-synthesis of 24 research papers, each of which explores the diagnostic experience of either Parkinson's disease, multiple sclerosis, motor neurone disease or Huntington's disease from the individual's perspective. Three major themes emerged: "A bomb that could not be absorbed": The emotional experience of receiving a diagnosis; "You've got what your cousin died from": Feeling dismissed and powerless and "Know thy enemy": To information seek or not? The findings provide insight into the traumatic experience of receiving a diagnosis, with certain factors found to exacerbate the situation, although some positives were identified. Clinical implications are discussed.

Section Two presents a research study exploring the lived experience of essential tremor. Using interpretative phenomenological analysis as the specific method, nine participants were interviewed and the data analysed. Three major themes were constructed: "But they often look at you like you're some drug addict or smack head": Social attitudes to difference; "I just couldn't do it anymore": The restrictive nature of ET and "You've got to cope; you've got to learn to fight different ways": Rescuing some normality amid physical deterioration. The findings provide much needed experiential understanding and interpretation of one of the most prevalent neurological conditions. Clinical implications are discussed.

Section Three presents a critical appraisal of the research study. The author has reflected upon the research study findings in the context of findings from the meta-synthesis. Furthermore, reasons for conducting the research, its strengths and limitations, reflexivity and ideas for future research are also explored.

Declaration

This thesis reports to research undertaken between September 2016 and June 2017 as part requirement of the Lancaster University Doctorate in Clinical Psychology. The work documented here is my own except where due reference has been made in the text. This thesis has not been submitted for an aware of a higher degree elsewhere.

Signature:

Print name:

Date:

Acknowledgements

I would first like to thank my participants for taking the time to share their experiences openly with me. I would also like to thank Dr Fiona Eccles and Dr Jane Simpson for their encouraging and supportive supervision throughout this doctoral thesis.

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Diagnosis of a motor neurodegenerative condition

Running Head: EXPERIENCE OF DIAGNOSIS OF A MOTOR NEURODEGENERATIVE
CONDITION

Section 1: Literature Review

A meta-synthesis of the experiences of diagnosis of a motor neurodegenerative disease

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Abstract

Objective: The aim of this meta-synthesis was to explore the diagnostic experience of individuals diagnosed with the four most commonly reported motor neurodegenerative conditions.

Justification: A number of reviews have been carried out into the diagnostic experience of other neurodegenerative conditions (e.g. dementia). However, no reviews have focused upon motor neurodegenerative conditions. Previous research has identified that motor conditions bring their own specific challenges and so focusing upon the experience of being diagnosed with such a condition could identify additional/different issues.

Findings: Three major themes emerged: “A bomb that could not be absorbed”: The emotional experience of receiving a diagnosis; “You’ve got what your cousin died from”: Feeling dismissed and powerless and “Know thy enemy”: To information seek or not?

Conclusion: The results identified the negative experiences of diagnosis and the contextual difficulties exacerbating the diagnostic process. However, some positives were identified. This review has implications for clinical psychologists since it highlights a clear gap in the consideration of the psychological needs of diagnosed individuals. Furthermore, medical professionals should be educated on the impact of diagnosis and trained to deliver such news. Future research should focus on this point in the chronic illness journey.

Keywords: motor neurodegenerative, diagnosis, meta-synthesis

Introduction

Receiving a diagnosis of a serious health condition is a defining and life-altering moment for many individuals (Guenther, Stiles & Champion, 2012; Krumwiede & Krumwiede, 2012). However, diagnosis can bring benefits. For example, a collective identity may emerge for patients with the same diagnosis, thus reducing the isolation of their illness experience and providing support networks from which they can draw (Chiong, 2001). Nonetheless, despite any potential benefits, the receipt of a diagnosis can have wide-reaching and lengthy psychological implications, with some arguing that the success of adjustment processes is hugely affected by the often very brief consultation where a diagnosis is given.

One type of condition where diagnosis is important from a psychological perspective are neurodegenerative conditions since these are conditions where the psychological implications have historically not been as researched as other conditions, for example cancer. Neurodegeneration refers to the progressive loss of neuronal structures and functions in the brain and central nervous system (CNS) (Burli, Thomas & Beaumont, 2010) and this can result in many different types of neurodegenerative conditions, with different patterns of neuronal loss.

Regardless of the site of the initial neurodegeneration, neurodegenerative conditions affect physical, psychological and cognitive functioning across a number of life domains including social, family and employment (Batista & Pereira, 2016). In addition, some neurodegenerative conditions also significantly affect life expectancy; for example over 50% of individuals diagnosed with motor neurone disease (MND) die within three years of symptom onset (Whitehead, O'Brien, Jack & Mitchell, 2011).

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The public health relevance of the high number of people with a neurodegenerative condition is clear; the World Health Organization (2007) has reported that up to one billion people worldwide have a neurodegenerative condition. Furthermore, this figure is set to rise due to an ageing population since the likelihood of having such a condition is known to increase with age (Kirton, Jack, O'Brien & Roe, 2011) and survival rates are increasing for individuals diagnosed (de Tommaso et al., 2016).

One neurodegenerative condition that has received considerable attention within the literature in relation to diagnosis is dementia (e.g. Caddell & Clare, 2011; Carpenter & Dave., 2004; Stokes, Combes & Stokes, 2015). A recent review identified a lack of information and support at diagnosis resulting in caregivers not being able to understand or adjust to the behavioural, physical and psychological changes in their partner (Stokes et al., 2015). Indeed, information on diagnosis and prognosis has been found to be associated with improved caregiver/partner well-being and improvement in cognitive ability for those patients with memory difficulties (Moniz-Cook, Agar, Gibson, Win & Wang, 1998). This review also found that caregivers requested that the diagnosis of their loved one was done in a compassionate manner to preserve dignity and hope (Stokes et al., 2015). Collectively, the reviews identified indicate the wide reaching impact of a diagnosis, indicating that these changes are not just limited to physical, behavioural and psychological changes, but also impact upon an individual's identity too.

However, no reviews to date have focused on motor neurodegenerative conditions for which the findings may be different from those reported for people with dementia.

Moreover, a number of specific challenges might be present regarding the effective diagnosis of motor neurodegenerative conditions. For example, diagnosing movement disorders can be challenging for health professionals, not least due to the similarities and overlap of symptoms across different conditions which cause difficulties in the ability to provide a differential diagnosis (Abdo, van de Warrenburg, Burn, Quinn & Bloem, 2010), resulting in a difficult and often protracted diagnostic process for individuals.

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Dementia, at least in the early stages, primarily causes cognitive decline whereas motor conditions affect not only cognition, but also many aspects of physical health and emotional wellbeing (Batista & Pereira, 2016). Indeed, some motor conditions, such as MS and PD, do not always initially present as motor symptoms due to the impact the conditions can also have on health and wellbeing. As an example, in one third of MS patients, fatigue is the presenting symptom (Krupp, Alvarez, LaRocca & Scheinberg, 1988). Nonetheless, difficulties in relation to movement can cause problems with activities of daily living (e.g. Hughes, Sinha, Higginson, Down & Leigh, 2005; Hodgson, Garcia & Tyndall, 2004). In addition, early dementia might be relatively easy to keep hidden from others, and consequently individuals can choose whether to disclose to others, whereas movement disorders are often visible from onset (Bhidayasiri, 2005) and so can be harder to keep hidden.

Consequently, this review will focus upon the four most common motor neurodegenerative conditions: PD, HD¹, multiple sclerosis (MS) and MND.

PD is a chronic and progressive condition characterised by motor disturbances (e.g. tremor, stiffness and slowness of movement). Autonomic nervous system complications and cognitive, behavioural and sensorial difficulties can also be experienced (Güngen et al., 2017). It typically affects those over 50 but younger people can also have the condition. More than 10 million people worldwide are reported to be living with Parkinson's disease (Parkinson's Disease Foundation, 2017).

HD is a hereditary, progressive neurodegenerative disorder characterised by symptoms including motor disturbances (chorea, dystonia), incoordination, cognitive decline and behavioural difficulties (Walker, 2007). In addition, psychological difficulties including depression, anxiety, apathy and irritability can also occur (Coppen & Roos, 2017). Age of onset is typically 35-55 (Myers, 2004) though it can occur at any age and children of an affected parent have a 50% chance of developing the condition. The prevalence of HD

¹ Only HD papers focused on diagnosis were included (papers regarding genetic testing results were excluded).

Diagnosis of a motor neurodegenerative condition worldwide varies, but Etchegary (2011) reported that prevalence in the general population is 1 in 10,000-20,000.

MS is characterised by the progressive degeneration of the central nervous system (CNS) (Neumann, 2003) with symptoms including problems with balance, mobility, neurological and sensory disturbances (Tsang & MacDonell, 2011). While the prevalence of MS worldwide also varies, it is estimated that 2.5 million people in the world have this condition with the average age of onset being in the 20s and 30s, although younger and older people can also be diagnosed (Multiple Sclerosis Trust, 2016).

Similarly, MND is a progressive neurodegenerative disorder of the CNS leading to progressive weakness of limb, bulbar and respiratory muscles, of which amyotrophic lateral sclerosis is the most common form (McDermott & Shaw, 2008). The prevalence of MND also varies worldwide; it affects up to 5000 adults in the UK at any one time (Motor Neurone Disease Association, 2017). The condition largely affects people within their 60s and 70s, although it can also present in much younger people (McDermott & Shaw, 2008). Death from MND typically occurs three-five years following diagnosis (Wood-Allum & Shaw, 2010).

Consequently, the purpose of the present systematic review was to understand the diagnostic experience of individuals diagnosed with the four most commonly reported motor neurodegenerative conditions. It is a review of qualitative studies as these are able to explore the lived experience of diagnosis.

The aim of conducting a meta-synthesis is to bring together findings from qualitative research in order for consistencies or differences to be identified (Tong, Flemming, McInnes, Oliver & Craig, 2012), to further elucidate the lived experience of participants (Cherry, Perkins, Dickson & Boland, 2014) and for new meanings and interpretations to be identified. A number of approaches to meta-synthesis exist (Edwards & Kaimal, 2016). However in order to best meet the aims of this review, a meta-ethnographic approach was chosen because meta-ethnography is interpretative in nature and seeks to go beyond single accounts to identify analogies between different accounts (Noblit & Hare, 1988).

Method

Database searches

Following advice from an academic librarian, PsycINFO, CINAHL and PubMed (which includes Medline) were the databases searched for appropriate studies. The research focus of each database was relevant to the nature of the present review; such interests included: nursing, health, health care and psychology. The searches were conducted in December 2016. To ensure no papers were missed the search terms were broad in nature and simply consisted of the names of the four neurodegenerative conditions and alternative, umbrella, terms for these conditions such as ‘movement disorders’. In particular, the free text search terms used in order to identify relevant research papers consisted of :

neurodegenerative OR movement disorder OR parkinson's disease OR parkinsonism
OR huntington's disease OR huntington's chorea OR motor neuron* disease OR
amyotrophic lateral sclerosis OR multiple sclerosis*

These terms were all searched within the ‘abstract’ and ‘title’ fields for all of the databases.

Following this, searches were then conducted using the relevant subject headings of each of the databases (Thesaurus- PsycINFO, CINAHL headings- CINAHL, MeSH Terms- PubMed). The results from both the abstract and title searches and the databases’ own subject heading searches were then combined using the term ‘OR’. Finally, in order to identify qualitative articles within the databases, each database’s qualitative filter was employed (see Table 1-A) and combined using the term ‘AND’ with the results from the abstract/title and subject headings. Certain limiters were applied to exclude papers which did not meet the inclusion criteria. Articles were limited to those that were peer-reviewed, written in English and, for CINAHL and PsycINFO, focused upon humans. The human limiter in PubMed was not applied as it can actually exclude some articles which are directly about, or relevant to, humans (Sladek, Tieman & Currow, 2010).

[Table 1-A about here]

Inclusion/Exclusion criteria

The criteria for inclusion of articles were: (1) written in English; (2) qualitative in method; (3) concerned with the experience of diagnosis for adults (as it was felt the experience of children/teenagers would be different) who had a diagnosis of either PD, MS, MND or HD; (4) qualitative studies which employed a method where the interview content was flexibly solicited (as opposed to, for example, fixed questions being asked). Mixed methods papers were included if the qualitative data reported met the other inclusion criteria. No date limiters were applied.

The criteria for exclusion of articles in the review included: (1) qualitative papers that also focused on other people's experiences of diagnosis (i.e. caregivers, medical professionals) without having a separate section for the individuals' experiences; (2) qualitative papers that focused upon the experiences of diagnosis of the neurodegenerative conditions in question alongside other non-motor conditions (such as rheumatoid arthritis and cancer) without having separate sections for each condition within the results section of the paper (e.g. Locock, Nettleton, Kirkpatrick, Ryan & Ziebland, 2016; Scheer, Kroll, Neri & Beatty, 2003); (3) qualitative papers which did not make it clear what method was used to analyse the qualitative data (e.g. Johnson, 2003); (4) qualitative studies which were focused on topics other than diagnosis and thus only included a very small amount of information regarding diagnosis. The 13 papers removed for this final reason were checked following completion of this meta-ethnography to ensure no significant themes were missed by excluding these. Please refer to Table 1-B for details of these papers.

[Table 1-B about here]

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Of the 24 papers included in the review, two used the same sample (Pinder, 1990; Pinder, 1992). However, due to the difference in topic focus across the two papers, both papers were included, while ensuring that the information from these two was not over-represented in the final themes. In addition, the author of one paper (Schwartz, 2010) was contacted to provide clarity on the sample. The author confirmed that all participants had a diagnosis of HD (rather than being pre-symptomatic individuals with the HD gene mutation) and so this paper was included. The reference lists of all included papers were also searched for any additional relevant papers.

A total of 35,599 papers were identified from the databases. When filters were employed to limit articles to both English and peer-reviewed journal articles, and after duplicates were removed, 4588 papers remained. The title and abstract of these papers were then screened for relevance which then left 60 papers; 36 of these were excluded for meeting exclusion criteria which left 24 papers remaining. The reference lists of these 24 papers were screened but no further relevant articles were identified. See Figure 1 for details of paper inclusion. See table 1-C for a summary of papers reviewed.

[Figure 1 about here]

[Table 1-C about here]

Quality appraisal

To appraise the quality of each of the 24 articles, the Critical Appraisal Skills Programme (CASP, 2013) was employed. The CASP consists of two screening questions and eight detailed questions designed to assess the strengths and weaknesses of qualitative research. The latter eight questions were scored using the three point rating system of Duggleby et al. (2010). A weak score was given one point, a moderate score two points, and a strong score three points.

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This point system resulted in each of the 24 papers receiving a quality appraisal score out of twenty four; CASP scores ranged from 13 to 24 (see Table 3). CASP scores were not used as a basis for exclusion since, although some papers were poorer in quality than others, each of the meta- synthesis themes is based upon findings from several papers thus providing a degree of triangulation (Carter, Bryant-Lukosius, DiCenso, Blythe & Neville, 2014).

Meta-ethnographic approach

The chosen method for the present review, meta-ethnography, followed Noblit and Hare's (1988) seven step process. These steps included: getting started (identifying an area of interest that qualitative research might inform); deciding what is relevant to the initial interest (through the use of extensive searches to identify relevant studies); reading the studies (repeated reading and detailed notes of concepts and themes made); determining how the studies are related (comparing themes and concepts across studies); translating the studies into one another (translating the meaning of themes and concepts across studies to provide explanation of the experience of diagnosis); synthesising translations (looking for common types of translations and new interpretations) and expressing the synthesis (conveying synthesis findings in an accessible way) (Noblit & Hare, 1988).

Table 1-D demonstrates the process of theme identification.

[Table 1-D about here]

The majority of included papers (14) were focused upon MS, with five focused upon PD, four on MND and only one paper focused upon HD. In addition, the majority of the papers (22) were from Western countries. Table 1-E demonstrates, in more detail, the characteristics of included papers.

[Table 1-E about here]

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Findings

Three themes were identified from this meta-synthesis. These were as follows: “A bomb that could not be absorbed”: the emotional experience of receiving a diagnosis; “You’ve got what your cousin died from”: feeling dismissed and powerless; and “Know thy enemy”: to information seek or not?. Each theme will now be explored in detail.

***“A bomb that could not be absorbed”*: The emotional experience of receiving a diagnosis**

The emotional experience of receiving a diagnosis was found to be complex in nature. The trauma of receiving a diagnosis was exacerbated by an unknown illness trajectory and unhelpful associations held by participants about the condition. However, some positives were noted. This theme comprises three subthemes: the trauma of diagnosis, fear of the unknown and finding positives.

The trauma of diagnosis

Regardless of whether receiving a diagnosis of PD, MND, MS or HD, the trauma of the diagnosis was evident across all papers. Many participants spoke of their experience of extreme shock and distress at the time of initial diagnosis, with some using combat metaphors: “It [MS diagnosis] hit me like a bullet right between the eyes” (Koopman & Schweitzer, 1999, p.21); “a bomb that could not be absorbed” (Pretorious & Joubert, 2014, p.6). Likening the experience of diagnosis to a bomb or being hit by a bullet highlights the emotional carnage caused by diagnosis and the feeling of one’s whole life, and future, being under immediate attack. One individual likened her response to the attack of diagnosis to shell-shock and this played out immediately after she left the clinic, even interfering with her ability to drive home following her appointment (Pinder, 1992). The devastating impact of a diagnosis was noted to last for a long time which affected self-confidence for some individuals (Irvine, Davidson, Hoy & Lowe-Strong, 2009). In addition, many participants spoke of their experience of depression in the months and years following diagnosis (Hogden, Greenfield, Nugus & Kiernan, 2012; Barker-Collo, Cartwright & Read, 2006; White, White & Russell, 2007). This depression appeared to arise as a consequence of the experience of

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continuous, overwhelming feelings:

The first 2 years, that was all I could think about [diagnosis of PD]. A long time. I wouldn't have expected it to last that long, 2 to 3 years. That's all I could think about. My whole thinking was not only colored by it but it was always there to think about (Habermann, 1996, p. 402).

The length of time that some participants experienced these emotions for, highlights the severity of the emotional disruption for individuals. In addition, the use of combat metaphors to describe the experience of diagnosis is indicative of participants feeling attacked, with this signalling the start of an emotional battle which, for some, lasted years.

Fear of the unknown

The uncertain nature of the illness trajectory brought much fear and distress for participants across all conditions (Irvine et al., 2009; Isaksson & Ahlstrom, 2006; Malcomson, Lowe-strong & Dunwoody, 2008; Ploughman et al., 2012; Strickland, Worth & Kennedy, 2016). Many participants highlighted that the uncertainty of how their condition would progress was a significant part of their emotional experience. For example, one participant reflected "It was a fear of the unknown. What is going to happen? What can happen?" (Ploughman et al., 2012, p.10). Indeed one participant described experiencing a "huge massive fear wash over me" in the days following diagnosis (Thorne, Con, McGuinness, McPherson & Harris, 2004, p.10). This gives a sense of being suffocated with an overwhelming tidal wave of negative emotion.

Participants had uncertainties as to how the conditions would personally affect them (Hogden et al., 2012; Malcomson et al., 2008; Pinder, 1990). Vickers (2010) found that individuals reported unhelpful discussions with their doctor which failed to provide clarity of what was to come for them personally, despite the doctor appearing confident:

But then he [the doctor] explained what it was and he explained you know, "You may finish up in a wheelchair, but that's only a small number of people in the overall", and

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you know, and he was very confident about the whole thing...and, you know, I wondered where it's going to go because my wife was, at the time, was pregnant with our second bub, so we were going to have two children (Vickers, 2010, p.214).

The absence of clarity and detailed information regarding their condition and prognosis was the driving force for many individuals in carrying out research into their condition (Dennison, McCloy Smith, Bradbury & Galea, 2016) – see theme three.

Finding positives

Despite the range of negative emotions arising following a diagnosis of PD, MS, MND and HD, individuals across the majority of papers also identified their experience of finding positives, often in the form of relief that the diagnosis had finally validated the symptoms they were experiencing (Thorne et al., 2004; Pretorius & Joubert, 2014; Edwards, Barlow & Turner, 2008; Seeber et al., 2016). Others spoke of the diagnosis confirming that they were not “crazy” (Barker-Collo et al., 2006, p.437), thus providing further validation for their experience of symptoms and indicating participants’ preference of having a neurodegenerative condition over mental health difficulties. Many individuals were also relieved to learn that their symptoms of PD were not those of a life limiting condition such as a brain tumour, as were some family members (Irvine et al., 2009; Warren et al., 2016; Strickland et al., 2016; Isaksson et al., 2016). This indicates that participants also felt it more preferable to have a neurodegenerative disorder compared to a terminal illness, although MND itself is life-limiting (Wood-Allum & Shaw, 2010).

Some individuals were determined to not let their condition take away desired life experiences and so reframed their diagnosis as an opportunity to not take life for granted and instead make the most of the time they had left and engage in pleasurable activities (Hogden et al., 2012; Mistry & Simpson, 2013; Isaksson & Ahlstrom, 2006; Koopman & Schweitzer, 1999).

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One individual reflected upon how fitting in desired activities allowed her to win in life, rather than MS winning. Consequently, MS became an entity outside of the individual and this appeared to provide her with a sense of control over both her experience of MS and, subsequently, her life:

It has made me realise how important it is for me to make the most of the time I have. I spend as much time with the kids as possible. I have also tried to think of those things that I most want to do and started planning to do them- the things I said I'd do when me and [my husband] retire. I just don't want to miss out on anything, because if I do that, it [the MS] will have won, won't it? (Barker-Collo et al., 2006, p.439).

Other examples of finding-positives following diagnosis included one individual who reframed their diagnosis of MS as being the result of "God's grace"; this demonstrated how some people draw on religion to both make sense of, and enhance, their experience (Fallahi-Khoshknab et al., 2014; Irvine et al., 2009) and the positivity of others was also found to be influential in maintaining more positive interpretations (White et al., 2007).

The strength and range of emotions experienced due to the trauma of diagnosis was compounded by both the uncertain illness trajectories and, much further down the line, the unhelpful, though often accurate, associations held by individuals about each of their conditions. Following the experience of shock and fear, and after a period of time, some individuals went on to engage in a process of finding positives which provided some relief from the negativity.

“You’ve got what your cousin died from”: Feeling dismissed and powerless

Individuals across the majority of articles spoke of vivid recollections of unhelpful encounters with health care professionals at the point of diagnosis. These recollections concerned medical professionals appearing to lack compassion and time, as well as long delays in receiving a correct diagnosis resulting in feelings of powerlessness; these serve as the two sub-themes.

Diagnosis of a motor neurodegenerative condition
Lack of compassion and time from professionals

Regardless of condition, individuals across many of the studies discussed the perceived lack of compassion and time received from the diagnosing health care professional (Barker-Collo et al., 2006; Habermann, 1996; Hugel et al., 2006; Irvine et al., 2009; Malcomson et al., 2008; Pretorius & Joubert, 2014; Seeber et al., 2016; Thorne et al., 2004; Warren et al., 2016). This experience served to enhance the distress experienced by individuals at this difficult time (see theme 1) and led to feelings of being dismissed, with the human significance of the diagnosis being seemingly lost by professionals:

He said, “Well, it’s a noncurable disease”. Told me the classic symptoms and these kind of things. I agreed with him that that’s probably the problem. And after about 5 minutes, he abruptly stood up and said, “Well, that’s all the time I have today and obviously this is a complex discussion and you won’t remember this anyway, so you’ll just have to come back another time”. I was shocked; in maybe 12 minutes of his total time seeing me, he diagnosed me with an illness and gave me no hope [and] erm told me to take some medicine, period. And then he dismissed me (Habermann, 1996, p. 404).

Of interest, although twenty years have passed since Habermann’s (1996) paper, similar findings are still reported with regards to the experience of a PD diagnosis. In particular, a recent paper highlighted one individual’s experience of shock at the way in which his diagnosis was given, with a sense of the experience being rushed and a perceived lack of understanding on the part of the health care professional with regards to the weight of their words:

I was disappointed in how it was broken to me. I really was...when I was told, and the manner in which I was told, it just, it knocked me for six. And then I wasn’t in the room much more than a couple of minutes after that before I was out the door and walking...I was pretty disgusted with it really, the way it was delivered. The

diagnosis, the words. I couldn't tell anybody like that...they kind of forget the impact that their words are going to have on you... (Warren et al., 2016, p.16).

The similar findings reported by Habermann (1996) and Warren et al. (2016), despite the significant time period between these papers, suggests long-standing issues with regards to the disclosure of diagnosis within the medical system. Such issues are also evident across other conditions, with one individual diagnosed with MS highlighting how the lack of support offered by their doctor at the time of being diagnosed resulted in them spending most of the weekend on the telephone to the Samaritans [a UK charity] (Dennison et al., 2016, p.5), a move indicative of the distress caused by diagnosis and the need for individuals to talk about this experience.

Some individuals acknowledged how the medical system played a role in limiting the amount of time doctors could spend with them, resulting in doctors appearing unsympathetic (Pretorius & Joubert, 2014) as well as the medical system limiting the opportunity for relevant interventions (Thorne et al., 2004). In a move further indicative of the lack of awareness of the impact of diagnosis, some doctors informed individuals of their diagnosis over the telephone (Thorne et al., 2004; Isaksson & Ahlstrom, 2006). This led to feelings of anger for individuals (Isaksson & Ahlstrom, 2006) due to the manner in which the diagnosis was given.

Another account highlights a difficult encounter with a medical professional in person:

“I was told, in the words of the consultant himself ‘you’ve got what your cousin died from’...I wasn’t happy about that. Then he just walked away, and I was left to work it out for myself” (Edwards et al., 2008, p.462).

This quote suggests that this individual felt alone in making sense of their diagnosis with regards to what the diagnosis was and what it might mean for them. Similar findings were reported in Thorne et al. (2004).

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Despite the overwhelming evidence to suggest that individuals experienced health care professionals as insensitive and lacking in compassion, there were also positive encounters noted of understanding and sensitive professionals (Thorne et al., 2004; Malcomson et al., 2008), though these were fewer in frequency.

Delays in diagnosis

Delays in receiving a diagnosis was a common theme across conditions (Mistry & Simpson, 2013; Edwards et al., 2008; Ploughman et al., 2012; Malcomson et al., 2008). The significant impact of the delay was clear, with one individual (who waited four months for a diagnosis) describing a sense of frustration, powerlessness and resentment towards health professionals due to the length of her wait. In addition, this individual also described a sense of her whole life being on hold during this time:

This was the longest period of my life...I don't think it is fair for anyone to have to go through four months of being "a yo-yo"...A yo-yo is when you are not sure where your life is going. You can't make plans for your future without knowing the final outcome, because there is so much that could chance either way. Life is at a standstill. You just don't progress any further till you finalise everything. To finish what was started (Koopman & Schweitzer, 1999, p.21).

Furthermore, individuals were sometimes dismissed by doctors due to a lack of recognition and awareness of the significance of their symptoms which ultimately led to delays in diagnosis (Warren et al., 2016; Phillips, 2006; White et al., 2007). Many people reported feeling powerless in the face of the diagnostic process with descriptions of multiple contacts with various medical professionals and numerous diagnostic tests; all of this took time and thus contributed to delays in diagnosis (Barker-Collo et al., 2006; Thorne et al., 2004).

The sub-themes of a lack of time and compassion from professionals and delays in diagnosis are useful in highlighting the context around the diagnosis of neurodegenerative conditions.

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Not only are individuals managing difficult emotions in the lead up to diagnosis, caused by delays and misdiagnoses, but the studies in this review suggest that they also often have to contend with professionals who are experienced as unsympathetic and insensitive.

“Know thy enemy”: To information seek or not?

A theme that was also evident across the different conditions was that of information seeking. There appeared to be a continuum of preferences regarding the desire for information, ranging from those who did want to gain information about their condition following diagnosis and those who preferred to resist having any further information about what was to come.

It is important to note the significance of illness associations that helped to provide some understanding of a condition for some individuals. Many individuals, across all four conditions, described how they made sense of their condition based on what they knew or had heard about it through the media or family or from individuals they had nursed themselves (Isaksson & Ahlstrom, 2006; Dennison et al., 2016; Pinder, 1992; Vickers, 2010; Hugel et al., 2012). Often these associations were unhelpful, but accurate. One individual, with a diagnosis of MS, spoke of seeing a television documentary regarding an actress who had the same condition:

I had just watched, a few months ago, the Annette Funicello story and seeing her at the end, she cannot hardly speak and she is in a wheel-chair. My immediate reaction was “oh no! I don’t want to be like her” (Koopman & Schweitzer, 1999, p. 21).

This quote suggests that individuals often look to celebrities for guidance and information as to how their condition might progress, and although this guidance was anxiety-provoking for individuals, it was often realistic.

For some individuals, the risk of uncovering potentially distressing information about their condition was still preferable to the uncertainty of not knowing at all (Pinder, 1990; Habermann, 1996) with some participants describing themselves as aggressively seeking information (Thorne et al., 2004).

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This indicates a sense of urgency to learn more about their condition.

Warren et al. (2016) highlighted some of the questions to which an individual with a diagnosis of PD sought to find answers:

Why are you heading to this position?"; "What is this? When I take these tablets what is it that comes out of tablets that has to go to my brain to replace what is not being made in my body?...What causes that? (Warren et al., 2016, p. 9-10).

Seeking answers to these questions suggests that either the individual did not initially ask such questions at diagnosis, or this information was not initially forthcoming from professionals. These questions are interesting as they demonstrate the level of detail desired by an individual regarding what has caused their condition, and what is occurring within their body. Indeed gaining more information about their condition was found to be empowering for some individuals (Malcomson et al., 2008), with one individual noting "it was like "know thy enemy" so that I feel like I am doing everything I can to stay well" (Barker-Collo et al., 2006, p. 438).

Some individuals deliberately chose not to find out the implications of the condition with which they had been diagnosed. For these individuals, information about their condition was a threat to peace of mind and uncertainty had definite advantages (Pinder, 1990). In particular, uncertainty appeared to engender hope. Adamson (1997) previously noted that clinical uncertainty can provide the grounds for hope and can help diminish feelings of uncertainty associated with the contemplation of worst-case scenarios. Furthermore, some individuals appeared to be conflicted about their desire for information and would often ask family members to seek, and interpret, information on their behalf (Hogden et al., 2012; Hugel et al., 2006) perhaps as a way of filtering out any information that was too overwhelming.

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Many people differed within, and across, conditions with regards to their preference for information. This finding has important medical implications which will be explored within the discussion. Pinder (1990) emphasised that individuals' responses regarding their need for information were found to change over the illness trajectory, at a pace that felt right for them (Seeber et al., 2016).

Discussion

This meta-synthesis has enhanced our understanding of the diagnostic experiences of individuals with a common motor neurodegenerative condition and identified the contextual difficulties which exacerbate the diagnostic process. Recent versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM- IV; APA, 2000; DSM-V; APA, 2013) suggest post-traumatic stress disorder (PTSD) can be precipitated by a diagnosis of a life-threatening disease (Rustad, David, & Currier, 2012) and the findings from this review support this notion since all diagnoses were experienced as life-shattering and life-altering (e.g. Janoff-Bulman, 1992). The immediate threat experienced by individuals was not always in relation to the physical (in terms of length of life) but also related to the cognitive and psychological threat caused by diagnosis, such as the threat to identity highlighted by Caddell and Clare (2011) in their study on dementia.

Shattered assumptions theory (Janoff-Bulman, 1992) posits that when individuals experience a traumatic event that damages their worldview, the world is no longer perceived as predictable since worldviews are undermined and individuals feel vulnerable. This review highlighted the presence of vulnerability for participants; indeed combat metaphors used suggested participants were left feeling vulnerable in this new, and unpredictable, battle with a motor neurodegenerative condition (e.g. Pretorious & Joubert, 2014; Irvine et al., 2009; Ploughman et al., 2012).. In addition, this personal vulnerability can give rise to the anxiety and physiological reactions that characterise post-traumatic stress disorder (PTSD) (Edmonson et al., 2011).

Similarly, Brennan's (2001) social cognitive transition model (developed in relation to cancer, though applicable to a range of conditions) suggests mental models are unconsciously acquired throughout our lives, and are important as they enable us to anticipate and negotiate life allowing for a reasonably continuous and coherent narrative.

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However, when faced with extreme events, such as a diagnosis, that violate our expectations and assumptions, we require a period of psychological adjustment while our, and other peoples', mental maps attempt to integrate these violations (Brennan, 2001). This period of adjustment is often a difficult one, with many participants within this review reporting the experience of depression during this period. These emotions lasted years for some participants, suggesting that the period of re-adjustment within participants' mental models took a substantial period of time, perhaps because the violation was so big.

In addition, many individuals were noted to make sense of their condition based on what they knew or had heard about it through the media and those celebrities who had been diagnosed with the same. Trying to make sense of a condition could well be a response to both the altered mental maps and the vulnerability and powerlessness experienced by participants, making some individuals keen to provide clarity on what might come for them in any way possible. Indeed, celebrities are often salient individuals given that they are highly influential people whose actions and decisions, including those about health, are often emulated by wide audiences (Hoffman et al., 2017). It has been noted that when a celebrity develops a health condition, public awareness of the disorder can increase dramatically (Tanne, 2000), however this awareness can sometimes be misleading and is not always well-informed (Hoffman & Tan, 2013).

Medical professionals in this review were identified as delivering the life-changing diagnosis of a neurodegenerative condition in a way which left participants feeling dismissed and powerless, further exacerbating the vulnerability. It is possible that medical professionals failed to recognise the vulnerability leading to missed opportunities to provide safety and containment.

NICE guidelines in relation to diagnosis do exist within the area of motor neurodegenerative conditions with regards to when a condition should be suspected and when a diagnosis should be reviewed (e.g. NICE, 2006; NICE, 2014). However, no guidance specifically refers to the communication of the diagnosis itself. Nonetheless, some research

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articles do provide guidance as to how a diagnosis should be given, for example McDermott (2008) in motor neurone disease noted the importance of honesty, without destroying hope, and a positive emphasis on what can be done to help.

Blight, Davis, Evans, Hawkes and Carroll (2016) focused upon 40 individuals' diagnostic experience of PD and identified that patients often feel vulnerable and confused following diagnosis and participants identified failings at the time of diagnosis including: failing to advise patients to bring somebody with them to the appointment, failing to signpost to Parkinson's UK and inadequate consultation time (Blight et al., 2016). Consequently, there appears to be a consistency in findings regardless of research methodology.

Patients hold expectations that doctors have sufficient expertise (Budysh, Helms & Schultz, 2012) and will treat their patients with compassion (Lateef, 2011). However, in the present review the expertise and compassion of professionals was found to be questionable with reports of a lack of understanding regarding neurodegenerative conditions and their symptoms (Phillips, 2006; Warren et al., 2016; White et al., 2007) and a lack of understanding with regards to the impact of the diagnosis (Habermann, 1996; Pretorius & Joubert, 2014; Seeber et al., 2016). This suggests that the expectations held by patients are not always met by the diagnosing professional. Unmet expectations were found to be linked to feelings of frustration in the present review and left participants feeling dismissed and often de-humanised. Unmet expectations are even more important when it is considered that these can result in either non or sub-optimal concordance with treatment by patients and affect doctors' reputations (Lateef, 2011).

Nonetheless, finding some positives amid the trauma of diagnosis was found to be a way of managing the experience for some individuals within this meta-synthesis. Indeed, the attempts to find positives helped relieve the trauma experienced; consequently, this might suggest that the period of adjustment following an extreme event, as identified by Brennan (2001), involves finding new, and more positive mental maps (Brennan, 2001).

Indeed finding positives to diagnosis has previously been highlighted in the literature

Diagnosis of a motor neurodegenerative condition across different conditions. For example, individuals diagnosed with HIV/AIDS reported re-evaluating life's values and feeling inspired to change their direction in life in order to 'better' themselves (Amos, 2015). Similarly, cancer survivors described no longer taking life for granted, doing more personally meaningful activities, enhanced self-awareness and understanding and finding spirituality (Connerty & Knott, 2013).

Strengths, limitations and future research

The studies included in this review recruited participants from a range of countries (including South Africa, United States, Canada, Australia, The Netherlands, Iran and the United Kingdom) which is a strength of this review; nonetheless, the studies are biased towards western countries.

However, since reciprocal translations were identified across these papers, this could be indicative of a diagnosis experience that was universal in nature for these four commonly reported motor neurodegenerative conditions.

A limitation of this review is the uneven representation of conditions since fourteen papers focused upon MS and just one paper focused on HD. This could possibly make the findings more relevant to a diagnosis of MS, rather than a diagnosis of HD. Although this distribution of papers is perhaps indicative of the higher prevalence of MS compared to HD, every effort was made to ensure that findings did not only consist of evidence from just one condition. Furthermore, as the experiences of individuals were common across papers, this enables some confidence that the findings also apply to the less represented conditions.

With regards to future research, it would be helpful for other meta-syntheses to focus on additional factors associated with motor neurodegenerative conditions, such as self-management including medication adherence or experiences of palliative care to continue to enhance, and build upon, our understanding of an individual's experience. For example, research in the area of PD has explored suboptimal medication adherence (Grosset, Bone & Grosset, 2005) and found poorer compliance to be associated with younger age, depression and increased numbers of PD medication.

It would be helpful to know whether these factors were specific to PD, or relevant to

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other motor neurodegenerative conditions, in order to determine the clinical implications concerning individuals who do not adhere to what doctors suggest regarding medication. It would also be useful for future research to focus upon individuals who have had positive experiences of diagnosis, in order to learn more about how this can be done.

Clinical implications

The findings from this meta-synthesis provide evidence to help justify the need to continue to educate medical professionals about the impact of a diagnosis of a neurodegenerative condition. Blight et al. (2016) has suggested improvements for the diagnostic process in PD, and these suggestions would be applicable to the diagnosis of all conditions and so are relevant to mention here. In particular, it was proposed that health professionals should: provide individuals with an information sheet with the contact details of services, and information about the resources available, relevant to their condition; explain all treatment choices to their patients; and copy patients into all clinic letters to enhance communication, with timely follow-up arrangements clearly communicated (Blight et al., 2016). If some of these suggestions were implemented within current medical practice, perhaps this would reduce the level of trauma experienced at diagnosis for individuals diagnosed with neurodegenerative conditions.

Borreani et al. (2011) has previously trialed an information aid for individuals newly diagnosed with MS; this consisted of a personal interview with a doctor using a CD, as well as a take-home booklet. Overall, this information aid was viewed positively by both patients and doctors, with patients noting that the information helped clarify any doubts they had. Similarly, Köpke et al. (2013) evaluated an evidence-based patient information programme for patients recently diagnosed with MS and high rates of autonomy and informed choice were identified among patients (Köpke et al., 2013). These studies highlight the benefits of the provision of information for individuals newly diagnosed with MS.

In support of the need for information provision for another neurodegenerative condition, that of dementia, the UK Department of Health (DoH, 2009) posited the need for specialist services to deliver early diagnosis, with emphasis on making and breaking a

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diagnosis well and providing appropriate treatment, information and support post-diagnosis.

Previous research has found that doctors themselves find delivering ‘bad news’ to patients difficult (Aoun et al., 2016; Martinelli et al., 2012; Ptacek & McIntosh, 2009). In particular, delivering bad news when feeling rushed, concerning an illness that they have never dealt with before, and for an illness with few treatment options exacerbate the difficulty of breaking bad news and often determine the response of doctors in that moment (Ptacek & McIntosh, 2009). Nonetheless, Martinelli et al., (2012) noted that having an awareness of such factors can help doctors with the communication process.

Despite the number of models that have been proposed to help with the task of breaking bad news (Rabow & Mcphee, 1999; Baile et al., 2000), this review suggests that difficulties in this area still remain. Similarly, so does the work of Aoun et al. (2016) who identified that some neurologists are interested in receiving further training in how to respond to patient emotions and in developing best practice standards for communicating the diagnosis of MND.

Participants also identified the uncertainties connected to each illness trajectory as problematic. Clearly, individuals are different and each case is unique; therefore a process tailored to the individual, where possible, should be considered. Perhaps information aids, such as those trialled by Borreani et al. (2011) and Köpke et al. (2013), would be helpful here for helping to reduce some of the uncertainties experienced. In addition, charities and specialist nurses affiliated with each of the conditions could (and for some, e.g. PD, they do) provide this information, although individuals would need signposting to this support; signposting was an activity which health care professionals frequently failed to do in the present review.

This review also identified the importance of individuals’ preference in relation to whether or not they desired information regarding their condition. This has further implications for medical professionals as each individual’s preference needs to be respected and so the question regarding whether an individual wants more information (and what type)

Diagnosis of a motor neurodegenerative condition should be raised soon after diagnosis and should be regularly re-assessed.

This review has implications for clinical psychologists since it highlights a clear gap in the consideration of the psychological needs of individuals who have received a diagnosis. The BPS (2009) has recommended in guidance specific on PD that specialist MDT PD clinics should have dedicated input from a clinical psychologist. However, this does not appear to be linked to the diagnostic process but, rather, psychological support for those at more advanced stages. The present review highlights the need for this support from the very beginning.

It could also be helpful for clinical psychologists to work alongside specialist nurses (across conditions) for the benefit of the patient. For example, clinical psychologists could have some input into educational groups, often facilitated by specialist nurses, around diagnosis and the impact of this. Furthermore, as nurse specialists are usually more available, and see patients more than doctors, there could also be a potential supervisory role for clinical psychologists here in supporting those who deal most frequently with patient difficulties and distress.

Conclusion

This review has investigated the experiences of being diagnosed with one of four most common motor neurodegenerative conditions. Both negative, and some positive, experiences of diagnosis were identified. This review has also highlighted some of the contextual difficulties which exacerbate the diagnostic process. Finally, the variation among individuals with regards to the preference, and need for information regarding their condition was also identified. Further attention needs to be paid to this point in the chronic illness journey by health professionals.

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*denotes papers included in the meta-synthesis

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Figure 1

Figure 1. A flow diagram of paper inclusion

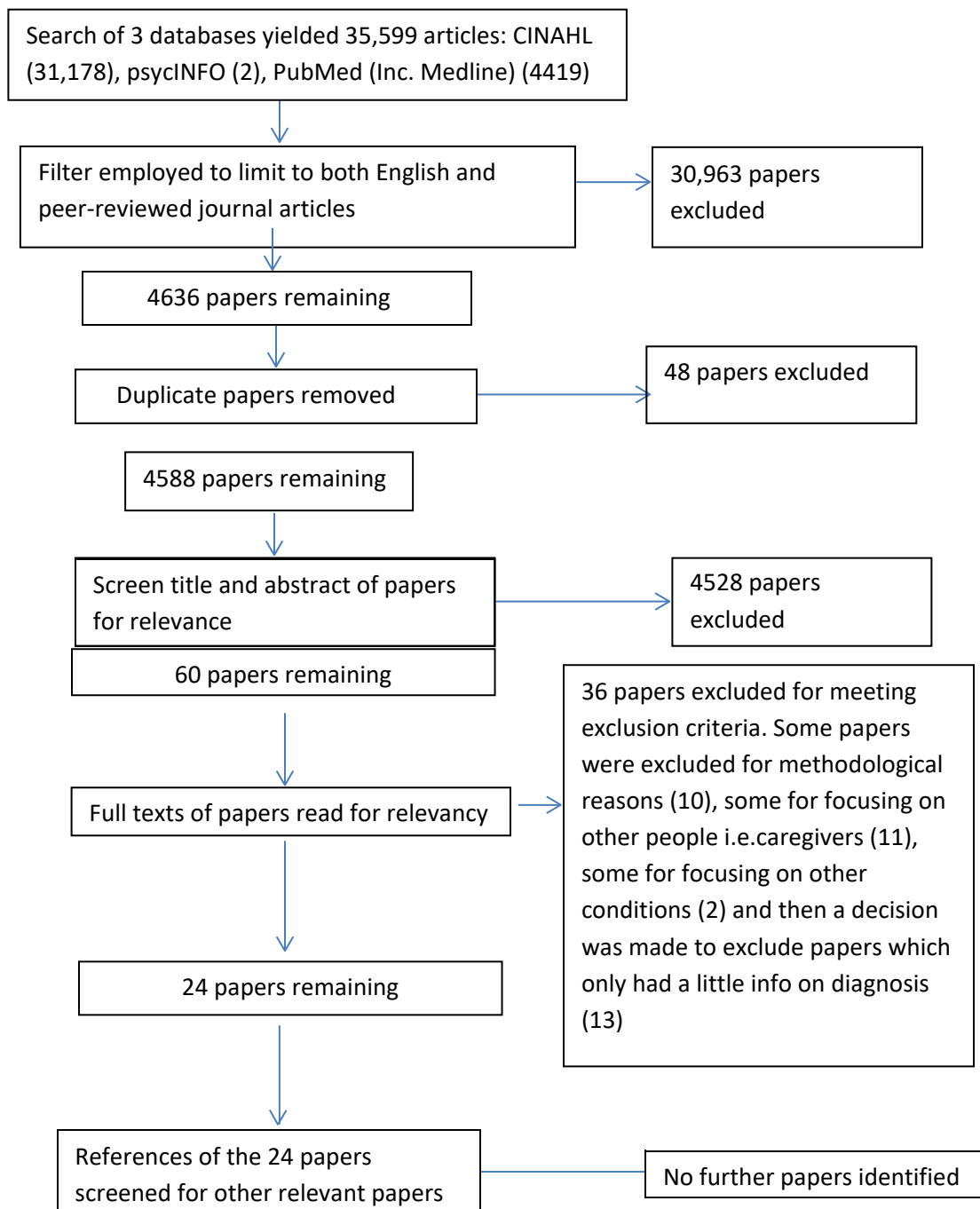


Figure 1 demonstrates the process undertaken when identifying relevant papers for inclusion in the review.

Table 1-A

Table 1-A. Qualitative filters for each database

Database	Qualitative filter
<i>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</i>	None in existence at the time of writing
<i>PsycINFO</i>	(((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or guides) adj3 (interview* or discussion* or questionnaire*)).ti,ab,id. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")).ti,ab,id. or exp qualitative research/ or exp interviews/ or exp group discussion/ or qualitative study.md. not "Literature Review".md.
<i>PubMed (including Medline)</i>	“interviews as topic”[Mesh:noexp] OR “focus groups”[Mesh:noexp] OR narration[Mesh:noexp] OR qualitative research[Mesh:noexp] OR (((“semi-structured”[TIAB] OR semistructured[TIAB] OR unstructured[TIAB] OR structured[TIAB] OR informal[TIAB] OR “in-depth”[TIAB] OR indepth[TIAB] OR “face-to-face”[TIAB] OR guide[TIAB] OR guides[TIAB]) AND (interview*[TIAB] OR discussion*[TIAB] OR questionnaire*[TIAB])) OR (“focus group”[TIAB] OR “focus groups”[TIAB] OR qualitative[TIAB] OR ethnograph*[TIAB] OR fieldwork[TIAB] OR “field work”[TIAB] OR “key informant”[TIAB]))

Table 1-B

Table 1-B. Papers not included in the meta-synthesis

Paper	Are findings regarding diagnosis in line with meta-synthesis findings?	Additional diagnostic themes?
Touching moments: a phenomenological society and the haptic dimension in the Lived experience of motor neurone disease (Allen-Collinson & Pavey, 2014)	Yes	No
“Putting one foot in front of the other”: A qualitative study of emotional experiences and help-seeking in women with multiple sclerosis (Blundell Jones, Walsh & Isaac, 2014).	Yes	No
How people with motor neurone disease talk about living with their illness: a narrative study (Brown & Addington-Hall, 2008)	Yes	No
Experiences of adjusting to early stage multiple sclerosis (Dennison, Yardley, Devereux & Moss-Morris, 2010).	Yes	No
Perceptions of cause and control in people with Parkinson’s disease (Eccles, Murray & Simpson, 2011).	Yes	No

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Table 1-B. (continued)

Paper	Are findings regarding diagnosis in line with meta-synthesis findings?	Additional diagnostic themes?
The intertwining of body, self and the world: A phenomenological study of living with recently-diagnosed multiple sclerosis (Finlay, 2003)	Yes	No
Understanding psycho-social processes underpinning engagement with services in motor nerve disease: A qualitative study (Foley, Timonen & Hardiman, 2014)	Yes	No
Barriers and facilitators related to rehabilitation stays in multiple sclerosis: a qualitative study (Hellend, Holmoy, Gulbrandsen, 2015).	Yes	No
Women coping successfully with multiple sclerosis and the precursors of change (Kirkpatrick Pinson, Ottens & Fisher, 2009)	Yes	No
MS and me: Exploring the impact of multiple sclerosis on perceptions of self (Mozo-Dutton, Simpson & Boot, 2012).	Yes	No
Patients' perspectives on quality of mental health care for people with MS (Rintell, Frankel, Minden & Glanz, 2012)	Yes	No

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Table 1-B. (continued)

Paper	Are findings regarding diagnosis in line with meta-synthesis findings?	Additional diagnostic themes?	
		Yes	No
Multiple sclerosis and quality of life: a qualitative investigation Somerset, Sharp & Campbell, 2002).	Yes		No

Table 1-C

Table 1-C. Summary of papers reviewed

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Barker-Collo, Cartwright, & Read (2006)	To explore participants' prediagnostic and diagnostic experiences of MS as well as the implications of living with this condition	Thematic analysis	16	Telephone interviews lasting between 1-2 hours	Prior to diagnosis participants had experienced different symptoms. Diagnosis itself was a complex process leading to varied responses and an inability to assimilate information about MS. Patient narratives reflected negative and positive aspects of living with a chronic illness including : shifting roles, discrimination re-evaluation of priorities, re-investment in the family and positive lifestyle changes. Fear and anxiety related to the unknown were present in all narratives.	16

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Dennison, McCloy Smith, Bradbury, & Galea (2016)	To understand how prognostic uncertainty affects people with MS, if and how people with MS form expectations about their disease trajectory and what communication they receive and want	Thematic analysis	15	Semi-structured interviews lasting 20-78 minutes	MS patients report having minimal communication with health care professionals (HCPs) about prognosis. MS patients develop expectations about their disease trajectories over time, but with little input from HCPs. Prognosis information given by HCPs appears to run counter to patients' focus on the present. Patients are often ambivalent about prognosis information and view it as emotionally dangerous and of limited usefulness.	22
Edwards, Barlow & Turner (2007)	To examine patients' experiences of being diagnosed with MS, with a focus on the information that they received at this time, subsequent treatment	Thematic content analysis	24	Semi-structured telephone interviews lasting between 30-60 minutes.	Many participants had experienced long delays in the diagnosis of MS. At the point of diagnosis, participants had to make sense	15

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
	and its impact on their lives.				of and understand their diagnosis- often with a lack of support. Some participants expressed anger about the way they were diagnosed and many felt they were given insufficient information about MS which led to participants searching for this information.	
Fallahi-Khoshknab, Ghafari, Nourozi & Mohammadi (2014)	To explore the experiences of patients in confronting their diagnosis of MS	Content Analysis	25	Unstructured interviews lasting between 45-75 minutes	Four main themes were identified: knowledge-deficit, concealing the disease, religiosity (all with 2 sub-themes) and emotional reactions (5 sub-themes)	23
Habermann (1996)	To broaden the discourse on what	Interpetive phenomenology	16	Semi-structured interviews lasting	The study found that the demands experienced	18

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Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
	<p>it is like to have a chronic, degenerative progressive illness such as PD and to explore the experience of having PD in middle life</p>			between 1-1.5 hours	<p>by people with PD included: acknowledging symptoms and seeking help; balancing emotional responses; dealing with a changing body and gaining formal and practical knowledge and dealing with unpredictability. PD also created demands related to changing roles, sense of identity and relationships.</p>	
Hogden, Greenfield, Nugus & Kiernan (2012)	To explore patient experiences of ALS and to identify factors influencing patient decision-making in the multidisciplinary care of ALS.	Thematic Analysis	14	Semi-structured interviews lasting up to 30 minutes	Decision-making was found to be influenced by three levels of factors: structural, interactional and personal factors. Patient approaches to decision-making reflected a focus on the present, rather than anticipating	22

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
					future progression of ALS and potential care needs.	
Hugel, Grundy Rigby & Young (2006)	To explore issues surrounding a new diagnosis for patients with MND	Interpretative Phenomenological Analysis	13	Semi-structured interviews	Nine major themes were identified: Family/carers, communication of the diagnosis, reaction to the diagnosis, physical difficulties, time before diagnosis, information, future, coping with the diagnosis and formal support	16
Irvine, Davidson, Hoy & Lowe-strong (2009)	To explore the subjective experiences of living with, and adjusting to, MS	IPA	8	Semi-structured focus group interview	Diagnosis was met with negative reactions: denial, concealment and diminished confidence. Over time there were positive changes in terms of values and outlook. Difficulties such as uncertainty and depression are ameliorated, to some extent, by an increased appreciation for life and spirituality.	18

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Isaksson, & Ahlstrom (2006)	To describe patients' conceptions of MS before diagnosis and their illness experiences connected with the initial symptoms and diagnosis of MS	Content analysis	61	Semi-structured interviews	The perception of MS for patients was often disablement and death but some had a more nuanced image of MS. Initial symptoms and diagnosis of MS were experienced as stressful and led to patients becoming vulnerable. Patients used a variety of ways to manage their situation and acquire Strength	13
Koopman & Schweitzer (1999)	To explore people's experiences of having symptoms of MS for a period of time before then being diagnosed with MS.	Phenomenology	5	Semi- structured interviews lasting between 1-2 hours	Central to the experience of MS are the voices that speak, respond and share the diagnosis of MS. Four major themes emerged: whispered beginnings; echoes of silence; the spoken words; re-creating voice. Each theme had separate sub-themes.	18

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Malcomson, Lowe-Strong, & Dunwoody (2008).	To explore the personal accounts of individuals with MS	Thematic analysis	13	Focus groups lasting 90 minutes	Seven themes emerged from the data: something is wrong; getting a name, getting help; consequences to lifestyle; getting on with day-to-day life; advice to others with MS and advice for health professionals.	18
Mistry & Simpson (2013)	To explore the personal and lived experiences of individuals with MND	Interpretative Phenomenological Analysis	7	Semi-structured interviews	Three themes emerged concerning receiving a diagnosis of MND, learning to live with MND and experiencing progressive loss. Participants described their diagnosis as a devastating experience but most could accept this diagnosis and used adaptive strategies to help them cope with functional decline. Nonetheless, functional	22

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Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
					changes did affect identity, social status and social relationships.	
Phillips (2006)	To examine the advice people with PD have for someone newly diagnosed	Content Analysis	11	Two semi-structured interviews each lasting between 45-90 minutes	One main theme emerged: dropping the bomb. This theme represented picking up the pieces of lives that are shattered by the diagnosis. Four sub-themes also emerged: guarded anticipation, becoming informed, disease dynamics and negotiating with Mr Parkinson.	17
Pinder (1990)	To explore the differing experience and management of uncertainty within PD for patients and GP's	Thematic Analysis	15 patients 18 GPs	Semi-structured interviews	Coming to terms with PD is a complex and changing process for patients. Patients wanted to preserve a sense of self in the face of actual and physical decline.	14

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
					<p>Clinical facts about PD took on different meanings to those given by doctors. Doctors were concerned with the uncertainty of whether patients wanted to know about PD and, if so, how they would react. GP's had anxieties about how they might handle a situation where a patient lost control in the surgery. GPs routinely used their assumptions about patients to resolve their dilemmas.</p>	
Pinder (1992)	To explore how GPs conceptualise the task of diagnosing patients with PD and the impact of diagnosis on patients in terms of coherence and incoherence.	Thematic Analysis	15 patients 18 GPs	Semi-structured interviews	Diagnosis is a time of maximum experiential incoherence for patients. For GPs, diagnosis was a positive moment, allowing prediction and informed management. Patients needed the descriptive	14

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
					knowledge of PD from doctors. Some doctors' lack of understanding of PD affected their ability to empathise with patients' distress. However, some doctors could approach their patients' inner pain.	
Ploughman, Austin, Murdoch, Kearney, Godwin & Stefanelli (2012)	To explore older people's experiences of ageing with MS and to describe self-management from their point of view.	Thematic content analysis	18	Semi-structured interviews lasting between 60-80 minutes	Participants described a process spanning years, and often decades, from a diagnosis of MS to gaining confidence in managing their MS. Three themes emerged which represented the natural continuum of self-management for MS: the MS recognition process; the MS experience and moving towards self-management. Each of these themes were made up of several sub-themes.	20

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Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Pretorius & Joubert (2014)	To explore the personal experiences of individuals with MS in the South African context	Thematic Analysis	10	Semi-structured interviews lasting between 60-90 minutes	The results of the study found that participants faced several challenges ie. diagnosis, daily-life, invisible illness and medical aid schemes. The resources that help participants to cope with MS consisted of social support, mobility-aids, religion and knowledge about MS.	24
Schwartz (2010)	To explore the meaning of being diagnosed with HD	Narrative Analysis	10	Narrative inquiry interviews	An integrated narrative named "the story of HD Ripples from a stone skipping across the lake" was identified. Four themes which formed the chapters for this narrative were also identified: discovering the existence of HD, confirming the diagnosis of HD, revealing the diagnosis to others	22

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Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
					and experiencing the reverberations of HD. Each 'chapter' also had its own sub-themes.	
Seeber, Pols, Hijdra, Grupstra, Willems & de Visser (2016)	To evaluate how patients with MND react to and view disclosure of their diagnosis in a 2-tiered approach	Inductive Analysis	- 10 patients observed - 21 patients interviewed	Non-participating observations and semi-structured interviews lasting between 45-120 minutes.	Participants experienced their diagnosis as devastating. Before the second (of a 2-tiered) appointment participants experienced a re-orientation on their changed perspective on life. The second appointment itself allowed for discussions about various aspects of MND and for a treatment plan to be drawn up.	17
Strickland Worth & Kennedy (2016)	To explore the lived experience of the meaning of being diagnosed with MS on the	Interpretative phenomenological analysis	10	Semi-structured interviews	Three main themes emerged from the data: road to diagnosis the liminal self and learning to live with MS	23

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
	individual's sense of self				:an uncertain future. An additional theme that ran across these three main themes was that of the impact on the self.	
Thorne, Con, McGuinness, McPherson & Harris (2004)	To explore how individuals with MS describe and explain helpful and unhelpful communication	Interpretive description methodology	12	Semi-structured interviews lasting between 1-2 hours and focus groups	The uncertainty of initial MS symptoms is not easily tolerated by patients or professionals. MS was found to have an uncertain course with little support available for symptom management. Patients with MS are required to exercise self-care management and lifestyle adaptation skills to try and achieve some normality.	16

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
Vickers (2010)	To explore the lived experience of the illness onset passage for people with MS	Heideggerian phenomenology	20	Semi-structured interviews lasting between 1.5- 3 hours.	Three key phases of the illness experience were identified: an unknown passage lived as either “harmless” symptoms or alarming symptoms (both of which are experienced before diagnosis); incomplete knowledge about MS at the point of diagnosis which is compounded by stigma of MS; Living thrownness where the person with MS is thrown into turmoil and ill-equipped to deal with changes.	20
Warren , Eccles, Travers & Simpson (2016)	To explore the personal experiences of being diagnosed with PD.	Thematic Analysis	6	Semi-structured interviews lasting between 32-67 minutes	Three major over-arching themes were identified concerning the value of knowledge; the social implications of being diagnosed with PD;	20

Diagnosis of a motor neurodegenerative condition

Table 1-C. (continued)

Paper	Research Aim	Methodology	Participants	Data Collection	Major Findings	CASP
White, White & Russell	To consider the experience of people with MS when talking to healthcare professionals about their emotional well-being both at the time of diagnosis and whilst living with the condition	Content Analysis	145 -20 of whom were interviewed by telephone	Semi-structured telephone interviews lasting between 1-2 hours	and the importance of supportive others. The diagnostic process was found to be complex and challenging for participants with regards to their own and others' understanding of PD. Seven themes were identified to describe the way health care (2007) professionals interact with patients about their emotions at the time of diagnosis: normalisation; provision of a psychological diagnosis; psychological referral to a support group; referral to the national MS society; encouragement and hope and distancing or controlling.	15

Table 1-D

Table 1-D. Process of Theme Identification Across Papers

Initial concepts identified	Themes emerging from concepts	Refining of Themes	Final concept	Relevant Studies
<p>Range of emotional reactions to diagnosis, relief felt, misconceptions of the condition, negative associations, associations with PD, associations of MS, uncertainty of diagnosis and illness trajectory, future plans on hold, fear at prospect of MND, negative associations of MND in the media, challenge of diagnosis, powerlessness, false perceptions of PD, diagnosis legitimised symptoms, unpredictability of illness trajectory, depression after diagnosis, thoughts of wheelchairs, relief diagnosis is not terminal, diagnosis is a distressing time, finding new meaning, re-framing</p>	<p>The complexity of emotions experienced at the time of diagnosis</p> <p>The uncertainty experienced due to the unpredictability of the illness trajectory</p> <p>Individuals associated their diagnosis with certain stereotypes</p>	<p>The unpredictability and uncertainty of the illness trajectory combined with negative associations of the condition compounded the emotions experienced at diagnosis.</p>	<p>The emotional experience of receiving a diagnosis</p>	<p>Pretorius & Joubert (2014); Pinder (1990); Pinder (1992); Schwartz (2010); Habermann (1996); White et al. (2007); Warren et al. (2016); Hogden et al. (2012); Strickland et al. (2016); Barker-Collo et al. (2006); Ploughman et al. (2012); Edwards et al. (2007); Isaksson & Ahlstrom (2006); Hugel et al. (2006); Vickers (2010); Koopman & Schweitzer (1999); Mistry & Simpson (2013); Seeber et al. (2016); Phillips (2006); Fallahi-Khosh-knab et al. (2014); Dennison et al. (2016), Malcomson et al. (2008);</p>

Diagnosis of a motor neurodegenerative condition

Table 1-D. (continued)

Initial concepts identified	Themes emerging from concepts	Refining of Themes	Final concept	Relevant Studies
experience				Thorne et al. (2004); Irvine et al. (2009)
Medical professionals' lack of awareness of MS, feeling dismissed by doctor, doctor's lack of experiencing in diagnosing, doctors not having time, lack of compassion/sensitivity from doctors, unhelpful neurologist, powerless, long journey to diagnosis negative experience of healthcare professionals, GP's lack of knowledge about PD, delays in obtaining a diagnosis; vivid recollections of diagnosis, difficulties with healthcare professionals	A lack of knowledge about conditions from doctors Lack of knowledge from doctors re the impact of diagnosis Insensitive doctors who are lacking in compassion Delays in the diagnostic process.	Individuals felt unsupported by doctors during the diagnostic process, and had no control over the process	Feeling dismissed and powerless	Pretorius & Joubert (2014); Pinder (1992); Habermann (1996); Strickland et al. (2016); Barker-Collo et al. (2006); Ploughman et al. (2012); Edwards et al. (2007); White et al. (2007); Schwartz (2010); Warren et al. (2016); Hogden et al. (2012); Seeber et al. (2016); Phillips (2006); Mistry & Simpson (2013); Isaksson & Ahlstrom (2006); Hugel et al. (2012); Irvine et al. (2009); Vickers (2010) Koopman & Schweitzer (1999); Dennison et al. (2016); Malcomson et al. (2008); Thorne et al. (2004)

Diagnosis of a motor neurodegenerative condition

Table 1-D. (continued)

Initial concepts identified	Themes emerging from concepts	Refining of Themes	Final concept	Relevant Studies
Individuals seeking information about their condition, need for information, want to know vs. not wanting to know, desire to learn more about their condition, only seeking out information compatible with preferred sense of self, not wanting information about MND, internet searching for information on HD, wanting understanding of PD, wanting information on MS, ambivalence, fluctuations in preference for information	<p>Conflict between wanting to know vs not wanting to know about conditions</p> <p>Wanting to be informed about the condition</p> <p>Wanting to be ignorant about the condition</p>	Individuals differed with regards to their preference to seek out information on their condition with some individuals feeling conflicted about this.	To information seek or not?	<p>Pinder (1990); Pinder (1992); Habermann (1996); Ploughman et al. (2012); Edwards et al. (2007); Barker-Collo et al. (2006); Warren et al. (2016); Hogden et al. (2012); Schwartz (2010); Seeber et al. (2016); Fallahi-Khoshknab et al. (2014); Phillips (2006); Hugel et al. (2006); Vickers (2010); Dennison et al. (2016); Thorne et al. (2004); Malcomson et al. (2008)</p>

Table 1-E

Table 1-E. Paper characteristics

Condition	How many papers?	Countries where research was conducted	Analyses employed
MS	14	South Africa, Iran, Sweden, Canada, Australia, New Zealand United States, United Kingdom	Thematic, Content, Heideggerian phenomenology, Thematic-content, Phenomenology, IPA, Interpretive description
PD	5	United Kingdom, The Netherlands, United States	Thematic, Content, Interpretive phenomenology
MND	4	United Kingdom, The Netherlands	Inductive, Thematic, IPA
HD	1	United States	Narrative

Appendix 1-A

Psychology & Health: Instructions for authors

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Section 2: Research Paper

Post-diagnostic lived experiences of individuals with essential tremor

Doctorate in Clinical Psychology

Lancaster University

2014 Intake

Jessica Moore

Word count: 7,995 (excluding title page, references, tables and appendix)

Prepared in accordance with Instructions for Authors for 'Psychology & Health'

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Abstract

Objective: This research study aimed to provide insight into the lived experience of individuals with essential tremor (ET).

Design: This study was qualitative in nature and employed semi-structured interviews to collect data from nine individuals with a diagnosis of ET. Interview transcripts were analysed using interpretative phenomenological analysis.

Findings: Three major themes were constructed: “But they often look at you like you’re some drug addict or smack head”: Social attitudes to difference; “I just couldn’t do it anymore”: The restrictive nature of ET and “You’ve got to cope; you’ve got to learn to fight different ways”: Rescuing some normality amid physical deterioration.

Conclusion: This study offers much needed experiential understanding and interpretation of one of the most prevalent neurological conditions with regard to the emotions associated with specific day-to-day experiences, the restrictions placed upon everyday practicalities and coping strategies implemented which allowed participants to retain some normality. This study has highlighted the need for health care professionals to provide individuals with information regarding psychological support, and a need for more public awareness campaigns centred around ET. Future research should focus on the lived experience of individuals with severe ET, recruited from clinics/hospitals.

Keywords: essential tremor, experiences, IPA

Introduction

Essential tremor (ET) is one of the most common neurological conditions (Louis & Ferreira, 2010), characterised by recurring oscillations of a body part involving one or more joints (Hess & Pullman, 2012). It is both chronic and progressive (Louis, Agnew, Gillman, Gerbin & Viner, 2011) and affects approximately 1% of the general population and 5% of the population over 65 years of age (Louis & Ferreira, 2010). ET is usually considered an action tremor since it is most often seen when performing movement or when maintaining a posture against gravity as opposed to being at rest (Hess & Pullman, 2012). The tremor usually involves upper limbs, although it can affect the head, chin, voice, tongue and other body parts (Jiménez-Jiménez et al., 2013).

The aetiology of ET remains unclear (Jiménez-Jiménez et al., 2013). The frequency of family history of tremor in individuals with ET is high at approximately 50-60% (Jiménez-Jiménez et al., 2013). Furthermore, previous research has reported distinctions between 'hereditary' ET and non-familial ET (Jiménez-Jiménez et al., 2013). For non-familial forms of ET, suggested environmental factors include exposure to pesticides, agricultural work and exposure to frosted glass (Jiménez-Jiménez et al., 2007).

Medication is commonly used as a treatment for ET, although not everyone experiences benefit (Thanvi, Lo & Robinson, 2006). For individuals who are intolerant of, or resistant to, medication, neurosurgery may be considered (Thanvi et al., 2006), including deep brain stimulation (DBS). This involves placing electrodes into the basal ganglia of the brain which deliver a high frequency signal (Flora, Perera, Cameron & Maddern, 2010). Although it can be effective, adverse effects include infection and equipment malfunction (Zesiewicz et al., 2005).

ET was once previously viewed as a solely motor disorder but psychological difficulties are increasingly being recognised as an accompanying feature of this condition

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(Jhunjhunwala & Pal, 2014). Furthermore, quality of life (QoL) is also found to be impaired for individuals with a diagnosis of ET (Lorenz, Schwieger, Moises & Deuschl, 2006). In common with other neurological conditions such as Parkinson's disease (PD) (Soh, Morris & McGinley, 2011), the main predictors of QoL are psychological and psychosocial factors, such as emotional well-being and social withdrawal, rather than illness severity (Lorenz et al., 2006). It has also been found that ability to perform at work, and during leisure activity, impacts upon levels of depression for individuals with ET (Chandran et al., 2012).

Furthermore individuals with ET experience increased prevalence and severity of depression, anxiety, sleep disturbances, pain and fatigue compared to 'healthy' controls with no diagnosis, or family history, of ET (Chandran et al., 2012). Depression may be an intrinsic part of the ET disease process (Musacchio et al., 2016). Alternatively, Chandran et al. (2012) suggested that the experience of depression and anxiety in individuals with ET can be attributed to (i) the impact of tremor on basic and fundamental activities of daily living (ii) the implications on both occupational performance and the ability to perform while partaking in hobbies/leisure activities (iii) the embarrassment experienced as a result of ET and subsequent social withdrawal and low self-esteem and (iv) side effects of the medications prescribed in the treatment of ET.

The experience of embarrassment as a result of ET was also highlighted in the work of Louis and Rios (2009) who found that embarrassment not only occurs when symptoms are mild but is also likely to be an important motivating feature that drives someone to seek treatment (Louis & Rios, 2009). These findings make it feasible to assume that embarrassment is another variable that impacts upon QoL for individuals with a diagnosis of ET. Similarly, Holding and Lew (2015) investigated relations between psychological avoidance (that is, avoidance of negative emotions connected to ET and in particular, embarrassment) symptom severity and embarrassment in ET. The severity of ET

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symptoms and the variable of psychological avoidance were independently found to make significant moderate contributions to embarrassment scores (Holding & Lew, 2015).

In addition, the diagnosis of ET is further complicated by a lack of understanding regarding the relationship (if any) of ET with other neurological conditions which also involve tremor, particularly Parkinson's disease (PD; Fekete & Jankovic, 2011); this results in some individuals being given an incorrect diagnosis. It has been suggested that while ET and PD are distinct entities, evidence of a clinical overlap in the features of the two conditions does exist (Kwon, Lee, Lee, Kang & Koh, 2016). This overlap may explain why approximately 30-50% of individuals with essential tremor are commonly misdiagnosed with PD (Jain, Lo & Louis, 2006). As a result of this overlap in ET and PD, previous research has not only explored the relationship between the two conditions (Thenganatt & Jankovic, 2016) but has also compared QoL (Louis & Machado, 2015). In particular this comparison identified that individuals with ET experienced more impairment in relation to writing, eating, drinking, embarrassment, and concentration (Louis & Machado, 2015) in comparison to individuals with PD. In addition, individuals with ET were also found to have higher self-ratings of tremor severity in their arms, and drink alcohol more frequently than they would like, compared to individuals with PD, whereas the latter were noted to have higher levels of speech impairment and higher self-ratings of tremor severity in their legs compared to individuals with ET (Louis & Machado, 2015).

However, while quantitative studies have highlighted the importance of such psychosocial factors and how these can impact upon quality of life, such research cannot explore the complex interplay of these factors or explore the meaning of these difficulties for individuals in their everyday lives. No qualitative studies have to date been conducted on the lived experience of people with ET. Consequently, by conducting a qualitative study about the post-diagnostic experiences of living with ET, how day-to-day life is experienced and

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made sense of by individuals with this condition can be explored for the first time. For the purposes of this study, the post-diagnostic period was defined as being a minimum of 12 months following receipt of a diagnosis. Being at least 12 months post diagnosis means the individual is more likely to have come to terms with their diagnosis of ET and this would allow for them to focus on the day-to-day experiences of living with this condition, rather than focusing upon the diagnostic process.

With regards to the method used, interpretative phenomenological analysis (IPA) is particularly suited to health psychology research (Brocki & Wearden, 2006) due to the fact that IPA moves away from a biomedical model of illness and moves towards the subjective sense-making of an illness. Furthermore, Thompson, Kent and Smith (2002) proposed that studies employing IPA methodology to explore process, rather than the end goal of adjustment, might usefully supplement quantitative studies in the area. It is therefore anticipated that this study will lead to an enhanced understanding of the lived experiences of individuals diagnosed with ET which could also help to inform more effective psychological support and intervention where this is needed.

Method

Participants

Participants were recruited from an essential tremor group in the North West of England. Potential participants were invited to take part in the present study if they were aged 18 or more (as it was felt the experience of children/teenagers would be different) and had a diagnosis of ET for at least 12 months. Participants also had to speak English. Those who had tremor from other conditions, e.g. PD, were excluded. On the three occasions that the researcher attended the ET group there were approximately 11 group members present each time. Nine individuals chose to participate.

Lived experiences of ET

Two participants identified as being White British, six participants as white English and one participant identified as being of Asian ethnicity. The ages of participants ranged from 38 to 77 ($M= 62.4$ years). Please see Table 1 for further details regarding participant demographics.

[Table 1 about here]

Procedure

The present study was reviewed by the Lancaster University Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee. The National Tremor Foundation confirmed that no permission was needed to attend the ET group. Following the researcher's attendance at the group to hand out study information packs, nine participants completed the consent to contact forms provided. The researcher contacted each participant, and a convenient date and time to conduct the interviews was arranged. On the day of the interview the researcher gave the participant chance to read through the information pack again and answered any questions. Formal written consent was gained prior to commencement of the interviews. Please refer to Appendix A-G of the ethics section for participant documents.

Data collection and analysis

Data for this study were collected through face to face interviews which ranged from 43 to 70 minutes ($M = 57.5$ minutes). A semi-structured interview schedule, created by the researcher, was informed by previous research (Lorenz et al., 2006; Chandran & Pal, 2013; Chandran et al., 2012) and received input from an expert by experience external to the study. This interview schedule was used to guide the discussions; discussions also evolved from participants' responses and what each participant felt it was important to talk about (Smith, Flowers & Larkin, 2009). Interview data were analysed using IPA. All interviews were transcribed by the researcher, with notes of expressions also included. For example,

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expressions of laughter or pauses were incorporated within the written transcript to give more context to what was being said. The analysis followed guidelines provided by Smith et al. (2009) which consisted of six steps: reading and re-reading of transcripts, initial noting (descriptive, linguistic and conceptual comments), developing emergent themes, searching for connections across emergent themes (See Table 2-B for an example of how initial concepts emerging from one transcript (Stephen) developed into emerging themes, and Appendix 2-B for an extract of Stephen's transcript), then moving to the next case and repeating the process and finally looking for patterns across cases (Smith et al., 2009).

[Table 2-B about here]

Following this process resulted in a final list of superordinate themes that accounted for every participants' data-themes. Please refer to table 2-C for details of theme identification.

[Table 2-C about here]

Ethical considerations

Prior to commencing the interviews, each participant was informed that the disclosure of any information regarding risk to themselves, or to others, would result in the researcher having to share this information with the academic supervisors of the study in the first instance in order to determine an appropriate course of action. In order to ensure the anonymity of participants, pseudonyms have been used throughout the reporting of this study and every attempt has been made to ensure that no identifiable quotes have been included.

Quality in qualitative research

Throughout the research process the researcher followed guidelines provided by Yardley (2008) which aim to improve the validity of qualitative research. The researcher used the supervisory process to enhance credibility of the interpretation of findings as well as the consistency and coherency of the analysis (Yardley, 2008). Furthermore the researcher engaged in peer supervision as another method of enhancing both the trustworthiness and quality of data. The researcher had no prior experience of ET however she was aware of previous literature that had highlighted the many difficulties associated with ET, including the presence of psychological difficulties (Lorenz et al., 2006; Chandran & Pal, 2013; Chandran et al., 2012; Jhunjhunwala & Pal, 2014), but she ensured that she remained open to the accounts of all participants, including those that might contradict the extant research.

Findings

Analysis identified three themes: “But they often look at you like you’re some drug addict or smack head”: Social attitudes to difference; “I just couldn’t do it any more”: The restrictive nature of ET, and “You’ve got to cope; you’ve got to learn to fight different ways”: Rescuing some normality amid physical deterioration. Each theme will now be explored in detail.

“But they often look at you like you’re some drug addict or smack head”: Social attitudes to difference

This theme captures participants’ ongoing struggles with embarrassment and anxiety directly linked to judgements made by others and a fear of what others will think of ET caused by social attitudes to difference.

All participants spoke of their experience of being judged by others which often resulted in embarrassment. Some participants spoke of how the general public misinterpreted their tremor, and then made presumptive remarks. John noted having experienced comments

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such as “you’re a nervous so and so aren’t you?” or “are you cold?”. When tremor was perceived to be attributed to the effects of drugs or alcohol then the embarrassment experienced was more severe, with one participant then feeling the need to justify to others the nature of his tremor:

But they often look at you like you’re some drug addict or smack head sort of thing...because...or an alchi...and then you end up going “no, it’s not that, its essential tremor- a bit like MS [multiple sclerosis] and Parkinson’s” and then the look on their face then changes to more sympathetic whereas the initial look is kind of “what’s he smoking or drinking?” (Mike).

Indeed, the use of words such as ‘smack head’ and ‘alchi’ are derogatory in nature and suggest a keenness from Mike to create distance between himself and people who are experiencing difficulties due to these other causes which are perceived to be more morally reprehensible. Consequently, Mike felt the need to clarify the cause of his tremor in order to avoid being given another, perhaps more undesirable, label which involves a moral judgement of character.

This fear of social embarrassment prevented Sandra from eating out in public with friends. Sandra appeared to be fearful that she would not be able to adhere to social norms while using a knife and fork in public, as she feared dropping food down her front and other people seeing this^{*2}. Sandra indicated that embarrassment for her in this instance was associated with her feeling she had regressed to a baby-like stage in terms of food spillages, which left her with corresponding feelings of vulnerability. Similar to Mike, Sandra also feared that people might misattribute her tremor to drugs/alcohol which reinforced her decision to forego social situations; this resulted in her feeling isolated.

Kevin spoke of how the battery device implanted following deep brain stimulation (DBS) had previously set an alarm off in a shop which he indicated was very embarrassing

^{2*} indicates a supporting quotation can be found in Appendix 2-A.

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for him due to how others then perceived him: “I used to feel that big [indicates small], you know, you come out and people are like “that thieving git” ”. Commenting upon how small he felt in this situation suggests high levels of embarrassment and a sense of unimportance and inferiority due to being judged by others who, inaccurately, perceived his behaviour to be immoral. This example, and the situation identified by Mike above, are powerful in highlighting how misattributions of the tremor by others results in participants experiencing judgements of their character.

The fear of how they might be perceived by others led to social anxiety for many participants with the prospect of social occasions filled with dread*. In addition, the unpredictable manifestation of ET exacerbated participants’ experience of anxiety. David spoke of the anxiety experienced when he had to carry a drink in public as he would become panicked about potentially spilling it, describing this as “a very subtle panic situation”*. David acknowledged how he could never predict whether he would spill a drink or not, and this level of uncertainty was the driving force behind his feelings of panic*. The fact this panic is ‘subtle’ suggests it could be hidden from others, which may result in David feeling alone in managing the impact of his condition.

Similarly, Sandra spoke of feeling extremely frustrated at being unable to predict tremor onset and would usually spill cups of tea; spilling tea was highly embarrassing for Sandra, and this embarrassment appeared to quickly turn to anger towards the condition itself*. Karen and John also struggled to cope with the unpredictable nature of ET which led to psychological difficulties for which they had both previously received support*. Nonetheless, this anxiety was still present for John, who acknowledged avoiding certain situations for fear of the impact of ET:

Oh I feel anxiety about erm if I have to go to a function of some kind, or a wedding or christening...funeral...any, name a function...any of those things I feel...I feel a

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level of anxiety over it that, you know, ‘god what are they going to serve me here’, you know, those sorts of worries...there’s a lot of things I don’t attend for that reason” (John).

This quote demonstrates the isolation that can be caused by ET since, due to the unpredictability of how ET might manifest in public, John ultimately declined to attend social events. Indeed, John later noted that this has caused him some problems in the past whereby people have been “offended” when he has not attended an event. Consequently, this highlights how anxiety can have much wider social implications for individuals with ET.

Alison spoke of experiencing anxiety concerning her tremor being exposed, resulting in social embarrassment. This had a major effect on Alison’s confidence, which led to her avoiding promotional opportunities at work due to a fear that being in a leadership role might expose her tremor more, and to a wider audience*. Thus the psychological effects of ET prevented Alison from furthering her career and reaching her full potential at work. There was also a sense from Alison’s account that ET automatically meant she was not ‘good enough’ for promotional opportunities and therefore needed to stay under the radar as much as possible.

With regards to the unpredictability of how ET might manifest in the future, Alison spoke poignantly about this; there was a history of ET in her family, and she felt that her 6 year old daughter was showing early signs of the condition. As a result, Alison had concerns for not only her own future with ET, but that of her daughter’s future too:

it does affect you, you worry about the future and if it gets worse what would I be able to do...erm the life for my daughter....But one minute she is wanting to be a teacher like me and the next minute she says a doctor and I think some of those things may be restricted for her that...if hers stays the way it is fine she might be able to, but if it progresses...things like that may be off the cards for her and that’s...heart breaking as a mum (Alison).

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Linked in with this anxiety for her daughter's future were feelings of guilt that her daughter would "have to deal with what you've dealt with" with regards to the impact of ET throughout the lifespan. Alison was almost more fearful for what her daughter might experience, since she was well aware of the pain and suffering that ET can bring. The use of the words 'dealt with' is indicative of a solely negative experience of ET as Alison suggests that ET is a problem which has required the use of internal (psychological) and external (environmental) resources in order for her to 'deal with' and manage the condition.

"I just couldn't do it anymore": The restrictive nature of ET

This theme captures the experience of restrictions that ET places upon the practicalities within participants' lives. The emotional response to restrictions was complex, with feelings of annoyance and frustration, low mood and/or depression, feelings of worthlessness and loss, embarrassment and a loss of identity identified by participants. There was also a continuum with regards to participants who experienced mild emotions and those who experienced more severe ones.

All participants spoke of how activities of daily living were restricted due to the nature of ET. Both making and carrying a hot drink were identified as being very difficult for participants due to the level of dexterity required. As George noted: "you can't touch anything with liquid in because that will end up on the floor. And as far as eating goes, knives and forks are out the question".

Furthermore, Mike explained that ET restricts his ability to eat healthily, noting:

like I'll often...even though I've got cereal and milk in, I'll go out to the bacon butty shop or I'll go and buy a bottle of coke...erm...because it's easier to drink a bottle of coke than it is to...use a spoon and that to have some cereal (Mike).

This suggests that individuals will risk their health (through unhealthy food choices and possible weight gain) for an 'easy' life. In addition, this is another example of a restriction caused by ET, as Mike was restricted in leading a healthy lifestyle.

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With regards to jobs around the home, it was often the smaller, more delicate, tasks that participants found most difficult. For instance, when asked what activities ET impacts upon, George noted:

Well anything and everything. I can't really...if it's big and bulky I can manage. But if it means...precision things no chance, you know. I used to...millions of wires I've worked with- no problem. Now, I can't even wire a plug. Well I can but it will take me about an hour to do it (George).

This quote highlights how Georges' previous vast experience of working with wires was now rendered useless in the face of this condition. George found this a little frustrating but, on the whole, appeared resigned to ET impacting upon his skills in this way. Other participants also reflected on the length of time it takes to carry out everyday activities, for example taking 20 minutes to button a shirt up (Kevin) and taking an hour to thread cotton through a needle (Karen). The length of time these, usually quick, activities take for individuals with ET further contextualise the frustration experienced.

In addition, Stephen spoke of his frustration that he now has to pay other people to do domestic repair tasks that he once did, such as servicing his vehicles and fixing his roof. Stephen acknowledged how he feels that other people do not carry out these jobs to the same standard as he once did:

I can lay bricks, I can lay concrete...well I used to be able to, you know, I can lay bricks, lay concrete, put windows on, fix roofs erm build my own extension, you know, I could do all that. But now I can't and I sit there thinking...and the clowns and you've gotta pay them, it annoys me, they're getting their money too easy, you know, so yeah and that...that's what winds me up, you know (Stephen).

There was a clear sense of loss of self and role emanating from Stephen's account of how ET prevents him from carrying out jobs around the home with Stephen describing this as: "you're not worthless, but you're not worth as much as you were".

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Stephen described how from a young age he placed importance on “earning your keep” at home and noted feeling as though he was now “falling on the wrong side” of this motto which led to frustration, anger and volatility. It would be feasible to assume that being unable to meet the ideals by which life was lived would result in some loss of identity, which would serve to heighten these difficult emotions. A sense of injustice was also indicated in Stephen’s account, since his annoyance of having to get other people to complete jobs for him reflected underlying feelings of this being unfair and he was powerless to do anything about it.

Kevin also sometimes relied on others to do jobs around the home, and felt let down when people did not honour their promise of help: “it leaves you feeling really down erm but I should imagine that is the same feeling most people get, you know, each feels the stuffing’s been kicked out of you sometimes”. Using the phrase “the stuffing’s been kicked out of you” conjures up feelings of weakness, feeling beaten and flat and indicates Kevin’s experience of feeling subjugated and powerless. Furthermore this phrase suggests that, when feeling down, Kevin sometimes views his body as being different to how it once was, he feels as though something has been intrinsically removed from his once whole body.

Of interest, Kevin described how he has a 10 minute reprieve from ET as soon as he wakes up: “when you wake up- it doesn’t matter what time, it could be 2 or 3 o’clock- you go and have a wet shave. Ten minutes later, forget it- you’ll cut your face off”. This is yet another example of the control ET can have, since Kevin has found himself in the situation of having to work around ET and is almost dictated to by this condition with regards to shaving.

Employment was also noted to be hugely affected by ET for some participants. Karen, a nurse, spoke of how tasks inherent to the role of a nurse became impossible, such as reading out updates at hand-over meetings (due to voice tremor) and writing up patient notes: “I was writing like a baby in the end”.

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Karen conveyed a sense of loss when talking about having to stop work; it became clear that she enjoyed her job but had no control over the impact of ET: “I had to retire on ill-health long before I was due to retire...I didn’t want to retire, I would have carried on, you know. But I had no choice”. Consequently, not only was Karen dealing with a tremor that was increasing with severity, but she also had to contend with the loss of her career and, consequently, the loss of both her nursing and working identities. In addition, the impact of tremor on her voice also prevented Karen from singing, an activity that had formed a part of Karen’s identity since she was a child; this further exacerbated her difficulties in mood.

John also acknowledged the impact of ET at work, describing this as being a “nightmare” for him due to the amount of precision work that his job entailed. This caused John “enormous stress” as he realised “I just couldn’t do it anymore”. Similarly, Mike also found himself in the stressful situation of having to stop working as an engineer due to the impact of his ET which resulted in Mike having to work longer hours to get tasks done for the same amount of money.

Of importance, John noted a positive to having ET both within the work environment and at home, noting how he feels he is “more ingenious”. John described how, because of ET: “I do sometimes have to make a gadget in order to enable me to use another gadget or I have to approach something in a different way”. Consequently, John described himself as being “less blinkered” and “more lateral” in his thinking, and this creativity was a positive for him.

“You’ve got to cope; you’ve got to learn to fight different ways”: Rescuing some normality amid physical deterioration

All participants gave accounts of how they navigated the emotional and physical experience of having ET. Many spoke of how they had learned to adapt and find alternate ways of managing life with their condition.

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The necessity of this requirement to adapt was highlighted by Kevin who stated: “you’ve got to cope, you’ve got to learn to fight different ways...because if you don’t nobody else will do it for you”.

The quote conveys a sense from Kevin that he felt unsupported, and perhaps alone, in his experience of coping with ET.

Many participants spoke of the strategies they employed to help them retain some normality within their experience of ET for instance, using plastic plates and mugs at home to minimise breakages (Kevin)*, making milky drinks in mugs with a lid (Mike)*, using two hands to lift up a cup and drink (David)* and using a straw when drinking, to reduce the amount of liquid spillage (George)*. Indeed, despite the use of a straw, George still used “normal” cups and glasses. This was important for George as there was a sense that, by doing this, he could retain some normality in public*. Furthermore, it was felt that this was a way in which he could maintain some control over his condition, thus helping him to cope.

Practical help from family was also acknowledged. For example, George noted that his wife will often cut up his food for him to make eating more manageable and will also help him with zips and shoelaces when getting dressed*. This again has connotations of regression back to an infantile stage. However, buying Velcro shirts that look like buttoned shirts was also a strategy employed by George to make dressing himself easier*. The purchase of such shirts was again another way in which George was able to retain some power and control over his condition, as this meant he could be more independent. Similarly, Kevin noted that he will only unbutton the first few buttons on a shirt and take it off, to make it quicker putting the shirt back on next-time*.

Familiarity was also key for some participants. In particular, participants found it helpful to shop in the same places where employees know them and know about their tremor (Kevin, George), or go to the same holiday destination where staff are familiar with ET (Stephen).

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Kevin described how, because employees know him in one particular food chain they will cut his toast into soldiers for him; this was something that Kevin was appreciative of as there was a sense of there being no fuss made about this. Familiarity allowed participants to feel more secure in themselves and thus more comfortable with their tremor.

Medication was another coping strategy that several participants had used at some point, to help reduce the effects of ET and live a normal life. Only Karen and Sandra reported still taking medication*. Some participants spoke of preferring not to take medication and indeed there was an element of choice involved with this*. Choosing to not take medication was again another way of regaining some control and normality; it was an aspect of their condition that they were able to have power over, in a situation where they often felt powerless.

Another form of treatment that dramatically changed one participant's life as it had a significant positive impact upon his ability to cope with the impact of ET was DBS. Specifically, Kevin spoke passionately of how DBS has enhanced his quality of life as he can do much more now than he could prior to having this procedure, describing DBS as giving him a "new lease of life". Using the phrase "a new lease of life" suggests that Kevin felt as though he was given a fresh start in life, as though life began again for him; this highlights both the destructive nature of ET and just how powerful DBS can be.

There was a real sense from participants that they all wanted to 'get on' with a normal life and be able to complete every-day tasks. In relation to this, Stephen noted:

my own GP before he retired he said to me one time, he said "do it until it hurts and then stop" you know, and I thought...you think about it and you think 'yeah, that's not a bad philosophy that' (Stephen).

This was the philosophy that Stephen appeared to live his life by and there was a sense of pride from him that he would always "have a crack" at something, which allowed him to retain an element of his 'strong work ethic' identity.

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This determination was present for all participants within this study.

Although not spoken about as much as the physical challenges, many participants also appeared to have their own, individual, coping strategies for how to manage the psychological impact of ET, including: talking to family (Alison), engaging in a talking therapy (Alison, Karen, John), attempting to stay in the present moment rather than worry about the future (Sandra), keeping active (David), giving self some time away from tasks to avoid frustration (Mike, Karen, George), and the ET group itself was mentioned as helpful in allowing people with similar experiences to meet (Stephen, Sandra, Karen).

Finally, George emphasised that, for him, the key to managing ET from a psychological point of view, was to remain positive at all times: “You’ve got to be positive. There’s no point being like “oh god, I’ve got it”. You’re not gonna die from it, it’s not a death sentence. It might be bloody annoying but it’s not a death sentence”. This sentiment was echoed by John who noted “there’s a lot worse things that happen than what I’ve got...a lot worse”. It would appear that acknowledging that there are other people who are ‘worse off’ was motivational for George and John, allowing them to remain positive in the face of a condition which they feel, ultimately, could have been more severe.

Of interest, some participants spoke of being aware of the potential benefits of drinking alcohol in an attempt to reduce the impact of tremor; indeed this awareness often came from health care professionals themselves and Karen acknowledged being almost encouraged by professionals to consume alcohol as a coping strategy. Nonetheless, Karen was against the use of alcohol for fear of damaging her health. Similarly, Stephen was also given the same message by a neurologist and he noted “but it’s a bit of a downer because you end up with cirrhosis of the liver and addicted to alcohol [laughing]”. Although making light of the situation here, Stephen highlights the dangers of using alcohol as a coping strategy. No participants in this study reported using alcohol as a coping mechanism for ET.

Discussion

This study has helped shed light on the day-to-day experiences of living with ET. Specifically the judgements made by others, and the social anxiety experienced, were identified. These factors appeared to be linked to non-accepting social attitudes to difference. In addition, the restrictions placed upon everyday practicalities, and the coping strategies implemented which allowed participants to rescue some normality amid their experience of living with ET, were also identified.

QoL is reported to often be impaired for individuals with ET (Lorenz et al., 2006). Indeed the present study identified emotions (embarrassment, frustration/anger, low mood/depression, and anxiety) that negatively affected quality of life for participants, and that others have previously identified (e.g. Holding & Lew, 2015; Louis & Rios, 2009). These emotions themselves support Jhunjhunwala and Pal's (2014) proposition that such psychological difficulties are an accompanying feature of ET and this study allows some understanding of how and why these emotions occur.

As Chandran et al. (2012) has previously identified, it was not the severity of the tremor per se that was important in the present study, or the number of activities that were restricted, but instead the impact that the tremor had on the individual's valued aspects of life and identity (Bishop, 2005). Similarly, previous research has shown that psychological wellbeing of those with multiple sclerosis (MS) was most affected, and sense of self fundamentally challenged, when valued aspects of self or life were lost, or interfered with, due to MS (Mozo-Dutton, Simpson & Boot, 2012). Such illness intrusiveness (Devins, 1994) is known to compromise psychological wellbeing and QoL, and contribute to emotional distress by reducing an individual's valued activities (and subsequent gratifying outcomes) and by reducing personal control by limiting the ability to both obtain positive outcomes and/or avoid negative ones (Devins, 1994).

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Furthermore, Bishop proposed that psychological wellbeing and QoL are more likely to be negatively affected if a chronic illness impacts upon those life domains that are particularly valued by an individual (such as the family domain), and if it takes away an individual's personal control to change an unsatisfactory lifestyle (Bishop, 2005).

With regards to the experience of embarrassment, some participants experienced embarrassment due to being unable to conform to social norms, whilst others experienced embarrassment due to being stigmatised as belonging to a group who were deemed to be responsible for their difficulties, such as Mike's experience of others assuming he had been drinking alcohol or taking drugs. Devins (2010) proposed that the impact of illness intrusiveness is greater when one feels stigmatised and, in support of this, social anxiety appeared to be greater in participants who felt others were judging.

Self-conscious emotions have been defined as social emotions elicited by real or imagined interactions with others and an awareness of how others perceive and evaluate the individual (Baldwin & Baccus, 2004). Consequently, when people feel ashamed, embarrassed, socially anxious or proud they are assessing themselves from the perspectives of real or imagined other people (Leary, 2007). Many participants spoke of avoiding social situations due to worrying that others would assess them negatively due to them being unable to conform to societal norms. For example, David spoke of avoiding social events where he might be required to carry a drink, Kevin avoided certain shops where staff were not aware of his tremor; and Sandra would avoid eating out with friends.

Furthermore, feeling unable to live up to ideal self-representations has been identified as resulting in shame and guilt (Katzir & Eyal, 2013). Consequently, it is also possible that, as well as perceived assessment from others, participants' own perceptions contributed to their experience of anxiety and embarrassment, which might also manifest as shame. Gilbert (2002) proposed that shame is an evolutionary response that facilitates the identification and correction of personal aspects or attitudes that could lead to social exclusion. Thus, shame is associated with the perception that the self presents unfavourable

Lived experiences of ET characteristics that others might find inadequate or unattractive (Gilbert, 2002). For the participants in this study, there was an awareness that they could not change the way in which ET manifested; as a result of this, some did not feel safe within social environments as they felt that their social position was at risk of being criticized or rejected (Gilbert, 2000). Furthermore, it is possible that some participants had internalized this shame (Gilbert, 2002) as there was a real sense that some individuals felt inferior to others in society, for example Kevin and Sandra.

Louis and Rios (2009) noted that the relationship between embarrassment and anxiety needed to be investigated, and the present study provides some understanding of this link between embarrassment, shame and social stigma in ET and social anxiety.

The findings also provide support for the social relational definition of disablism i.e. a form of social oppression involving restrictions of activity for individuals with impairment, and the undermining of their psycho-emotional wellbeing (Thomas, 2007). Reeve (2011) extended this definition further, noting that psycho-emotional disablism occurs when an individual with an impairment experiences negative social interactions, such as hurtful comments from others, which undermines their psycho-emotional well-being and sense of self (Reeve, 2011).

Within the present study, the fact that Mike felt the need to justify his tremor to strangers who presumed the tremor was the result of drug/alcohol use may well reflect current, negative, societal attitudes with regards to people who have an addiction. Distancing himself from more negative (and therefore more hurtful) labels concerning drugs/alcohol might help Mike to preserve his emotional well-being and sense of self by reducing felt sense of stigma. Indeed, the stigma experienced due to assumptions made by the general public of alcohol use has been found in other movement disorders, such as PD (Parkinson's UK, 2013).

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Bury (1982) described the development of a chronic illness as being a form of biographical disruption with responses to such disruption noted to involve the mobilisation of resources to try to help maintain some normality within the chronic illness experience (and perhaps reduce the experience of self-conscious emotions; Leary, 2007). The present findings provide support for this notion since participants did use a range of resources, including practical and emotional ones, to help them manage their experience of living with ET. One finding emerging from Bury's (1982) research, which was also identified within the present study, was the importance of familiarity in maintaining normality. Specifically, one participant diagnosed with rheumatoid arthritis noted how he will only go to his local club; a place where everybody knows and accepts him and his condition.

Similarly, participants in the present study spoke of how they will go to the same food chains (Kevin) and holiday destinations (Stephen), where staff both accepted and helped in the management of ET. This was another way in which participants were able to rescue some normality by accepting the support of others and being accepted themselves.

However, for some aspects of life, participants were unable to maintain previous normality but instead inhabited a new normality. As an example, George would utilise mugs with lids and wear shirts with Velcro on in order to rescue some normality with regards to avoiding drink spillages in public and saving time when dressing.

However, these strategies could not restore previous normality for George, but instead helped him to adapt to a reconstructed new 'normal'/new way of living with ET. Similarly those living with inflammatory bowel disease have also discussed how adjustments made to their life had become the new normal for them (Hall et al., 2005). Of relevance, Sanderson, Calnan, Morris, Richards and Hewlett (2011) have identified different typologies of normality for individuals diagnosed with rheumatoid arthritis; disrupted normality, struggling for normality, fluctuating normality, returning to normality and continuing normality.

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Some of these typologies were evident for participants in the present study, particularly the disruption to, and struggling for normality, as well as the resetting of normality. In relation to the latter, participants in the present study did appear to reconceptualise normality by incorporating their illness and changed identity/self into this (Sanderson et al., 2011). However, in contrast to Sanderson et al. (2011) no participants noted a return to normality (with previous normal life reinstated) or a continuing of normality (with normal life unchallenged). Even those participants who were able to maintain some aspects of normality and implemented effective coping strategies acknowledged that life was now different. No participant identified their life with ET as having been unchallenged.

Clinical Implications

Participants within the present study noted that they had not been routinely offered psychological support when coming to terms with their diagnosis. Some participants had accessed support, but had sought this out for themselves. Guidance from the UK National Institute for Health and Care Excellence (NICE, 2016) states that the diagnosing health professional should provide information, advice and support at diagnosis for neurological conditions arguably similar to ET including motor neurone disease (NICE, July 2016) and multiple sclerosis (NICE, January 2016). This guidance seems almost more pertinent in the area of ET due to the fact that there is a lack of awareness of this condition as highlighted by participants themselves.

In addition, participants experienced a range of emotions due to the individual impact of the condition on their lives. One particular therapy that could potentially be of benefit to individuals who are experiencing difficult emotions in the context of ET is Acceptance and Commitment Therapy (ACT). The aim of ACT is to “help us create a rich, full and meaningful life, while accepting the pain that life inevitably brings” (Harris, 2009, p. 2) by using mindfulness skills and taking action that enriches our lives (Harris, 2009).

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While no research has been conducted into the use of ACT with ET, Pakenham and Fleming (2011) have noted its relevance within the area of MS; greater acceptance (as defined in ACT) was found to be related to better adjustment, with the valued 'action' dimension a consistent predictor of enhanced adjustment.

In addition, lack of public awareness of ET contributed to the stigma they experienced. This identifies a clear need for more public awareness campaigns that are centred around the condition of ET, particularly given that ET is one of the most common neurological conditions (Louis & Ferreira, 2010). A multi-disciplinary approach to raising public awareness is crucial in order to enhance knowledge of the holistic needs of individuals diagnosed; consequently there is a role for clinical psychologists to work alongside other health care professionals and promote understanding of the psychological and physical impact of ET. Raising the profile of this common neurological disorder amongst the general public might also help to reduce some of the stigma experienced with regards to people making assumptions concerning alcohol and/or drugs, which can result in psychoemotional disability (Simpson, McMillan & Reeve, 2013). In addition, there is a role for clinical psychologists in providing psychological input to those individuals with ET who desire this, as well as providing supervision for those professionals working with ET, for example; specialist nurses.

Limitations and future research

One limitation of the current research is that, as per requirements for IPA, participants were selected from a homogenous group, with tremor severity ranging from mild-moderate (as noted by participants themselves). One participant (Kevin) had a more severe tremor but had undergone DBS which brought the tremor back into the moderate range. Consequently, the current research has not captured the experience of individuals with ET who are severely affected. Future research with individuals with severe ET could help shed light on whether there are any additional concerns for those affected. Furthermore, future qualitative research

Lived experiences of ET focusing upon the impact of DBS on psychological wellbeing for individuals with ET could add to the quantitative literature (e.g. Diamond & Jankovic, 2005; Huss et al., 2015) and also help to inform the wider benefits of this treatment.

In addition, the fact that participants were recruited from a group which they actively attended by choice perhaps reflects a group of individuals who are pro-active in managing their experience of ET, and so may have better self-management skills than those who do not attend such support groups. Future research which recruits participants from clinics/hospitals could help to identify whether these individuals have any additional/different difficulties in relation to their experience of living with ET.

Conclusion

This research study has investigated the lived experience of individuals diagnosed with ET. It has helped to identify some of the difficult day-to-day experiences of individuals and the resulting emotional responses. This study has also shed light on the ways in which ET restricts everyday activities and the emotions this can cause. Finally, the coping strategies employed to help retain some normality have been identified. These findings have implications for health care professionals with regards to the need to routinely offer psychological support for individuals living with ET. In addition, more public awareness campaigns centred around ET are required to enhance understanding, and to reduce some of the stigma, of this condition. Future research should focus on the experiences of individuals with more severe ET and/or those with poor self-management skills.

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Table 2-A

Table 2-A. Participant demographics

Participant	Gender	Age	Years since diagnosis	Prescribed medication?
Stephen	Male	67	Approx. 10-15 years	No
Alison	Female	38	12 years	No
George	Male	74	10 years	No
Mike	Male	43	Approx. 5 years	Yes
Kevin	Male	68	Approx. 15 years	Yes
David	Male	77	10 years	No
Sandra	Female	69	Approx. 2/3 years	Yes
Karen	Female	68	Approx. 30 years	Yes
John	Male	58	22 years	No

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Table 2-B. From initial concepts to emerging themes (Stephen).

Initial concepts identified	Emerging themes
<p>Loss- physical health, lack of support at diagnosis, anger and frustration, problematic aspects of ET, reasonable normality, aspects of ET, problematic symptoms, the questioning self, uncertain illness trajectory, gaining of knowledge, ignorance towards ET, self-reliance, contrasting perceptions of ET, support gained from group, sceptical of professionals, making sense of the situation, own experience in the context of others' experience, loss of hobby/leisure activities, determination to get on with life, coping strategies, strong values and attitudes, loss of future self, impact of ET upon employment, loss of skills/abilities, loss of 'expected' self, loss of self-worth, frustration at relying on others, self-criticism, support from wife, seeing the positive, concerned with how others perceive him, importance of time, depression, time bringing improvement in mood, advice/support from others, humour as a coping strategy.</p>	<p>Multiple losses leading to poignant life changes</p> <p>Implementing different coping strategies</p> <p>Frustration, anger & depression at life with ET</p> <p>Unable to do activities once took for granted</p> <p>Ignorance towards ET as problematic</p>

Table 2-C

Table 2-C. Process of theme identification across participants

Emergent themes from across participants	Refining of Themes	Final theme	Participants contributing to theme
Overwhelming emotions, embarrassment above all else, unpredictability of ET, lack of control over impact of ET, lack of control over others' judgements, negative judgements made by others, the negative experience of ET, anxiety in social situations, fear of evaluation	Specific emotions experienced due to impact of ET	Social attitudes to difference	Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, David
Loss of control across life domains, difficulties intrinsic to ET, losing control over one's life, lack of control over impact of ET, missed life experiences, difficulties at work, loss of career	ET limits many aspects of the participants' lives.	The restrictive nature of ET	Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, David
Making the most out of life, making experience of ET more manageable, being informed about what works for ET, having the strength to cope, strategies for coping with ET, preservation of positives, learning to adapt in social situations, ways of preserving a normal life.	Knowing what helps experience of ET feel more manageable	Rescuing some normality amid physical deterioration	Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, David

Appendix 2-A- Additional quotes to evidence findings

Location of finding that quote relates to	Participant	Quote
Page 2-17; Paragraph 2	Mike	“My coffee I tend to have in a mug with a lid on it erm I’ve got in the habit of having it quite milky so it’s cooler”.
Page 2-11 ; Paragraph 3	Karen	“I was that desperate one time I even paid to see a psychologist...privately...I would pay quite a lot per hour just to do relaxation...I was desperate, I wanted it sorted, you know, but I didn’t know. I thought “I need help here and it’s not getting better and erm nobody is giving me a definite answer” ”.
Page 2-11; Paragraph 3		“Yeah [also saw a psychologist at Mind]...well she was a behaviour therapist or something...she did her best but still...”.
Page 2-18; Paragraph 2		I noticed when I’m taking it [the medication] with the tremor, you know. It was a big difference...if I stopped taking it now I’d be all over the place, you know, the tremor would get worse...it’s not doing me any harm-it’s making my life easier, you know, so I take it”.
Page 2-11; Paragraph 3	John	Oh god yes, yes erm that was my reason...that’s basically what drove me out of work, you know, I was struggling to cope and it wasn’t much fun that and when I...they did give me the diagnosis of anxiety which, like I say, it wasn’t appropriate but it was what caused it basically wasn’t it...an inability to cope [with the tremor]... yeah there’s absolutely no doubt about that”.
Page 2-11; Paragraph 3		“..they treated me for anxiety and they...after a few months because I was sort of hiding away a bit of the time although it was the tremor that caused it...erm...I don’t know what you would call it-counselling of some sort. I used to see a chap every week or two and chat and, you know, fill in sort of exercise things and that so I supposed we’d call it NHS counselling would we now...”.
Page 2-11; Paragraph 3		“the view I take is that my tremor isn’t bad enough to justify that [medication], you know, I can pick up a glass and I can drink...the benefits [of medication] might be this much [indicates small] but the downside is enormous so I don’t take anything”.

Appendix 2-A- Additional quotes to evidence findings

Location of finding that quote relates to	Participant	Quote
Page 2-10; Paragraph 4	Sandra	“...sometimes my friends ask me to go for a meal...I don’t go because erm you know the knife and fork and that and all this carry on [indicates dropping food down her front and feeling embarrassed]...even the ones who know about the tremor, I don’t go. They say “Sandra, why don’t you come out for a meal” and I go “I can’t go out for meals or anything like that...””.
Page 2-11; Paragraph 3		“Making the tea was very stressful, very very very stressful because I get scared. I get scared, you see”.
Page 2-11; Paragraph 3		“I can get angry when I spill tea. You know when I spill the tea, I get angry...”god these bloody tremors, I’m fed up with them”, do you know what I mean?”
Page 2-11; Paragraph 3		“I used to make the tea and I spilled the tea once or something...and they told me to stop. I can’t...can’t put tea out. I cannot pour tea out at all. I can’t....can’t. I’m a liability, but I erm...I can’t do it, I just don’t do it”.
Page 2-11; Paragraph 2		“My tremor is absolutely terrible...and that’s when I get angry because, as I told you, a person was sitting there and a person was sitting there [indicating where people were sat]...”My god, oh god almighty, they’ll hear the vibrations coming from me”. It was terrible, so I got up and I lifted my bag and I just went and sat somewhere else”.
Page 2-11; Paragraph 2		“Say I was outside and I was talking to people, it [the tremor] gets worse, so sometimes I don’t talk to people, do you know what I mean?”
Page 2-12; Paragraph 3	Alison	“It [ET] makes me more conscious and I am far more nervous about doing things”
Page 2-12; Paragraph 3		“I’d say confidence wise it does affect me and I’d avoid trying to do, like if you want promotion and that, you’d have to go for leading staff meetings and all that sort of thing...and I try to avoid that sort of thing...I try and avoid too much writing on the board in front of people if I can erm...I can get the children to do, if there is any activity that might require me to fill...like in science if you are filling a cup to the top and doing measures, I’d get the children to assist...”
Page 2-18; Paragraph 2		“I think I’m pretty anti-taking things so I only take them if it’s really essential...I don’t like the idea of medicating for life and the worry of if it plateaus...what happens down the line if I’m 50-60 and I’ve still got my children to look after and it’s [the medication]...not having any effect at that point?”.

Appendix 2-A- Additional quotes to evidence findings

Location of finding that quote relates to	Participant	Quote
Page 2-17; Paragraph 3	George	“No somebody else will do them for me [later specified this was his wife]. My shoes have got Velcro, you see, it’s easily done. But you can buy things but, you know, like look as though they are buttons but they are actually velcroed together”.
Page 2-18; Paragraph 2		“...they [pharmaceutical company] asked a couple of us to go to Stockport to a pharmaceutical thing and we were asked “if they found the magic bullet, would we take it?” and it was a case of “if you find it and you find people it will work on and I can see the results...I’ll go” ”.
Page 2-17; Paragraph 2		“No, no, no [does not have lid on mug- very assertive about this]. Normal cups, normal glasses I just use a straw, you know. Sometimes when they get to a point in the cup or glass you can manage to pick it up”.
Page 2-11; Paragraph 2	David	“Mainly the cups situation...”will you get us”, you know, “can you get us 3 cups of coffee?” you know...even putting them on a tray will not be a safe method of getting it across, you know, the tremor might suddenly...show itself erm...and other times I can do it, you know, it’s...it’s subtle, a very subtle panic situation”.
Page 2-11; Paragraph 2		“the panic sets in if I know that I’m going to spill something half way across a room or something erm...I might set off thinking “I’ll manage” but then I realise and then I panic...”.
Page 2-18; Paragraph 2		They experimented I think with a certain tablet and...then I came out in a rash and I...just gave up on it [on medication in general]”.
Page 2-17; Paragraph 2		“Well if I was sitting at the table I’d ask them to just leave it [hot drink] there, you know, and then use two hands sort of thing to get it to my mouth erm...”.
Page 2-17; Paragraph 3	Kevin	Like with shirts, it can take me 20 minutes to button a shirt up so I just open it down to there [indicates where on his own shirt] and take it off. That’s easier otherwise I’d be there forever and a day trying to fasten these erm...so it’s how you want to go about it. If you want to go about it and learn then you do”
Page 2-17; Paragraph 2		“I have erm plastic plates, plastic mugs because...you know if it drops it’s gonna break. So I have plastic”.

Appendix 2-B: Transcript extract

<p>- Depression</p> <p>- Time period important</p> <p>- Improvement in mood over the years</p> <p>- The questioning self</p> <p>- Sense making</p> <p>- Loss - multiple losses: physical health, job/career, future self, provider role in family</p> <p>- sense making</p> <p>- Depression</p> <p>- Improvement in mood over the years</p> <p>- Sense of loss - unable to complete "simple" things - loss of ability/worth</p>	<p>psychological difficulties as a result of essential tremor that you feel able to talk about?</p> <p>Participant: When you say psychological difficulties, what do you mean?</p> <p>Interviewer: So for example low mood, depression...</p> <p>Participant: Oooh I get...^{hard to talk about this ('erm' + pause)}terribly depressed erm...yeah erm not so much now erm but...in the first few years yeah erm...you sort of say "why me, what else have I gotta put up with?", and erm you know, very self-pitying and that sort of stuff.</p> <p>Interviewer: Did you recognise those feelings right from the point of being diagnosed with essential tremor?</p> <p>Participant: Yeah, yeah, you know, because I'd gone through erm the...the assault erm...being pensioned off erm... not getting any higher than inspector and I had passed all my exams erm sort of stuff erm...I couldn't, I couldn't bring home the bacon erm as I thought I should have done. And then you get this [essential tremor] on top of that, you know, and you say, you know, "what have I done?, you know, have I run over Mother Theresa or something and not noticed it?", you know, erm and...there was some very dark days, you know, very very dark days erm...you know I'm the first to admit it erm and like I say I must have been an absolute pig to live with, you know. I mean only my little lady could tell you that, you know, but erm...it doesn't come to the fore anything like it used to, but it certainly did at the time.</p> <p>Interviewer: And how did you manage that at the time?</p> <p>Participant: Erm, I got very frustrated because I...I had to find things to do and...simple things like wiring a plug...erm I'd start to wire it and then everything starts shaking, you know, and, you know, then the screw driver would get launched up the garden and stuff like that, you know, all sorts of bits and pieces erm because...my own doctor, my own GP before he retired he said to me one</p>	<p>- seeking clarification re "psychological difficulties".</p> <p>- so have things now changed. In what way? why is he less depressed now?</p> <p>- Has questioned "why me?" Describes this as self-pitying.</p> <p>- Questioning why bad things happen to him. Wanting to make sense of this? Pattern.</p> <p>- Felt depressed from the beginning of being diagnosed with ET due to past experience of assault and being pensioned off + not being able to get higher than inspector etc. Felt he couldn't "bring home the bacon". Questioned why?</p> <p>- couldn't support his family or achieve success.</p> <p>- felt a sense of loss? felt unable to support his family in the way he once had - let family down?</p> <p>- repetition of 'erm' to highlight how dark his days were.</p> <p>- Got very frustrated as had to find things to do + when he did the tremor interfered with being able to do these things eg wiring a plug - frustration would show in throwing things up the garden.</p> <p>- Difficult to recall how he managed his feelings at that time</p>
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Appendix 2-B: Transcript extract

- Advice / support from others (GP)
- values / attitudes
- concerns of how others perceive him
- determined - not to succumb to injuries / tremor
- loss - of skills / ability in servicing own vehicle
- coping - humour
- not allowed to do a particular job
- Protection from family?
- Problematic aspects of ET
- determined to get on with life
- Problematic aspects of ET
- coping - humour

time, he said "do it until it hurts and then stop" you know, and I thought...you think about it and you think "yeah, that's not a bad philosophy that", you know...and I hate people saying "I can't do that, I've got a bad back". I hate it, you know. And there's this sort of musical joke isn't there about bad backs and lazy people and all that sort of stuff and I...I didn't want to get into that. So, I never used to say "I can't do it", I'll have a crack at it and when I couldn't do it by I was like a bear with a sore head, you know, I'll admit it, I will, you know.

Interviewer: Yes...yes and you gave the example there of the plug, is there anything else, any other tasks that you might find difficult due to essential tremor?

Participant: Erm...well like servicing my own vehicles. I always serviced my own vehicle but you can't physically crawl underneath and... and do something when everything's...you lie on your back and you're trying to do something and everything's shaking sort of thing. I mean, I did do it and I got a hell of a shouting at from her in doors. Because I'd brought a new tractor, not a new...a new tractor to me called a 'Triton' and that won't mean a lot to you and erm...it wanted a new fuel light on it and the fuel light was as far underneath as you could possibly get, you see. And I kept saying "I'll have to change that fuel light"..."you're not doing it" [wife's response]...you know...good natured banter, you know, type of thing and she was out one day and *laughs* I thought "right, I'm gonna go and do it, I'll have it done before she comes back and she'll know nout about it", you see...and I get everything ready and I crawl under the tractor and I'm playing about and I get it fixed, get it in, and then I couldn't get out.

Interviewer: Oh gosh, what happened?

Participant: I had to just lie there, you know, until everything had stopped shaking and the pain had subsided and all that. But in the meantime, she comes home *laughs*, see and I'll not...she can't find me, you know, because I'm lied under this tractor you see.. It makes me laugh as it's made you laugh but by she didn't half give me a telling off...yeah.

Advice given by his GP - thinks this is not a bad philosophy to have. feels strongly about people saying they can't do things.

Dislikes / hates people saying they have a bad back + can't do things and didn't want to be categorised in no same way, i.e. as being lazy. So for that reason will always have a go at something. But gets frustrated if he can't do it.

Explains he also can't service his own vehicles due to being unable to crawl underneath + due to the tremor when lying on his back. But will still try + do it + get told off from his wife.

Describes his knee needing the fuel light changed and his wife didn't want him to change this bar - he did when she went out one day + he couldn't get out due to tremor + pain. Had to lie there until it all stopped.

Making light of the situation - using humour. wife came home + told him off.

still continuing to try everything - only stopping when it hurts. allow him to retain self-worth.

Has this made ET more difficult to adjust to + cope w/?

Worried about how he might be perceived by others

sense of loss as used to do this?

Humour

humour

they can't do things.

Making light of the situation - using humour.

Appendix 2-C

Psychology & Health: Instructions for authors

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Section 3: Critical appraisal
Critical appraisal: Research reflections

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2014 Intake

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Critical appraisal: Reflections

This section of the thesis aims to give some context to the literature review and research paper, as well as providing my reflections on the research process. I will first give an overview of the findings of each paper and consider how they might interact with one another. I will then explore my personal reflections on choosing this topic, the importance of reflexivity and the strengths and weaknesses of the thesis, before suggesting areas for future research.

Research Findings

This research found three themes that captured participants' experiences of living with essential tremor (ET): "But they often look at you like you're some drug addict or smack head": Social attitudes to difference; "I just couldn't do it anymore": The restrictive nature of ET; "You've got to cope; you've got to learn to fight different ways": Rescuing some normality amid physical deterioration. These findings are interesting to compare to the three themes found in the meta-synthesis which focused on the diagnostic experience of the four most common motor neurodegenerative conditions (Parkinson's disease (PD), motor neurone disease (MND), multiple sclerosis (MS) and Huntington's disease (HD)): "A bomb that could not be absorbed": The emotional experience of receiving a diagnosis; "You've got what your cousin died from": Feeling dismissed and powerless; "Know thy enemy": To information seek or not?

Reflections from participants across the papers indicated that trauma is experienced from the moment a diagnosis is given and continues in the weeks, months and years after, while attempting to adjust to living with a motor neurodegenerative condition. The emotions associated with receiving a diagnosis, including fear and uncertainty of what this diagnosis meant for participants within the literature review (with many combat metaphors used to reflect the traumatic experience), were aligned with the emotions reported by participants in the research study who were at least 12 months post-diagnosis. In particular, the

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unpredictable nature of the illness trajectory in ET left many participants interviewed fearful for the future, as they were uncertain of whether their tremor would worsen and subsequently impinge on existing abilities. For some participants this fear extended to the judgements that members of the general public might make about how ET manifested for them; this led to social anxiety for some individuals. Consequently, there was a clear link between fear and anxiety found across both papers. The fact that such emotions were prolonged, from the point of diagnosis to years afterwards, is indicative of the need for psychological support to be offered for those individuals who desire this. Or, at the very least, individuals should be informed about the support available.

Nonetheless there were positives acknowledged in the experience of some participants across both papers. Within the meta-synthesis, some participants reported finding benefit from their diagnosis which tended to be centred around re-evaluating life's priorities and values; indeed some participants appeared to experience post-traumatic growth, a process most usually investigated in relation to cancer (e.g. Connerty & Kent, 2013). On the other hand, although focusing on a different angle of positivity, participants in the research paper reported finding useful strategies that helped them cope with their experience of living with ET. Strategies included practical ones such as the use of a straw when drinking, giving oneself more time to complete tasks and leaning on family for support in public. These strategies were positive in allowing participants to navigate their experience of ET in a way that ultimately enhanced quality of life (QoL).

It could be argued that benefit-finding is a process which precedes the practical step of finding coping strategies. Indeed, it is a feasible suggestion that only by coming to some acceptance of a diagnosis and finding some positives to this experience can one be motivated to implement strategies that will enhance the experience of living with this diagnosis. Of relevance here, Sharpe and Curran (2006) in their review focusing upon the process of

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adjustment to illness noted that benefit-finding in chronic illness is an adaptive strategy that decreases the incongruence between situational and global meaning (how the world operates) (Sharpe & Curran, 2006). However, the opposite could be true for some individuals; that is, finding strategies to help one cope with the impact of a movement disorder could help to improve QoL, thus resulting in some acceptance and benefit-finding of the experience.

Despite some consistencies in findings across the two papers, novel findings were also found. In particular, the research paper shed light on the emotional experience that follows diagnosis. The literature review was informative of the trauma experienced at diagnosis, but nothing alluded to the complexity of emotions that followed years after diagnosis. The research paper highlighted the contextual factors contributing to the emotions experienced when living with a movement disorder, including: judgements from others, feeling powerless due to a loss of control, experiencing a sense of loss and the unpredictable nature of ET.

The literature review also highlighted a 'fear of the unknown' as a factor which contributed to the emotional experience for diagnosed individuals. However, what the research paper highlighted was that this 'fear of the unknown' transformed into a fear of the unpredictable nature of the movement disorder, with anxiety a key emotion. Consequently, the research paper has provided some understanding of how emotions experienced at diagnosis of a movement disorder, extend into the experience of living with the condition.

In addition, the literature review highlighted some positives to diagnosis, with some individuals finding benefit in their diagnosis, such as re-evaluating life's values and priorities. However, benefit-finding was not evident in the accounts of individuals living with ET; indeed many participants were vocal about the absence of positives within their experience. This could be due to fact that participants in the research study had already identified some benefits at diagnosis and these were not spoken about due to the focus being on post-

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diagnostic experiences. However, it could also be possible that ET is a condition where finding benefit is difficult, perhaps due to the contextual factors identified within theme one (having to contend with judgements from others, unpredictability of ET). In addition, the general public's ignorance towards ET may exacerbate the difficulties experienced in finding any benefit to this condition. As noted by some participants in the research study, movement disorders such as PD and MS are more well-known and understood by the general public and so finding benefit when diagnosed with these conditions could be much easier.

This research indicates a gap in the consideration of psychological support for those individuals recently diagnosed, or living with, a motor neurodegenerative condition. In particular, the meta-synthesis highlighted a lack of signposting to relevant support for participants at the point of diagnosis, and the research paper indicated a need for support at certain times, such as when tremor worsens and previously valued abilities, hobbies or careers are lost. Clinical psychologists could offer this support from the point of diagnosis (where this is desired) by completing work around adjustment and trauma. As an example, clinical psychologists could draw on Brennan's (2001) social cognitive transition model (developed in relation to cancer, though applicable to a range of conditions) when working with individuals; this model aims to make sense of psychological distress to physical illness (particularly cancer, though applicable to a range of conditions) through exploring individuals' mental maps, life expectations and the consequences of a disconfirmation of these.

More long-term interventions would be needed for those individuals who are a number of years post-diagnosis but who are still struggling with the impact that ET has on their life, in such cases the use of acceptance and commitment therapy (ACT) may be helpful. The aim of ACT is to create acceptance of a situation (such as being diagnosed with a health condition) and to continue living by one's values in spite of the situation; this is achieved through the use of mindfulness skills and taking action that enriches our lives (Harris, 2009).

Why this research?

As someone who has a strong interest in health both from an academic and clinical perspective, I always knew I wanted to do a thesis which focused upon a health condition, or set of conditions. In addition, I have a passion for qualitative research as I feel this type of research allows for a richer and more meaningful understanding of participants' experience of a given phenomenon. Consequently, I sought out the possibility of carrying out qualitative research within the area of health. My interest in the area of motor neurodegenerative conditions arose following my grandfather's passing from MND when I was a child. To hear of the devastation this caused within my family, both at diagnosis and while my grandfather lived with the condition, I have always wondered whether this was a universal experience of motor neurodegenerative conditions, or specific to MND itself. In addition, while completing my clinical training, two members of my family were diagnosed with cancer (an adult who was terminal and a child whose parent was told the diagnosis); listening to the contrasting stories of how the diagnoses were given and the impact of this made me consider the diagnostic process, and what factors determined the experience for each person. The meta-synthesis allowed me to indulge my interest in motor neurodegeneration conditions with my interest in the process of receiving a diagnosis.

The research paper enabled me to continue to build on my interests of motor conditions by exploring one of the most prevalent ones but one which, admittedly, I knew very little. I was interested in the fact that no research had focused upon the experience of living with this condition; this seemed to be a significant gap in the literature considering the prevalence of ET. As a result, I felt passionate about investigating this experience.

Reflexivity

Following guidelines provided by Yardley (2008) I implemented a number of

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processes to improve the validity of this qualitative research. A major part of this was the supervisory process which I used to enhance credibility of the interpretation of findings as well as the consistency and coherency of the analysis (Yardley, 2008). In addition, peer supervision was another method I used which helped to enhance both the trustworthiness and quality of data. In particular, theme identification and content was explored with peers (Yardley, 2008).

However, ultimately having awareness of my inevitable impact upon the collection and interpretation of data was crucial (Finlay, 2002). I was aware of how my role as a trainee clinical psychologist could have influenced the study and, as I will expand on later, I found it difficult to balance participants' expectations of me. In addition, since I had read previous literature that had highlighted the many difficulties associated with ET, including the presence of psychological difficulties (Lorenz, Schwieger, Moises & Deuschl, 2006; Chandran & Pal., 2013; Chandran et al., 2012; Jhunjhunwala & Pal, 2014), it was important for me to remain open to the accounts of all participants. The use of a reflective diary to allow for self-reflection during the collection and interpretation stages of this research enabled me to remain open to all accounts.

Strengths and Limitations

I will now discuss some of the strengths and limitations of this research. However, sometimes strengths were not independent of limitations, as was the case with the first issue discussed: the recruitment of participants who were keen to be 'heard'.

Participants

Recruitment itself was, fortunately, a smooth process. I was very lucky in finding a support group for ET in the North West who were keen for me to come and discuss my research. I attended the group on three occasions to distribute information packs about the research I was undertaking. I attended on three occasions to ensure I had reached as many

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group members as possible (as some members did not attend every week). During my attendance on each occasion, all group members were exceptionally welcoming and grateful of my being there and of my plan to conduct research within the area of ET. I was asked many questions from group members who wanted to know where my interest of ET had come from- as this was something alien to them, a professional wanting to know more about ET.

Common questions asked of me included whether I had had a family member with ET and, if I published my research, which health care professionals were likely to have access to this. In addition, during the three occasions I attended the group, group members spoke briefly of the difficulties they had encountered in having ET recognised as a condition in its own right and with its own difficulties. The openness and frankness of participants during group meetings, and later during interviews themselves, was a major strength of this research as participants felt able to be open with me despite my position as a trainee clinical psychologist. There was a risk that, given participants' accounts of previous experiences of health care professionals at diagnosis, that I would be viewed in the same negative way. However, if anything, my position was viewed as a positive by participants and perhaps the fact I was not fully qualified helped with this, as I got a sense from the group that they wanted to 'teach' me about their experience so that I could take this knowledge with me into qualified life. There was also a sense from participants that a health care professional talking about other people's lived experiences of ET would be taken more seriously than they themselves would be if they were to tell their doctor or neurologist for example (and indeed this had been their previous experience). Furthermore there was also a hope that a health care professional could reach a wider audience, and so could tell more people about their lived experience, than they themselves would be able.

However, although I was fortunate enough to have a group of individuals who were

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keen to participate in my research, I found it difficult to balance participants' expectations of me. I was aware of how passionate participants were to speak to me about their experiences of living with ET and how keen they were for these experiences to be heard by other professionals from both the medical and mental health fields. As a result of this, I did feel an element of added pressure to do justice to participants' accounts of their experience of living with ET since I knew that participants viewed both my profession and my study as a platform for allowing their experiences to be acknowledged by others.

Furthermore, there was a sense from participants that my study might be the only chance they would get to let other people know about some of the difficulties they encountered living with ET. I feel this made me more meticulous when conducting participant interviews, carrying out the analysis and when completing the write-up of the research paper, as I wanted to draw out as much pertinent information from participants as I could and represent this in the most accessible and informative way. This was something I was aware of throughout the research process. That said, I do still feel that I would not have been any less meticulous as a researcher had the participants not been as enthusiastic to have their experiences heard, since I am generally passionate about individuals' experiences of chronic illness. Through open discussions with participants I was able to manage their expectations of what can, and would, be done with the study findings whilst managing to gain detailed accounts of participants' experiences of living with ET. In addition, it is possible that the thought of other health professionals potentially reading my research led to some participants deciding to open up more and share as much as possible. If this did happen, then this could have benefitted my research in allowing for richer interpretations to be gleaned from analysis.

Confidentiality

While being fortunate enough to find an ET support group who were keen to

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participate, the size of the group had implications for recruitment, the write-up of the research and feeding back to participants. Difficulties with confidentiality among a small research sample have been documented previously (Damianakis & Woodford, 2012; Petrova, Dewing & Camilleri, 2016). Indeed, the fact that participants knew each other well only served to exacerbate difficulties with confidentiality. Although participants were open in telling each other whether they planned to participate, or not, as a researcher I still had a duty to protect the anonymity of participants. While recruiting, I either ensured I left enough time between participant interviews for one participant to leave before the next arrived or, if this was not possible, then I would interview a participant on a different day.

The write-up of the research was perhaps the most difficult issue to navigate since I had to consider which quotes would make a participant recognisable to the other group members. This was particularly important where a quote was of a sensitive nature. Indeed, although this is an issue that is more pertinent for publication, I tried to protect anonymity as much as was possible in the current write-up; for example, by talking about a job more generally, rather than specifying the job role itself. However, a limitation of this was losing important context that would have added to the level of interpretation. Similarly, some powerful quotes that helped to illustrate the themes identified were also unable to be used due to the need to protect anonymity. When feeding back the research to participants, only a summary of the findings were presented, with all quotes removed. This again meant that some of the findings were lacking in context and lost some richness of detail which, as a researcher, was frustrating at times. Nonetheless, I acknowledge the necessity of this.

Another limitation linked to the group itself was the fact that participants were selected from a homogenous group where tremors ranged from mild to moderate in severity. Only one participant had experienced a tremor that was severe in nature, although this had been reduced to a moderate level through DBS treatment. Consequently, the current research

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did not capture the experiences of those individuals who had ET that was severe, and so the lived experience of such individuals remains unclear. Linked in with this, the fact that participants were recruited from a support group, the location of which participants travelled to, is confirmation of the fact that participants' tremors were not severe, since their tremor did not prevent them from attending the group. Furthermore, the fact that participants were, on the whole, regular attenders at this group suggests a pro-active set of individuals who perhaps have effective self-management skills. In particular, perhaps the participants have better self-management skills than those individuals with ET who do not attend such support groups. Consequently, as well as not capturing experiences of severe ET, the present research may also not have captured the experiences of those individuals who have poorer self-management skills. These limitations lead on to the next section, that of future research.

Future research

With regards to future research, and given the current findings, the meta-synthesis has highlighted the need for future research to focus upon individuals with a diagnosis of PD, MND, HD and MS who have had positive experiences of diagnosis, in order to learn more about how this can be done. Highlighting ways in which the diagnostic process can be experienced as positive could be educative for health care professionals and could help reduce some of the trauma and perceived lack of compassion identified in the meta-synthesis. In addition, since this review focuses solely on the experience of diagnosis, it would be helpful for other meta-syntheses to focus on additional factors associated with motor neurodegenerative conditions, such as self-management including medication adherence or experiences of palliative care, to continue to enhance, and build upon, our understanding of an individual's experience. Such research would allow for a more holistic understanding of the experience from the point of diagnosis onwards into everyday life.

Since ET is one of the most common neurological conditions (Louis & Ferreira 2010),

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understanding is needed of the experience at each level of tremor severity. Consequently, and due to the limitations outlined previously with regards to the research paper, future research should focus upon investigating the lived experience of ET for those individuals whose tremor is severe in nature. Such individuals may be 'hard to reach' and so recruitment from hospitals/clinics may be the most effective way of recruiting individuals. However, there may be some individuals whose tremor is so severe that they are unable to attend clinic appointments; feelings of isolation may further decrease some individuals' motivation to attend such appointments. However, focusing upon these individuals may help to identify additional, or indeed different, difficulties and issues in relation to their experience of living with ET. In such cases, telephone interviews, or skype may be the only way of enabling these participants to partake in the study.

Furthermore, the current research recruited one participant who had had DBS treatment. This participant spoke passionately of how DBS had enhanced his QoL and thus his lived experience of ET. It remains unclear at this present time whether this experience of DBS is shared by many other individuals who have received this treatment, or if the participant in the present study is in the minority in relation to this experience. Future research focusing upon the impact of DBS (if any) on psychological wellbeing could help inform the wider benefits of this treatment for individuals with a diagnosis of ET. Of interest, Jankovic (2005) has reviewed the effect of DBS on health related QoL in PD, ET, MS and dystonia and found that, on the whole, DBS had a favourable impact on tremor and improvements on dimensions of emotion, such as depression (across conditions). It could be feasible to assume that improvements to health related QoL would result in enhanced psychological wellbeing; though this notion would need further exploration.

Conclusion

This thesis has explored the experience of being diagnosed with one of the four most common motor neurodegenerative conditions and is the first piece of qualitative research to explore the lived experiences of one of the most common movement disorders, that of ET. The findings suggest that the diagnostic process for PD, MND, MS and HD is fraught with uncertainty and fear, and is generally experienced as traumatic for individuals. These emotions are not dissimilar to those experienced by individuals living with ET, although the source of these emotions is different. Of importance, amid the difficult emotions experienced at the diagnosis of, and while living with, a motor neurodegenerative condition, positives were highlighted. The findings have implications for a range of healthcare professionals working with individuals who receive a diagnosis of the conditions studied within this research, and perhaps motor neurodegenerative conditions more widely.

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Running Head: ETHICS SECTION

Section 4: Ethics Section

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2014 Intake

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Includes *direct* involvement by human subjects.

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: [LU Ethics](#). Submit this, along with all project documentation, to Diane Hopkins.

4. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PG Diploma	Masters dissertation	PhD Thesis	PhD Pall. Care
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PhD Pub. Health	PhD Org. Health & Well Being	PhD Mental Health	MD
DClInPsy SRP	[if SRP Service Evaluation, please also indicate here:]	DClInPsy Thesis	
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

Applicant Information

Appointment/position held by applicant and Division within FHM

Trainee Clinical Psychologist- Clinical Psychology

Contact information for applicant:

E-mail: j.moore1@lancaster.ac.uk

Telephone: 07745351977 (please give a number on which you can be contacted at short notice)

Address: Faculty of Health and Medicine, Clinical Psychology- Division of Health Research, Furness College, Lancaster University, Lancaster, LA1 4YG.

7. **Project supervisor(s), if different from applicant:** Dr Jane Simpson and Dr Fiona Eccles

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable):** Dr Jane Simpson- Director of Education at Lancaster University ; Dr Fiona Eccles- Lecturer in Research Methods at Lancaster University

9. **Names and appointments of all members of the research team (including degree where applicable)**

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (indicative maximum length 150 words):

Essential tremor (ET) is one of the most prevalent neurological conditions. Individuals with ET experience a rhythmic trembling of a part of the body, most often the hands, but it can affect legs, head, trunk, voice and other areas. Quantitative evidence suggests that quality of life can be affected, not only by the physical symptoms, but also by the associated psychological and social difficulties that occur. However, detailed personal accounts of the experience of living with ET are scarce. This qualitative study aims to recruit approximately 8-12 individuals with a diagnosis of ET and interview them in order to shed light on their lived experiences of ET. The semi-structured interviews will last for approximately 1 hour and will be recorded onto a digital recorder. Following this, all interviews will be transcribed and analysed using interpretative phenomenological analysis (IPA) in order to understand how participants make sense of their experiences of living with ET.

11. Anticipated project dates (month and year only)

Start date: August 2016

End date May 2017

12. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Purposive sampling will be used when recruiting for this study.

Inclusion criteria will consist of the following; individuals aged 18 or over, of any gender, with a diagnosis of ET who have had this diagnosis for a minimum of one year (due to the study's focus on post-diagnostic experiences) and individuals who speak English.

Exclusion criterion is: individuals who have a tremor which is caused by other conditions (not related to ET), such as Parkinson's disease.

This study will be restricted to English speaking participants due to a lack of resources for funding interpreters and limited time for collecting and analysing the data. However, this will not be an issue within the proposed research as it is known that the ET groups that this study will recruit from are facilitated in English.

It is hoped that the minimum number of participants recruited will be 8, and the maximum number will be 12. The minimum number of participants needed to ensure this study is viable is 5.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited for this study via purposive sampling. Two stages of recruitment have been planned,

the second of which will only take place if the target number of participants cannot be gained from the first stage. The first wave of recruitment will concern the researcher attending the XXXXXXXX ET support/social group to distribute information packs about the study. It will be explained to potential participants that, if they wish to participate, then they can make this known to the researcher through email (non-personal) or telephone (research phone) or by completing the consent to contact form which will be attached to the information pack.

The researcher's email and research telephone number will be provided on the participant information sheet. The researcher may attend more than one support/social group meeting in order to distribute information packs.

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However, in order to also reach those group members who are not in attendance at the groups when information packs are given out, the researcher will ask the group facilitator to post a short message regarding the study, with a link to the participant information sheet, on the group's XXXXXXXX ET Facebook group. This will enhance the likelihood of recruiting the target number of participants. However, if the target number of participants cannot be gained from this group, then the second wave of recruitment will begin. This second wave will involve the researcher contacting Mary Ramsay (expert by experience who has ET) in XXXXXXXX who facilitates an ET group.

The researcher will either email study documents to Mary to distribute in her ET group, or the researcher may post information packs out in the post to Mary to distribute if potential participants do not have access to the internet. Participants will be given the option of contacting the researcher by email or telephone, or by post.

The researcher will speak with all potential participants on the phone before conducting the interview. During this phone call, the researcher will explain that, in order to take part in the study, individuals must have a diagnosis of essential tremor, and must have had this for at least twelve months. Consequently, details regarding their diagnosis will be ascertained. In particular, confirmation will also be needed as to the diagnosis definitely being one of ET, as opposed to a neurodegenerative disease diagnosis such as Parkinson's disease. During this discussion, it would also be helpful to establish who gave the individuals their diagnosis; for instance, was this a GP or a neurologist. Any questions arising from these discussions will be answered by the researcher.

14. What procedure is proposed for obtaining consent?

Participants will either be interviewed face-to-face, by Skype or by telephone and will be asked to give either written or verbal consent prior to their participation. On the day of the interview, the researcher will first read through the participant information sheet and answer any questions that participants may have. Following this, the researcher will then read through the consent form with participants, again answering any questions that arise. For those participating in face to face interviews, the consent form will then be signed. This consent form will ask participants to 'tick' the boxes to indicate their agreement with each item on the form. It is anticipated that placing a tick in the box will be easier for participants to do (in comparison to initialing) due to their tremor. For those participants interviewed using Skype or telephone, verbal consent to participate will be sought. In particular, the researcher will read through each item on the consent form with these participants, before asking for verbal confirmation of their consent to participate.

15. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

It is possible that some participants may feel uncomfortable discussing their experiences of living with ET. It will be highlighted to participants that they do not have to answer any questions that they feel uncomfortable with. If a participant does become distressed during the interview then the researcher will offer to stop the interview and will offer the participant a break. The participant will then be given the option of either continuing with the interview, or arranging to complete the interview at a later date. Participants will also be referred to the participant information sheet which will detail how they can access support; the researcher will discuss with the participant which support may be most helpful for them.

for them. At any point in the interview participants can terminate the interview and their data can be withdrawn. In addition, participants will be able to withdraw their data up to two weeks following the date of their interview without giving any reason. After this time it is likely that analysis of the participant's data will have commenced. The researcher acknowledges the possible overlap of some symptoms in ET and Parkinson's disease (PD) and that it can sometimes be hard for clinicians to distinguish between the two conditions (Thenganatt & Louis, 2012). In addition, there does appear to be some pathogenetic relationship between the conditions, at least for some subgroups (Fekete & Jankovic, 2011). For example, one longitudinal study suggests approximately 5.8% of people with ET develop PD, as opposed to 1.6% of the general population (Benito-León, Louis & Bermejo-Pareja, 2009) and a higher proportion may develop rest tremor, (more characteristic of PD (Cohen, Pullman, Jurewicz, Watner & Louis, 2003)). The researcher will acknowledge this situation with participants and will again emphasise that this study is only looking to focus upon individuals who currently have a diagnosis of ET (and not PD), and individuals who are uncertain as to their diagnosis will be advised to contact their GP and/or Neurologist or other health professional to clarify this. Until this is clarified, it will be explained to participants that they will, unfortunately, be unable to participate.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Since the researcher will be working alone when conducting interviews, the researcher will follow Lancaster University's guidance on safety in field work. In particular, the guidance on 'personal safety when working off campus' (pg. 8), the code of practice (fieldwork; pg. 9), lone working (pg. 11) and risk from respondents (pg. 12) will all be adhered to by the researcher. In addition, Lancashire care NHS foundation trust's lone working policy will also be adhered to. The researcher will assign a buddy (from their cohort) who they will give interview details to. These details will include where the researcher is going to conduct their interview and with whom; this information will be enclosed in an envelope or a password protected document. The researcher will then telephone their buddy upon arrival at the interview, and when they are leaving the interview. If the buddy does not hear from the researcher then they will attempt to contact the researcher themselves. However, if the buddy cannot get in contact with the researcher then they will open the envelope/document and telephone the police.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits expected from taking part. However, it is hoped that participants may find it validating to talk about their experiences of living with ET and therefore may find it a positive experience to participate in this study. Furthermore, it is hoped that this research will emphasise how day-to-day life is experienced by individuals with ET and may inform future support.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Participants will not receive any payment for their participation. However, the researcher plans to conduct interviews at a convenient site of the participant's choosing, for example; a community venue or their home. For those participants travelling to a community venue for their interview, travel expenses will be reimbursed up to a maximum of £20

19. Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Data will be collected for this study either through face to face interviews with participants or via Skype or telephone interviews. It is anticipated that interviews will last for approximately one hour. If participants wish to continue for longer then they will first be offered a break, or offered another date and time to continue with the interview. Questions asked during each interview will follow an interview schedule which has been guided by previous research in ET and other similar movement disorders as well as by consultation with a group of individuals with ET and by the expert by experience. Questions asked during the interview will also be guided by the responses of participants. At the end of the interview, participants will be given a debrief sheet which will outline the process of what happens next, and who they should contact (researcher) should they have any questions and relevant contact details will be provided (non-personal details). Interpretative phenomenological analysis will be used to analyse the data. IPA is appropriate given the nature of the present study which aims to focus on a homogenous group of individuals who all share a common life experience, that of having a diagnosis of ET. IPA is concerned with conducting an in-depth investigation of a shared aspect of lived experience (Smith & Osborn, 2008) and so is congruent with the aims of the present study and the intended sample size.

With regards to confidentiality, all interviews will be recorded onto a digital recorder and uploaded onto the researcher's password protected drive at Lancaster University at the earliest opportunity. Only the researcher and academic supervisors will have access to participants' personal data. In addition, Skype may be used to interview some participants. The researcher will set up a professional Skype account for research use only and this account will not be used for any other purpose. At the start of the Skype interview, it will be highlighted to participants that the internet is not secure, and their right to withdraw will be highlighted. This information will also be included in the participant information sheet.

The researcher will also explain the limits to confidentiality to all participants. Specifically, participants will be informed that if they disclose any information regarding risk to themselves, or to others, then the researcher will have to share this information with the academic supervisors of the study in the first instance to determine an appropriate course of action. This is also outlined on the participant information sheet.

In relation to anonymity, interviews will be transcribed by the researcher and all transcripts will be anonymized and pseudonyms will be used throughout the write-up of this study. Every attempt will be made to try and ensure that the final summary report does not contain any identifiable data, such as specific quotes (e.g. turns of phrase) that may allow for participants to be identified. In addition, every effort will be made to try and ensure that publications of this study will also be free of identifiable participant data.

Risk Management. At the beginning of all interviews, participants will be made aware that if they disclose any information regarding risk to themselves or others, then the researcher will have to share this information with the academic supervisors of the study in the first instance, in order to decide an appropriate course of action. Furthermore, it will be emphasised to participants that they do not have to answer any questions that they feel uncomfortable with during the interview. If participants report experiencing distress following their interview, the researcher will refer them to the participant information sheet which will detail information of where participants can access support. A discussion will then be had with participants as to what might be the most helpful form of support for them.

20. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The researcher has consulted with Mary Ramsay, an 'expert by experience' contact from XXXXXXXX who facilitates an ET group. Mary has read through the participant documents (interview schedule, consent form, demographic questionnaire, participant information sheet, debrief sheet and consent to contact form) and has provided feedback on these. Mary may also have input into the conduct of the research in terms of facilitating recruitment if necessary, and also may be involved in looking at final themes from the data. In addition, the researcher attended a XXXXXX ET group at an early stage to discuss the research aims of the project and received input into the design of the study from this group.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

All interviews will then be transcribed verbatim by the researcher. Interview transcripts, and any coded data produced, will be stored electronically for ten years in an approved location on the Lancaster University network, such as 'Box' or on the clinical psychology shared drive. The storage will be the responsibility of the programme or research director who will delegate tasks to an appropriate administrator such as the research co-ordinator. Consent forms and demographic questionnaires will also be scanned and stored electronically for ten years, but these will be kept separate from interview transcripts. Information such as the consent to contact form will be destroyed once the project has been completed. However, if participants have requested an end of study summary report, then documents such as the consent to contact forms will be stored until this information has been distributed to participants.

22. Will audio or video recording take place? No Audio Video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

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All interviews will be recorded on a digital recorder. All audio files containing interview data will be transferred to a Lancaster University approved location (such as VPN, Box) as soon as possible following the interview. The digital recorder will be stored securely until this transfer has taken place. Audio files will then be deleted from the digital recorder immediately following this transfer. Audio files will be deleted from the approved location once the viva voce examination has been completed. Once the researcher has completed the clinical psychology doctorate course, it will be the responsibility of the programme or research director (who will delegate tasks to an appropriate administrator, such as the research co-ordinator) to store all study data for a maximum of ten years in line with Lancaster University policy. After this time, a designated research administrator will delete all data.

23. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

With regards to dissemination a thesis report will be produced following completion of the project. In addition, a final summary report regarding this research study will be distributed to all participants once completed if they wish for this to happen. The researcher will also present the study findings to the groups from which participants have been recruited. Furthermore, data from this project may be submitted for publication to journals and presented in conferences and to support groups.

24. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

As noted above, verbal consent is proposed for interviews in situations whereby participants will find it difficult to meet face-to-face (i.e. long distance interviews) and so will be interviewed via Skype or telephone. Verbal consent will be recorded onto a separate audio file prior to the start of the interview. We would welcome the committee's opinion as to whether this is acceptable.

Signatures:

Applicant:.....Jessica Moore.....

Date: 20.05.16.....

*Project Supervisor (if applicable):Fiona Eccles

Date:.....23/5/2016.....

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

THE UNIVERSITY OF LANCASTER

Nov 2009

PFACT project information and ethics questionnaire

(To be completed by the student together with their supervisor in all cases)

Name of student: Jessica Moore

Name of supervisor: Dr Jane Simpson and Dr Fiona Eccles

Project Title: Post-diagnostic lived experiences of individuals with essential tremor

FHM Division: Health and Medicine

1. General information

1.1 Have you, if relevant, discussed the project with

- the Data Protection Officer?
- the Freedom of Information Officer?
- N/A

(Please tick as appropriate.)

1.1 Does any of the intellectual property to be used in the research belong to a third party?

Ethics

N

1.2 Are you involved in any other activities that may result in a conflict of interest with this research?

N

1.3 Will you be working with an NHS Trust?

N

1.4 If yes to 1.3, what steps are you taking to obtain NHS approval?

_____NA

1.5 If yes to 1.3, who will be named as sponsor of the project?

_____NA

1.6 What consideration has been given to the health and safety requirements of the research?

The chief investigator of the study will follow Lancaster University's lone worker policy when conducting interviews with participants.

2. Information for insurance or commercial purposes

(Please put N/A where relevant, and provide details where the answer is yes.)

2.1 Will the research involve making a prototype?

N

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2.2 Will the research involve an aircraft or the aircraft industry?

N

2.3 Will the research involve the nuclear industry?

N

2.4 Will the research involve the specialist disposal of waste material?

N

2.5 Do you intend to file a patent application on an invention that may relate in some way to the area of research in this proposal? If YES, contact Gavin Smith, Research and Enterprise Services Division. (ext. 93298)

N

3. Ethical information

(Please confirm this research grant will be managed by you, the student and supervisor, in an ethically appropriate manner according to:

- (a) the subject matter involved;*
- (b) the code of practice of the relevant funding body; and*
- (c) the code of ethics and procedures of the university.)*

3.1 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the avoidance of plagiarism and fabrication of results.

✓

3.2 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the observance of the rules for the exploitation of intellectual property.

✓

3.3 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to adherence to the university code of ethics.

Ethics



- 3.4 Will you give all staff and students involved in the project guidance on the ethical standards expected in the project in accordance with the university code of ethics?
Y
- 3.5 Will you take steps to ensure that all students and staff involved in the project will not be exposed to inappropriate situations when carrying out fieldwork?
Y
- 3.6 Is the establishment of a research ethics committee required as part of your collaboration? (This is a requirement for some large-scale European Commission funded projects, for example.)
N
- 3.7 Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans, human tissue etc.?
Y
- 3.7.1 Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?
Y
- 3.7.2 Will you take the necessary steps to find out the applicable law?
Y

Ethics

3.73 Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

Y

3.74 Will you take appropriate action to ensure that the position under 3.7.1 – 3.7.3 are fully understood and acted on by staff or students connected with the project in accordance with the university ethics code of practice?

Y

3.13 Does your work involve animals? If yes you should specifically detail this in a submission to the Research Ethics Committee. The term animals shall be taken to include any vertebrate other than man.

3.13.1 Have you carefully considered alternatives to the use of animals in this project? If yes, give details.

N/A

3.13.2 Will you use techniques that involve any of the following: any experimental or scientific procedure applied to an animal which may have the effect of causing that animal pain, suffering, distress, or lasting harm? If yes, these must be separately identified.

N / N/A

Signature (student): Jessica Moore

Date: 20.05.16

Signature (supervisor): _____ Date: _____

N.B. Do not submit this form without completing and attaching the Stage 1 self-assessment form

Stage 1 Self-Assessment Form (Part A) - for Research Students

*(To be completed by the student together with the supervisor in all cases;
send signed original to Research Support)*

Student name and Jessica Moore; j.moore1@lancaster.ac.uk

Supervisor Dr Jane Simpson and Dr Department: Clinical
Fiona Eccles

Title of Post-diagnostic lived experiences of individuals with essential
project: tremor)

Proposed funding source (if

1. Please confirm that you have read the code of practice, '[Research Ethics at Lancaster: a code of practice](#)' and are willing to abide by it in relation to the current proposal? **Yes**
If no, please provide explanation on separate page
2. Does your research project involve non-human vertebrates, cephalopods or decapod crustaceans? **No**
*If yes, have you contacted the Ethical Review
Process Committee (ERP) via the
University Secretary (Fiona Aiken)?
?*
- 3a. Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans etc? **Yes**
If yes, you must complete Part B unless your project is being reviewed by an ethics committee
- 3b. If the research involves human participants please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data **Yes**
- 3c. If the research involves human participants, are any of the following relevant:
 - No** The involvement of vulnerable participants or groups, such as children, people with a learning disability or cognitive impairment, or persons in a dependent relationship
 - No** The sensitivity of the research topic e.g. the participants' sexual, political or legal behaviour, or their experience of violence, abuse or exploitation
 - No** The gender, ethnicity, language or cultural status of the participants
 - No** Deception, trickery or other procedures that may contravene participants' full and informed consent, without timely and appropriate debriefing, or activities that cause stress, humiliation, anxiety or the infliction of more than minimal pain
 - No** Access to records of personal or other confidential information, including genetic or other biological information, concerning identifiable individuals, without their knowledge or consent

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No The use of intrusive interventions, including the administration of drugs, or other treatments, excessive physical exertion, or techniques such as hypnotherapy, without the participants' knowledge or consent

No Any other potential areas of ethical concern? (Please give brief description)

N/A

4. Are any of the following potential areas of ethical concern relevant to your research?

No- Could the funding source be considered controversial?

Yes- Does the research involve lone working or travel to areas where researchers may be at risk (eg countries that the FCO advises against travelling to)? If yes give details.

No - Does the research involve the use of human cells or tissues other than those established in laboratory cultures?

No- Does the research involve non-human vertebrates?

If yes, has the University Secretary signified her approval? ?

No - Any other potential areas of ethical concern? (Please give brief description)

5. Please select **ONE** appropriate option for this project, take any action indicated below and in all cases

submit the fully signed original self-assessment to RSO.

- (a) Low risk, no potential concerns identified**
The research does **NOT** involve human participants, response to all parts of Q.4 is 'NO'. No further action required once this signed form has been submitted to RSO
- (b) Project will be reviewed by NHS ethics committee**
Part B/Stage 2 not usually required, liaise with RSO for further information. If Lancaster will be named as sponsor, contact RSO for details of the procedure
- (c) Project will be reviewed by other external ethics committee**
Please contact RSO for details of the information to submit with this form
- (d) Project routed to UREC via internal ethics committee**

SHM and Psychology only. Please follow specific guidance for your School or Department and submit this signed original self-assessment to RSO

- (e) Potential ethical concerns, review by UREC required**
Potential ethical concerns requiring review by UREC, please contact RSO to register your intention to submit a [Stage 2](#) form and to discuss timescales

Ethics

(f) Potential ethical concerns but considered low risk, (a)-(e) above not ticked
Research involves human participants and/or response to one or more parts of Q.4 is 'YES' but ethical risk is considered low. Provide further information by completing [PART B](#) and submitting with this signed original PART A to RSO

Student signature: Date:

Supervisor: _____ Date:

Head of Department (or delegated Name:

Signature: Date:

Research Protocol

Title of Project: **Post-diagnostic lived experiences of individuals with essential tremor**

Researcher: Jessica Moore

Academic Supervisors: Dr Jane Simpson

Dr Fiona Eccles

Introduction

Essential tremor (ET) is one of the most prevalent neurological conditions (Louis & Ferreira, 2010) and is characterised by recurring oscillations of a body part involving one or more joints (Hess & Pullman, 2012). It has been found to be chronic and progressive (Louis, Agnew, Gillman, Gerbin & Viner, 2011). ET is usually considered an action tremor, i.e. it is seen when performing movement or when maintaining a posture against gravity as opposed to being at rest (Hess & Pullman, 2012). The tremor usually involves upper limbs in the main, although it can affect the head, chin, voice, tongue and other body parts (Jiménez-Jiménez et al., 2013). Despite the fact that ET is considered to be one of the most prevalent neurological conditions, its aetiology remains unclear (Jiménez-Jiménez et al., 2013). The frequency of family history of tremor in individuals with ET is high at approximately 50-60%; however, for non-familial forms of ET, environmental factors have been suggested (Jiménez-Jiménez et al., 2013) including exposure to agricultural work and frosted glass (Jiménez-Jiménez et al., 2007).

Previous research into the area of ET suggests that individuals with this diagnosis not only experience symptoms of tremor, but also find that their quality of life (QoL) is impaired (Lorenz, Schwieger, Moises & Deuschl, 2006). Lorenz et al. (2006) specified that the main predictors of QoL concern psychological and psychosocial factors, such as emotional well-being and social withdrawal, rather than the functional limitations of ET. In line with this, Chandran and Pal (2013) also identified that psychosocial aspects of ET are the most important in determining QoL for individuals. Tremor severity

Ethics

and anxiety and depression were found to be associated with lower QoL in individuals with ET; though specific characteristics of the tremor such as age of onset and duration were not found to have an impact (Chandran & Pal, 2013). In addition, it has also been found that ability to perform at work, and during leisure activity, also impacts upon levels of depression for individuals with ET (Chandran et al., 2012).

A particular salient issue for individuals with ET, particularly women and those with young onset, is embarrassment associated with having a tremor. This occurs even when symptoms are mild, and is likely to be an important motivating feature that drives someone to seek treatment (Louis & Rios, 2009). Embarrassment has been described as an experience of having an undesirable act or condition witnessed by, or exposed to, others leading to a loss of dignity (Louis & Rios, 2009). Thus, it would be feasible to assume that this too impacts upon QoL for individuals. It remains unclear whether these commonly reported psychological difficulties (such as low mood and anxiety) are (at least in part) an intrinsic part of ET, or if they occur as a result of the experience of living with ET (Musacchio et al., 2016). Nonetheless, regardless of their origin, these difficulties impact more upon an individual's QoL than motor symptoms. While quantitative work has highlighted the importance of psychosocial factors in determining quality of life, it cannot explore the complex interplay of these factors and does not allow the exploration of the meaning of the difficulties for individuals in their everyday lives. Consequently, by conducting a qualitative study about the post-diagnostic experiences of ET, this research will aim to identify how day- to-day life is experienced by individuals, with a focus on their psychological wellbeing. The study aims to shed light on any difficulties, as well as any positive experiences, that living with ET brings across various life domains, for example: personal, social, employment. Interpretative phenomenological analysis (IPA) has been chosen as the methodology due to its focus on in-depth investigation of individuals who share a specific life experience (Smith & Osborn., 2008). This enhanced understanding of the lived experiences of individuals with ET could also help to inform more effective psychological support and intervention where this is needed.

Method

Participants

It is anticipated that 8-12 participants will be recruited for this qualitative study. The inclusion criteria for potential participants will consist of the following:

- Individuals who have had a diagnosis of ET for a minimum of 12 months who are aged 18+
- Individuals who speak English

Being 12 months post diagnosis is to allow for the individual to have time to come to terms with the diagnosis and so the focus can be on the day to day living experiences, rather than the diagnostic process.

The exclusion criterion is:

- Individuals who have a tremor which is caused by other conditions (not related to ET) such as Parkinson's disease

A demographic questionnaire will be given in order to obtain some basic information about the sample of participants recruited. This questionnaire will gather information such as participants' gender, ethnicity, relationship status, how long they have had a diagnosis of ET and from whom they received this diagnosis. Please refer to appendix 1 (attached) for a copy of this demographic questionnaire.

Design

The proposed research study is qualitative in nature and will use IPA in order to analyse data collected via individual semi-structured interviews. IPA is appropriate given the nature of the present study which aims to conduct an in-depth investigation on a small homogenous group of individuals who all share a common life experience, that of having a diagnosis of ET (Smith & Osborn, 2008).

The researcher attended a XXXXXX group of people with ET and these discussions have informed the focus of the research and the interview schedule. In addition, Mary Ramsay (an expert by experience who has ET) has been consulted and has provided feedback on the demographic questionnaire (appendix 1),

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interview schedule (appendix 2), consent to contact form (appendix 3) participant information sheet (appendix 5), consent form (appendix 6) and the debrief sheet (appendix 7).

Recruitment

Participants will be recruited for this study via purposive sampling, and participants will either be interviewed face-to-face or via Skype or telephone. Two stages of recruitment have been planned, the second of which will only take place if the target number of participants cannot be gained from the first stage. The first wave of recruitment will concern the researcher attending the XXXXXXXXXX ET support/social group to distribute information packs about the study. It will be explained to potential participants that, if they wish to participate, then they can make this known to the researcher through email (non-personal) or telephone (research phone) or by completing the consent to contact form which will be in the information pack. The researcher's email and research telephone number will be provided on the participant information sheet. Please refer to appendix 3 for a copy of the consent to contact form. The researcher may attend more than one support/social group meeting in order to distribute information packs. However, in order to also reach those group members who are not in attendance at the groups when information packs are given out, the researcher will ask the group facilitator to post a short message regarding the study, with a link to the participant information sheet, on the group's XXXXXXXXXX ET Facebook group. This will enhance the likelihood of recruiting the target number of participants. Please refer to appendix 4 for a copy of this social media post.

However, if the target number of participants cannot be gained from this group, then the second wave of recruitment will begin. This second wave will involve the researcher contacting Mary Ramsay in XXXXXXXXXX who facilitates an ET group. The researcher will either email study documents to Mary to distribute in her ET group, or the researcher may post information packs out in the post to Mary for her to distribute if potential participants do not have access to the internet. As in the first stage of recruitment, participants will be given the option of contacting the researcher by email or telephone, or by post.

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Similarly, participants from XXXXXXXXX can also be interviewed via face-to-face, Skype or telephone interviews. It will be highlighted on the participant information sheet that confidentiality cannot be fully ensured when using Skype and the researcher will emphasise this on the day of the interview. The researcher will speak with potential participants on the phone before meeting with them for the interview. During this phone call, the researcher will explain that, in order to take part in the study, individuals must have a diagnosis of essential tremor, and must have had this for at least twelve months. Consequently, details regarding their diagnosis will be ascertained. In particular, confirmation will also be needed as to the diagnosis definitely being one of ET, as opposed to a neurodegenerative disease, such as Parkinson's disease. During this discussion, it would also be helpful to establish who gave the individuals their diagnosis; for instance, was this a GP or a neurologist. Any questions arising from these discussions will be answered by the researcher. Please refer to appendix 5 for a copy of the participant information sheet. The researcher will make it clear to any groups attended (and to Mary Ramsay if the XXXXXXXXX group is also approached) that the maximum number of participants required for the present study is 12.

Process

Participants will either be interviewed face-to-face, by Skype or by telephone. On the day of the interview, the researcher will first read through the participant information sheet and answer any questions that participants may have. Following this, the researcher will then read through the consent form with participants, again answering any questions that arise. Once questions have been answered, consent will be taken. For those participating in face to face interviews participants will sign a consent form. In addition, all participants will be informed of their rights to withdraw from the study up until two weeks from the date of their interview. This consent form will ask participants to 'tick' the boxes to indicate their agreement with each item on the form. It is anticipated that placing a tick in the box will be easier for participants to do (in comparison to initialing) due to their tremor. For those participants interviewed using Skype or telephone, verbal consent to participate will be sought. In particular, the researcher will read through each item on the consent form with these participants, before asking for

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verbal confirmation of their consent to participate. Verbal consent will be recorded onto a separate audio file prior to the start of the interview. Following this, the demographic questionnaire (appendix 1) will then be given to participants to complete. (Again if completing via telephone or Skype, the questions will be asked verbally). Once this questionnaire has been completed, the interview will begin. It is anticipated that interviews will last for approximately one hour. If participants wish to continue for longer then they will first be offered a break, or offered another date and time to continue with the interview.

At the end of the interview, all participants will be given a debrief sheet which will thank them for taking part and inform them of who they should contact (researcher) should they have any questions. The researcher's contact details (non-personal) will be provided on the debrief sheet. Please refer to appendix 7 for a copy of the debrief sheet. Participants will also be informed of their right to withdraw their data up until two weeks from the date of their interview.

Lone working

Since the researcher will be working alone when conducting interviews, potential risk will be managed by following both Lancaster University's guidance in fieldwork and Lancashire care NHS foundation trust's lone working policy. In particular, the researcher will assign a buddy (from their cohort) who they will give interview details to. These details will include where the researcher is going to conduct their interview and with whom; this information will be enclosed in an envelope or a password protected document. The researcher will then telephone their buddy upon arrival at the interview, and when they are leaving the interview. If the buddy does not hear from the researcher then they will attempt to contact the researcher themselves. However, if the buddy cannot get in contact with the researcher then they will open the envelope/document and telephone the police.

Analysis

Data produced from each interview will be analysed using IPA. The researcher will transcribe the audio data, documenting the interview verbatim. Initial coding of the data will be documented in the margin, before emerging themes for each transcript are identified. As suggested by Smith and Osborn

Ethics

(2008), final themes will be identified through an iterative procedure involving the identification of emerging themes across transcripts that connect with one another.

Storage

All data generated from this study will be accessible to the researcher and the academic supervisors. Each participant interview will be recorded onto a digital recorder and then transferred as soon as possible to a Lancaster University approved location such as the virtual private network (VPN) or Box. The audio files will then be deleted from the digital recorder immediately following this transfer. All interviews will then be transcribed verbatim. Interview transcripts, and any coded data produced, will be stored electronically for ten years in an approved location on the Lancaster University network, such as 'Box' or on the clinical psychology shared drive. The storage will be the responsibility of the programme or research director who will delegate tasks to an appropriate administrator such as the research co-ordinator. Consent forms and demographic questionnaires will also be scanned and stored electronically for ten years, but these will be kept separate from interview transcripts. Information such as the consent to contact form will be destroyed once the project has been completed. However, if participants have requested an end of study summary report, then documents such as the consent to contact forms will be stored until this information has been distributed to participants. All audio files will be deleted after the researcher's viva voce examination.

Once the researcher has completed the clinical psychology doctorate course, it will be the responsibility of the programme or research director (who will delegate tasks to an appropriate administrator, such as the research co-ordinator) to store all study data for a maximum of ten years in line with Lancaster University policy. After this time, a designated research administrator will delete all data.

Costs

There will be a time cost for participants in the form of an hour of their time in which to be interviewed. The researcher plans to conduct interviews at a convenient site of each participant's choosing, for example; a community venue or at their home. For those participants travelling to a

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community venue for their interview, travel expenses will be reimbursed following the DClInPsy policy – up to £20 per interview.

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Confidentiality. As previously noted, in order to ensure confidentiality is adhered to, all interviews will be recorded onto a digital recorder and uploaded onto the researcher's password protected drive at Lancaster University at the earliest opportunity. Interview transcripts will be anonymised and only the researcher and academic supervisors will have access to participants' personal data. In addition, Skype may be used to interview some participants. The researcher will set up a professional Skype account for research use only and this account will not be used for any other purpose. At the start of the Skype interview, it will be highlighted to participants that the internet is not secure, and their right to withdraw will be highlighted. This information will also be included in the participant information sheet.

Furthermore, the researcher will also explain the limits to confidentiality to all participants. Specifically, participants will be informed that if they disclose any information regarding risk to themselves, or to others, then the researcher will have to share this information with the academic supervisors of the study in the first instance to determine an appropriate course of action. This is also outlined on the participant information sheet.

Anonymity. Pseudonyms will be used throughout the write-up of this study. Every attempt will be made to try and ensure that the final summary report will not contain any identifiable data, such as specific quotes that may allow for participants to be identified. In addition, every effort will be made to try and ensure that publications of this study will also be free of identifiable participant data

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The researcher acknowledges the possible overlap of some symptoms in ET and Parkinson's disease (PD) and that it can sometimes be hard for clinicians to distinguish between the two conditions (Thenganatt & Louis, 2012). In addition, there does appear to be some pathogenetic relationship between the conditions, at least for some subgroups (Fekete & Jankovic, 2011). For example, one longitudinal study suggests approximately 5.8% of people with ET develop PD, as opposed to 1.6% of the general population (Benito-León, Louis & Bermejo-Pareja, 2009) and a higher proportion may develop rest tremor, (more characteristic of PD (Cohen, Pullman, Jurewicz, Watner & Louis, 2003)). The researcher will acknowledge this situation with participants and will again emphasise that this study is only looking to focus upon individuals who currently have a diagnosis of ET (and not PD), and individuals who are uncertain as to their diagnosis will be advised to contact their GP and/or Neurologist or other health professional to clarify this. Until this is clarified, it will be explained to participants that they will, unfortunately, be unable to participate.

Risk Management. At the beginning of all interviews, participants will be made aware that if they disclose any information regarding risk to themselves or others, then the researcher will have to share this information with the academic supervisors of the study in the first instance, in order to decide an appropriate course of action. Furthermore, it will be emphasised to participants that they do not have to answer any questions that they feel uncomfortable with during the interview. If participants report experiencing distress following their interview, the researcher will refer them to the participant information sheet which will detail information of where participants can access support. A discussion will then be had with participants as to what might be the most helpful form of support for them.

Timescale

- 23rd May 2016: Submit FHM ethics application and await feedback
- 27th June- July 11th 2016: Make any amendments to ethics application and submit
- August- September 2016: Attend XXXXXXXXXX group to distribute study information packs

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- 3rd October-21st November 2016: Data collection and write up of literature review
- 30th November: Submit first draft of literature review
- 5th December- 30th December 2016: Data analysis
- 2nd January: Submit second draft of literature review
- 23rd Jan 2017: Submit first draft of introduction and method
- 13th February 2017: Submit second draft of introduction and method
- 27th March 2017: Submit first draft of results and discussion
- 17th April 2017: Submit second draft of result and discussion
- 12th May 2017: Submit Thesis

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Ethics Committee Approval Letter

Applicant: Jess Moore

Supervisors: Jane Simpson and Fiona Eccles

Department: Health Research

FHMREC Reference: FHMREC15093 12 July

2016

Dear Jess

Re: Post-diagnostic lived experiences of individuals with essential tremor

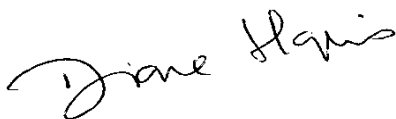
Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 fhmresearchsupport@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,



Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC

Appendix 4-A: Demographic Questionnaire

V1

Number:

In order to be able to describe some detail about the sample of participants used within this research, please could you take the time to answer the following questions.

Gender (Please circle): **Male / Female**

Age: _____

What is your ethnic group? (Please circle)

(Ethnic categories taken from Office for National Statistics web page, 2015)

A. White

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other White background, please state _____

B. Mixed/Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/Multiple ethnic background, please state _____

C. Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, please state _____

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D. Black/ African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background, please state _____

E. Other ethnic group

- Arab
- Any other ethnic group, please state _____

What is your relationship status? (e.g. single, have partner)

What is your employment status? (E.g. employed, retired, full time education etc)

For how long have you had a diagnosis of essential tremor?

From whom did you receive your diagnosis of essential tremor (e.g. GP, Neurologist)?

Are you prescribed medication for essential tremor? If so, what medication?

If you answered ‘yes’ to the above, for how long have you been prescribed medication for essential tremor?

Thank you for completing this questionnaire.

Jessica Moore

Trainee Clinical Psychologist

Appendix 4-B: Interview Schedule

V1

This interview schedule gives indication of the topic areas to be discussed in the interview with example questions. The precise questions will be dependent on participants' responses and the focus of each interview will be guided in part by what is deemed important to the individual being interviewed.

1. Introduction

To introduce the topic and help build rapport, the interview will start with discussion around how long the participant has been accessing the ET social/support group and how they found out about the group, how long they have had a diagnosis of ET and whether their symptoms have changed overtime.

2. Psychosocial

For this part of the interview, questions will be concerned with the impact of ET across different life domains, i.e. social life, employment, relationships, psychological difficulties.

Example prompts:

- Does ET affect your ability to do day to day tasks such as washing/dressing? Are you able to say more?
- Does your experience of living with ET impact on your ability to engage in hobbies/leisure activities
- Do you have a family history of ET? (hereditary ET vs no known cause)
- At what age did you first notice the presence of a tremor?
- What has been your experience of employment in the context of ET? (colleagues/job role)
- Did you/do you feel adequately supported at work?
- What were/are the main difficulties you encountered whilst working? (if any)
- What were/are the benefits of working? (if any)- for yourself.

- Have you ever experienced any psychological difficulties due to your experience of ET? Are you able to say more?
- Do you have any other difficulties in relation to ET? Are you able to expand on these?
- What emotions do you associate with your experience of ET? (embarrassment, sadness, anger, indifferent etc)

- Does your tremor interfere with your personal (family/friends) relationships? If so, how?
- How do you feel you are perceived by others in the context of your diagnosis of ET? (family, acquaintances, strangers)
- Do you feel you have missed out on any life experiences due to your experience of ET? Are you able to say more?

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- Do you feel your experience of living with ET has enhanced your life in any way (any positives to this diagnosis?)
- How do you cope with your experience of living with ET?(strategies?)
- Have you ever accessed any formal support to help with your experience of living with ET (psychological input?)
- Do you feel psychological support would have been helpful to you at any particular times? If so, could you say more about this?
- How do you feel clinical psychology could best be used to help with experiences of living with ET (if at all)?

3. Treatment and effects

This part of the interview will focus on the medication (if any) that participants receive to help manage ET and the impact of any treatment. .

Example prompts:

- Do you receive any form of treatment for ET or have you in the past? If so, could you expand on this? (medication, deep brain stimulation (DBS) etc)
- What impact (if any) does this treatment have on day-to-day life?
- What are the benefits (if any) of treatment?
- What are the drawbacks (if any) of treatment?

4. Additional information

This part of the interview will focus upon giving the participant chance to reflect on whether they wish to add any additional information, as well as capturing any last participant reflections about ET and the interview before closing.

Example prompts:

- Is there anything you wish to talk about in relation to your experience of living with ET that we have not covered?
- Do you feel we have sufficiently captured your experience of living with ET?
- Any last reflections?

Appendix 4-C: Consent to contact form

CONSENT TO CONTACT FORM

Post-diagnostic lived experiences of individuals with essential tremor

If you are interested in learning more about the study please contact the researcher Jessica Moore. You can do this by phoning Jessica directly (XXX), by email (j.moore1@lancaster.ac.uk) or by filling in this form and returning it in the stamped addressed envelope provided and Jessica will then contact you.

Name: _____

Contact details

Telephone number: _____

Email address: _____

I would prefer to be contacted by (please circle): phone email don't mind

Any other details (e.g. times that are preferable for us to phone you):

Appendix 4-D: Social Media (Facebook) Message

V1

Hello,

My name is Jessica Moore and I am a trainee clinical psychologist at Lancaster University. I am really interested in finding out about the experiences of having ET and I am carrying out a research study to explore this topic. If you would like to participate in this study, please click on the link below which will take you to the participant information sheet where you can find out more, including how to contact me.

Many thanks,

Jessica Moore

{Insert link }

Appendix 4-E: Participant Information Sheet

V1

Post-diagnostic lived experiences of individuals with essential tremor

My name is Jessica Moore and I am conducting this research as part of a doctorate in clinical psychology at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this research study is to find out what it is like to have essential tremor (ET) and how ET affects people on a day to day basis. No previous research has focused in depth upon individuals' experiences of living with ET. It is important to establish what these experiences are, as these findings may help inform future support for those living with this condition.

Who is carrying out the study?

The study is being carried out by Jessica Moore, trainee clinical psychologist based at Lancaster University, as part of a doctorate in clinical psychology. The study will be supervised by Dr Jane Simpson and Dr Fiona Eccles. Dr Jane Simpson is Director of Education for the Division of Health Research at Lancaster University and Dr Fiona Eccles is a lecturer in research methods at Lancaster University.

Do I have to take part?

You do not have to take part in this study; participation is completely voluntary. Choosing not to take part will have no negative repercussions in relation to any treatment.

What will my participation involve?

If you do decide to participate, this will require about an hour of your time to take part in an interview with the researcher (Jessica Moore). The interview can be conducted face-to-face, via telephone or Skype. You can ask any questions before the interview starts and then you will be asked to complete a consent form prior to taking part in the interview. Interview questions will be open-ended and will be guided by your responses. All interviews will be recorded on a digital recorder.

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At the end of the interview, you will be given a debrief sheet which will outline who you should contact should you have any questions.

The interview data will be anonymised and any identifiable information will be changed or removed to maintain your anonymity.

Are there any risks anticipated from participating in the study?

There are no specific risks anticipated with participating in this study. However, due to the sensitive nature of the topic that this study is investigating, you are encouraged to inform the researcher (Jessica Moore) if you experience any distress following participation. In addition, you are also encouraged to utilise the resources provided at the end of this information sheet in the event of such distress.

Are there any benefits to taking part?

There are no direct benefits to taking part. However, it is hoped that you may find it validating to talk about your experiences of living with ET and therefore you may find it a positive experience to participate in this study. Furthermore, it is hoped that this research will emphasise how day-to-day life is experienced by individuals with ET and may inform future support.

Will my data be identifiable?

Data collected for this study will be stored securely and only the researcher and academic supervisors will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been examined
- Electronic files on the computer will be stored in a password protected Lancaster University approved location such as the virtual private network (VPN) or Box
- At the end of the study, interview transcripts and any coded data produced, consent forms, demographic questionnaires of questionnaires will be scanned and stored electronically for ten years on the Lancaster University network. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be stored separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to the supervisors of the research. If possible, I will tell you if I have to do this. In addition, participants

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interviewed via Skype should be aware that the internet cannot be guaranteed to be a completely secure means of communication.

What will happen to the results of the study?

Once all interviews have taken place, the researcher will transcribe each interview and analyse these before writing up the results for her doctoral thesis. A final summary report regarding this research study will be distributed to all participants once completed if they wish for this to happen. The researcher will also present the study findings to the groups from which participants have been recruited.

Furthermore, data from this project may be submitted for publication to journals and presented in conferences and to support groups.

Will I receive payment for taking part?

You will not receive any payment for your participation. However, the researcher plans to conduct interviews at a convenient site of your choosing, for example; a community venue or your home. For those participants travelling to a community venue for their interview, travel expenses will be reimbursed up to a maximum of £20.

Who has reviewed the study?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Can I withdraw from the study at a later date?

You can withdraw from the study up to 2 weeks after the date of your interview. You will not be asked for the reason for your withdrawal.

How do I express an interest in participating in this study?

You can inform the researcher of your interest in participating in this study either by email: j.moore1@lancaster.ac.uk, via telephone: (research phone number xxx) or by completing the consent to contact form if you received this information sheet with the information pack.

Where can I obtain further information about the study if I need it?

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If you have any questions about the study, or want to obtain further information, then you can contact the researcher, Jessica Moore, in the first instance. You can also contact her supervisors Dr Jane Simpson and Dr Fiona Eccles. Please see the contact details below.

Jessica Moore

Trainee Clinical Psychologist

Division of Health Research
Furness College

Lancaster University
Furness Building
Lancaster

LA1 4YG

Email: j.moore1@lancaster.ac.uk

Research telephone number:

Supervisors

Dr Jane Simpson

Director of Education

Division of Health Research
Lancaster University

Lancaster

LA1 4YG

Email: j.simpson2@lancaster.ac.uk

Telephone number: 01524 592858

Dr Fiona Eccles

Lecturer in Research Method

Division of Health Research
Lancaster University

Lancaster

LA1 4YG

Email: f.eccles@lancaster.ac.uk

Telephone number: 01524 592807

What if I want to make a complaint?

If you wish to comment on, or have a complaint about, any aspect of this research study then please contact:

Professor Bill Sellwood

Ethics

**Programme Director (Lancaster University Doctorate in Clinical Psychology)
Lancaster University**

**Furness Building
Lancaster**

LA1 4YG

Email: b.sellwood@lancaster.ac.uk

Tel: 01524 593998

However, if you wish to speak with somebody outside of the clinical psychology doctorate programme then you may also contact:

**Professor Roger Pickup Associate
Dean for Research Faculty of
Health and Medicine**
(Division of Biomedical and Life
Sciences)

Lancaster University

Lancaster

LA1 4YG

Email:

r.pickup@lancaster.ac.uk

Tel: 01524 593746

Ethics

Useful information in the event of distress

Although it is not anticipated that participation in this study will lead to distress, in the event of this happening the following resources/information may be of use:

- National Tremor Foundation (NTF): the NTF can offer help and support for individuals with ET; the NTF can be contacted via telephone on: 01708 386399. In addition, you can also visit the NTF website for further information and advice: <http://www.tremor.org.uk/>
- Northumberland, Tyne and Wear (NTW) NHS Foundation Trust: the NTW NHS website has a variety of self help guides that you may find helpful during difficult times. Examples of self-help guides available include; panic, anxiety, health anxiety, depression and low mood, stress (toname but a few). The website from which to access these self help guides is: <https://www.ntw.nhs.uk/pic/selfhelp/>
- Samaritans: You can telephone the free Samaritans helpline on 116 123 to discuss anything that may be troubling you. This helpline is available 24 hours a day, 365 days a year. You can also visit the Samaritan's website for further information: <http://www.samaritans.org/>
- GP: if you book an appointment with your GP to discuss how you are feeling, your GP will be able to suggest an appropriate, local, service (s) that you can access for support.

Thank you for taking the time to read this information sheet.

Jessica Moore

Trainee Clinical Psychologist

Lancaster University

Furness Building

Lancaster

LA1 4YG

Email: j.moore1@lancaster.ac.uk

Appendix 4-F: Consent Form

v1

Study Title: Post-diagnostic lived experiences of individuals with essential tremor

We are asking if you would like to take part in a research project which aims to explore what experiences individuals with a diagnosis of ET have on a day to day basis.

Before you consent to participating in the study we ask that you read the participant information sheet and put a tick in each box below if you agree. If you have any questions or queries before signing the consent form please speak to the researcher [Jessica Moore]

Please tick each
statement

- | | |
|--|--------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the recording has been transferred to a university approved location | <input type="checkbox"/> |
| 5. I understand that my participation is voluntary and that I am free to withdraw up until two weeks following the date of my interview, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 6. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. | <input type="checkbox"/> |
| 7. I consent to information and quotations from my interview being used in reports, conferences and training events. | <input type="checkbox"/> |
| 8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share this information with her research supervisors. | <input type="checkbox"/> |
| 9. I understand that my data will be shared and discussed with the supervisors of this research (Dr Jane Simpson and Dr Fiona Eccles). | <input type="checkbox"/> |
| 10. I consent to Lancaster University keeping written transcriptions of the interview, coded data, consent forms and demographic information for 10 years after the study has finished. | <input type="checkbox"/> |
| 11. I consent to take part in the above study. | <input type="checkbox"/> |

Ethics

Name of Participant _____ **Signature** _____
Date _____

Name of Researcher _____ **Signature** _____
Date _____

Appendix 4-G: Participant Debrief Sheet

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Thank you for taking the time to participate in this research study.

If, following your interview, you feel anxious, distressed or worried about something you have discussed and you would like to seek support and advice regarding this, then please speak with the researcher (Jessica Moore) and you will be supported with this. In addition, please also refer to the resources listed on the participant information sheet for details of where you can access support and advice.

If you decide after the interview that you do not wish for your data to be used in this research, you have the right to request for your data to be removed from the study and permanently deleted up to 2 weeks following the date of your interview. Please contact Jessica Moore via email on j.moore1@lancaster.ac.uk or telephone (research number: XXX) if you wish to do this. You will not be asked for a reason for your withdrawal.

A final summary report regarding this research study will be distributed to those participants who have opted in to receive this. You are welcome to share this report with whomever you wish. The researcher will also present the study findings to any ET groups from which participants were recruited.

If you have any questions or concerns regarding any aspect of this research study please feel free to contact the researcher, Jessica Moore, on the above email address.

Please keep a copy of this debrief sheet for your future reference.

Once again, thank you for your participation.

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