# Post-diagnostic lived experiences of individuals with essential tremor

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## Abstract

Purpose: This research study aimed to explore the lived experience of individuals with essential tremor.

Method: This study was qualitative in nature and informed by interpretative phenomenological analysis methodology. Semi-structured interviews were conducted with a relatively homogenous sample of nine individuals with a diagnosis of essential tremor.

Results: Three major themes were constructed: “But they often look at you like you’re some drug addict or smackhead”: Social attitudes to difference; “I just couldn’t do it anymore”: The restrictive nature of essential tremor; 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 the coping strategies employed. 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 essential tremor.

*Keywords:* essential tremor, experiences, IPA

## Introduction

Essential tremor, one of the most common neurological conditions  [1], is characterised by recurring oscillations of a body part involving one or more joints [2]. It is both chronic and progressive [3] and affects approximately 1% of the general population and 5% of the population over 65 years of age [1]. Essential tremor 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 [2]. The tremor usually involves upper limbs, although it can affect the head, chin, voice, tongue and other body parts [4].

The aetiology of essential tremor remains unclear [4] although the frequency of family history of tremor in individuals with essential tremor is high at approximately 50-60% [4]. Furthermore, previous research has reported distinctions between ‘hereditary’ essential tremor and non-familial essential tremor [4]. For non-familial forms of essential tremor, suggested environmental factors include exposure to pesticides and frosted glass and agricultural work [5].

The diagnosis of essential tremor is complicated by a lack of understanding regarding the relationship (if any) of the condition with other neurological conditions which also involve tremor, particularly Parkinson’s disease [6]; this results in some individuals being given an incorrect diagnosis. It has been suggested that while essential tremor and Parkinson’s disease are distinct entities, evidence of a clinical overlap in the features of the two conditions does exist [7]. This overlap may explain why approximately 30-50% of individuals with essential tremor are commonly misdiagnosed with Parkinson’s disease [8]. Medication is commonly used as a treatment for essential tremor, although not everyone experiences benefit [9]. For individuals who are intolerant of, or resistant to, medication, neurosurgery may be considered [9] including deep brain stimulation.

Essential tremor was once previously viewed as a solely motor disorder but psychological difficulties are increasingly being recognized [10]. Furthermore, quality of life is also found to be impaired for individuals with a diagnosis of essential tremor [11]. In common with other neurological conditions such as Parkinson's disease [12] the main predictors of quality of life are psychological and psychosocial factors, such as emotional well-being and social withdrawal, rather than illness severity [11]. It has also been found that ability to perform at work, and during leisure activity, impacts upon levels of depression for individuals with essential tremor [13]. As a result of the overlap in essential tremor and Parkinson's disease, previous research has not only explored the relationship between the two conditions [14] but has also compared quality of life [15]. In particular this comparison identified that individuals with essential tremor experienced more impairment in relation to writing, eating, drinking, embarrassment, and concentration [15] in comparison to individuals with Parkinson's disease. In addition, individuals with essential tremor 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 Parkinson's disease, 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 essential tremor [15].

Individuals with essential tremor tend to experience more psychological difficulties, including depression, anxiety, sleep disturbances, pain and fatigue, compared to 'healthy' controls with no diagnosis, or family history, of the condition [13]. Depression has been argued to be an intrinsic part of the essential tremor disease process [16]. Alternatively, Chandran et al. [13] suggested that the experience of depression and anxiety in individuals with essential tremor 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 the condition and subsequent social withdrawal and low self-esteem and (iv) side effects of the medications prescribed for treatment. However, while quantitative studies have highlighted the importance of 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 essential tremor. Consequently, this qualitative study about the post-diagnostic experiences of living with essential tremor will provide the first exploration of how day-to-day life is experienced and individually constructed. 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 essential tremor and this would allow 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 [17] due to the fact that IPA emphasises the subjective sense-making of an illness. Consequently, IPA helps facilitate as close an understanding of an experience as possible as it allows us to access an individual’s cognitive world [17]. Furthermore, Thompson, Kent and Smith [18] proposed that studies employing IPA methodology to explore process, rather than the end goal of adjustment, might usefully supplement quantitative studies within health psychology. Consequently, using an IPA methodology, this study set out to answer the research question: what is the lived experience of individuals with essential tremor?

## Method

### *Participants*

Participants were recruited from an essential tremor group in the North West of England. This support group was advertised on the United Kingdom (UK) National Tremor Foundation website. Potential participants were invited to take part in the present study if they were aged 18 or more and had a diagnosis of essential tremor for at least 12 months. Participants also had to speak English. Those who had tremor from other conditions, e.g. Parkinson's disease, were excluded. On the three occasions that the researcher attended the essential tremor group there were approximately 11 group members present each time. Nine individuals (six men and three women) chose to participate. Samples in IPA studies tend to be between 8-12; this is due to the idiographic focus, which would be reduced with larger number of participants [19]. Two participants identified as being White British, six participants as White English and one of Asian ethnicity. The ages of participants ranged from 38 to 77, with a median age of 68. Participants had lived with essential tremor from 2 to 30 years, with a median time since diagnosis of 12.5 years. All participants were of adult age when they received their diagnosis of essential tremor, although many alluded to how symptoms had been present since childhood. Of the nine participants, one was in full time employment and one was attending university. The other participants had retired - two as a direct result of the impact of essential tremor.

### ***Procedure and data collection***

The present study was reviewed and approved by the authors' university ethics committee. The UK National Tremor Foundation confirmed that no permission was needed to attend the essential tremor group. Formal written consent was gained prior to commencement of the interviews once participants had read through the participant information sheet. This was given to participants in advance of interviews, and handed out by the researcher when attending the support group. This information sheet contained important material such as why the research was being carried out, what participation involved, possible benefits and risks of taking part and what would happen to the data. In addition, participants were also shown a copy of the interview schedule on the day of the interview itself, so that they were aware of the types of questions that would be asked.

Data for this study were collected through individual 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 [11, 13, 20] and received input from an expert by experience external to the study. The expert by experience was an individual who, as well as living with essential tremor, was an active campaigner and well-known member of the essential tremor community, who ran a support group in another part of the country. The National Tremor Foundation provided the contact details for this individual. The interview schedule was used to guide the discussions; discussions also evolved from participants' responses and subjects of interest to participants [19]. Interview data were analysed using IPA. All interviews were transcribed by the first author, with notes of expressions also included. For example, expressions of laughter or pauses were incorporated within the written transcript to give more context. The analysis followed guidelines provided by Smith et al. [19] 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 and developed into emerging themes; moving to the next case and repeating the process; and finally looking for patterns across cases [19]. Although there are varying approaches to the concept of data saturation, the above six step process enabled the researcher to code each participant transcript, separately, until coding was complete (or saturated). The researcher was then able to compare themes across participants and then combine themes to represent the whole group (while at the same time staying true to each participant's experience). This process resulted in a final list of superordinate themes that accounted for every participant’s data themes; see table 1 for theme construction overview.

[Table 1 around here please]

In order to ensure the anonymity of participants, pseudonyms were used throughout the reporting of this study and every attempt was made to ensure that no identifiable quotes were included.

## Findings

To protect anonymity of participants, the exact age and years since diagnosis of each person is not stated. However after each quote, an indication is given as to whether the participant is above or below the median age, as well as whether they are above or below the median length of time since diagnosis.

The data analysis identified three main themes.

### *“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 how others were appraising their condition.

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 (below median age, above median time since diagnosis) noted having experienced comments 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 the nature of his tremor:

“But they often look at you like you’re some drug addict or smackhead [drug addict]

> sort of thing…because…or an alchie [alcoholic] …and then you end up going “no, it’s not that, it’s 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, below median age, above median time since diagnosis).

It is striking that Mike wishes to create a distance from individuals derided as a ‘smackhead’ or ‘alchie’. His emphasis on the physical avoids him being given (or accepting) a label which represents a moral (as opposed to physical) judgement on his character.

The fear of social embarrassment also prevented Sandra (above median age, below median time since diagnosis) from eating in public with friends. Sandra was fearful that she would not be able to adhere to social norms while using a knife and fork, as she was concerned about dropping food and others seeing this. Sandra indicated that embarrassment for her in this instance was associated with 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; however, this resulted in her feeling isolated.

The fear of how they might be perceived by others led to social anxiety for many participants with the prospect of social occasions evoking dread. In addition, the unpredictable manifestation of essential tremor exacerbated participants’ experience of anxiety. David (above median age, below median time since diagnosis) spoke of the anxiety experienced when he had to carry a drink in public, describing this as ‘a very subtle panic situation’, given that he was never sure whether it would spill. This pervasive sense of anxiety was also discussed by John:

> “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 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, below median age, above median time since diagnosis).

This quote demonstrates the isolation that can be caused by essential tremor since, due to the unpredictability of how essential tremor might manifest in public, John ultimately declined to attend social events. This also caused him some interpersonal difficulties as people were 'offended' when he did not attend an event.

Tremors also restricted occupational achievement. Alison (below median age, below median time since diagnosis) spoke of experiencing anxiety concerning her tremor being exposed, 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. There was also a sense from Alison's account that essential tremor 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 essential tremor might manifest in the future, Alison spoke poignantly about this; there was a history of the condition in her family, and she felt that her daughter was showing early signs of it. As a result, Alison had concerns for not only her own future with essential tremor, but that of her daughter's 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… and the next minute she says a doctor and I think some of those things may be restricted for her that…if hers [the tremor] 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, below median age, below median time since diagnosis).

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 essential tremor throughout the lifespan.

### ***"I just couldn't do it anymore": The restrictive nature of essential tremor***

This theme captures the experience of restrictions that essential tremor 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 essential tremor. For example, eating healthily was challenging:

> "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, below median age, above median time since diagnosis).

This suggests that physical difficulties can determine often unhealthy food choices.

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 essential tremor impacted 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, above median age, below median time since diagnosis).

This quote highlights how George's previous experience was now rendered useless in the face of this condition. George found this a little frustrating but, on the whole, appeared resigned to essential tremor affecting his skills in this way. Other participants also reflected on the length of time it took to carry out everyday activities, for example taking 20 minutes to button a shirt up (Kevin, at median age, above median time since diagnosis) and taking an hour to thread cotton through a needle (Karen, at median age, above median time since diagnosis).

In addition, Stephen spoke of his frustration that he now had to pay other people to do the domestic repair tasks he once managed, such as servicing his vehicles and fixing his roof. He felt that these contracted individuals did 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, below median age, at median time since diagnosis).

There was a clear sense of loss of self and role emanating from Stephen's account of how essential tremor prevented 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'.

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 adage 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 respond.

Kevin (at median age, above median time since diagnosis) 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 whole body as being fundamentally altered.

Of interest, Kevin described how he experienced a 10 minute reprieve from essential tremor as soon as he awoke: ‘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’.

Employment was also noted to be hugely affected by essential tremor for some participants. Karen (at median age, above median time since diagnosis) spoke of how tasks inherent to her role became impossible, such as reading out updates at hand-over meetings (due to voice tremor) and writing up notes: ‘I was writing like a baby in the end’. Again this phrase is resonant of individuals feeling they have regressed to a helpless period of their lives.

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 essential tremor: ‘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 professional 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 as she described how this “mortified” her and left her feeling “really really down”.

John (below median age, above median time since diagnosis) also acknowledged the impact of essential tremor 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 realized; ‘I just couldn’t do it anymore’. Similarly, Mike (below median age, above median time since diagnosis) also found himself in the stressful situation of having to stop working due to the impact of his tremor.

Of importance, John (below median age, above median time since diagnosis) acknowledged a positive to having essential tremor both within the work environment and at home, noting he felt ‘more ingenious’. John described how, because of his tremor: ‘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 essential tremor. Many spoke of how they had learned to adapt and find alternate ways of managing life with their condition.

The necessity of this requirement to adapt was highlighted by Kevin (at median age, above median time since diagnosis) who commented: ‘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’.

Many participants spoke of the strategies they employed to help them retain some normality within their experience of essential tremor for instance, using plastic plates and mugs at home to minimise breakages, making milky drinks in mugs with a lid, using two hands to lift up a cup and drink and using a straw when drinking. Indeed, despite the use of a straw, George (above median age, below median time since diagnosis) 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.

Practical help from family was also acknowledged by George and Stephen. For example, George noted that his wife would often cut up his food for him to make eating more manageable and would 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 (at median age, above median time since diagnosis) noted that he would 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 knew them and their tremor, or go to the same holiday destination where staff were familiar with essential tremor.

Kevin (at median age, above median time since diagnosis) described how, because employees know him in one particular food chain, they would cut his toast into ‘soldiers’ [long strips] for him; this was something that Kevin was appreciative of as there was a sense of 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 essential tremor and live a normal life. However, only Karen (at median age, above median time since diagnosis) and Sandra (above median age, below median time since diagnosis) reported still taking medication. Some participants spoke of preferring not to take medication and indeed there was an element of choice involved with this. This finding fits with that of Thanvi and Robinson (2006) who noted that medication is commonly used as a treatment for essential tremor, although not everyone experiences benefit [9]. Many participants in this sample had used medication previously but chose to stop due to little improvement in tremor severity. In addition, 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 essential tremor was deep brain stimulation. Specifically, Kevin (at median age, above median time since diagnosis) spoke passionately of how this treatment has enhanced his quality of life as he could do much more afterwards, describing it as giving him a 'new lease of life'.

There was a real sense from participants that they all wanted to 'get on' with a normal life and be able to complete everyday 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, below median age, at median time since diagnosis).

This was subsequently the philosophy by which Stephen appeared to live his life and there was a sense of pride from him that he would always 'have a crack' at an activity, which allowed him to retain an element of his 'strong work ethic' identity. A determination to at least try an activity/job 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 managing the psychological impact of essential tremor, including: talking to family (Alison, below median age, below median time since diagnosis), attempting to stay in the present moment rather than worry about the future (Sandra, above median age, below median time since diagnosis), keeping active (David, above median age, below median time since diagnosis), giving self some time away from tasks to avoid frustration (Mike, below median age, above median time since diagnosis; Karen, at median age, above median time since diagnosis; George, above median age, below median time since diagnosis), and the essential tremor support group itself was mentioned as helpful in allowing people with similar experiences to meet (Stephen, below median age, at median time since diagnosis; Sandra, above median age, below median time since diagnosis; Karen, at median age, above median time since diagnosis).

Finally, George (above median age, below median time since diagnosis) emphasised that, for him, the key to managing essential tremor 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 (below median age, above median time since diagnosis) 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 were other people who were ‘worse off’ was motivational for George and John, allowing them to remain positive in the face of a condition which they felt, ultimately, could have been more severe.

## Discussion

This study has helped illustrate the day-to-day experiences of living with essential tremor. 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 essential tremor, were also explored.

Quality of life is reported often to be impaired for individuals with essential tremor [11]. 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. 21, 22]. These emotions themselves support Jhunjhunwala and Pal's [10] proposition that such psychological difficulties are an accompanying feature of essential tremor and this study allows some understanding of how and why these emotions and mood states occur.

As Bishop (2005) has previously identified,  the impact of the tremor on the individual's valued aspects of life and identity was of importance [23]. Similarly, previous research has shown that psychological wellbeing of those with multiple sclerosis was most affected, and a sense of self fundamentally challenged, when valued aspects of self or life were lost, or interfered with, due to this condition [24]. Such illness intrusiveness [25] is known to compromise psychological wellbeing and quality of life, 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 [25].

Furthermore, Bishop proposed that psychological wellbeing and quality of life were more likely to be negatively affected if a chronic illness impacted 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 [23].

With regards to the experience of embarrassment, some participants experienced embarrassment due to being unable to conform to social norms, while others experienced embarrassment due to being stigmatised as belonging to a group who were considered to be personally responsible for their difficulties, such as Mike's experience of others assuming he had been drinking alcohol or taking drugs. Devins [26] 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 [27]. Consequently, when people feel ashamed, embarrassed, socially anxious or proud, they are assessing themselves from the perspectives of real or imagined other people [28]. 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.

Furthermore, feeling unable to live up to ideal self-representations has been identified as resulting in shame and guilt [29]. 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 [30] 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 characteristics that others might find inadequate or unattractive [30]. For the participants in this study, there was an awareness that they could not change the way in which essential tremor 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 [31].

Furthermore, it is possible that some participants had internalized this shame [30] as there was a real sense that some individuals felt inferior to others in society. Louis and Rios [22] 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 essential tremor 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 [32]. Reeve [33] 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 [33, 34].

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 helped 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 Parkinson's disease [35].

Bury [36] 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; [28]). 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 essential tremor. One finding emerging from Bury's [36] research, which was also identified within the present study, was the importance of familiarity in maintaining normality. Similarly, participants in the present study spoke of how they would go to the same food chains (Kevin) and holiday destinations (Stephen), where staff both accepted and helped in the management of essential tremor. This was another way in which participants were able to rescue some normality by accepting the support of others and being accepted themselves.

However this does run the risk of social worlds becoming smaller as preference for familiarity means individuals may restrict themselves from trying new experiences, This could result in frustration for those individuals who do wish to widen their social worlds but do not feel safe, or confident, in doing so.

However, for some aspects of life, participants were unable to maintain their previous normality but instead adopted 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 adapt to a reconstructed new ‘normal’/new way of living with essential tremor. Similarly those living with inflammatory bowel disease have also discussed how adjustments made to their life, such as the need to keep close proximity to a toilet, had become the new normal for them [37]. Of relevance, Sanderson et al. [38] 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.

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  [38]. However, in contrast to Sanderson et al. [38] 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 essential tremor 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 states that the diagnosing health professional should provide information, advice and support at diagnosis for neurological conditions arguably similar to essential tremor including multiple sclerosis [39]. This guidance seems almost more pertinent in the area of essential tremor due to the lack of awareness of this condition as highlighted by participants themselves. If advice was provided at diagnosis, individuals would be equipped with knowledge from the start with regards to support, symptoms and treatment and therefore could link in with support sooner. This could help avoid some of the difficulties in mood experienced by individuals, and potentially act as a buffer with regards to managing the impact of essential tremor.

In addition, participants experienced a range of emotions due to the individual impact of the condition on their lives. One specific therapy that could potentially be of benefit to individuals who are experiencing difficult emotions in the context of essential tremor is Acceptance and Commitment Therapy. The aim of this therapy is to “help us create a rich, full and meaningful life, while accepting the pain that life inevitably brings”[40,p.2] by using mindfulness skills and “taking action that enriches our lives” [40]. While no research has been conducted into the use of this therapy with essential tremor, Pakenham and Fleming [41] have noted its relevance for people with multiple sclerosis; greater acceptance (as defined in Acceptance and Commitment Therapy) was found to be related to better adjustment.

In addition, lack of public awareness of essential tremor contributed to the stigma they experienced. This identifies a clear need for more public awareness campaigns that are centred around the condition of essential tremor, particularly given that it is one of the most common neurological conditions [1]. 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 essential tremor. Raising the profile of this common neurological disorder among the general public might also help reduce some of the stigma experienced with regards to people making assumptions concerning alcohol and/or drugs, which can result in psycho-emotional disablism [34].

## Limitations and future research

One limitation of the current research is that, as in the requirements for IPA, participants were selected from a homogenous group, with tremor severity ranging from mild-moderate (as rated by participants themselves). One participant (Kevin) had a more severe tremor but had undergone deep brain stimulation which brought the tremor back into the moderate range. Consequently, the current research has not captured the experience of individuals with essential tremor who are severely affected. Future research with individuals with severe essential tremor could help shed light on whether there are any additional concerns for those affected. Furthermore, future qualitative research focusing upon the impact of deep brain stimulation on psychological wellbeing for individuals with essential tremor could add to the quantitative literature [e.g. 42, 43] and also help 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 were proactive in managing their experience of essential tremor, 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 identify whether these individuals have any additional/different difficulties in relation to their experience of living with essential tremor.

## Conclusion

This research study has investigated the lived experience of individuals diagnosed with essential tremor. It has helped identify some of the difficult day-to-day experiences of individuals and the resulting emotional responses. This study has also illustrated the ways in which essential tremor 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 essential tremor. In addition, more public awareness campaigns centred around essential tremor 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 essential tremor and/or those with poor self-management skills.

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## Declaration of interest

The authors declare that there is no conflict of interest.

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## Table 1

Table 1: 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 essential tremor, lack of control over others' judgements, negative judgements made by others, the negative experience of essential tremor, anxiety in social situations, fear of evaluation | Specific emotions experienced in response to unpredictability of essential tremor | Social attitudes to difference | Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, David |
| Loss of control across life domains, difficulties intrinsic to essential tremor, losing control over one's life, lack of | Essential tremor limits many aspects of the participants' lives | The restrictive nature of essential tremor | Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, |

| | | | |
|---|---|---|---|
| control over impact of essential tremor, missed life experiences, difficulties at work, loss of career | | | David |
| Making the most out of life, making experience of essential tremor more manageable, being informed about what works for essential tremor, having the strength to cope, strategies for coping with essential tremor, preservation of positives, learning to adapt in social situations, ways of preserving a normal life | Knowing what helps experience of essential tremor feel more manageable | Rescuing some normality amid physical deterioration | Alison, Sandra, Mike, Kevin, Stephen, George, Karen, John, David |