

“THEY DON’T CARE HOW MUCH THEY HURT YOU TO SAVE YOU”: THE LIVED EXPERIENCE OF MANAGING CHRONIC DISEASE AND NEEDLE PHOBIA

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ABSTRACT

Several chronic diseases, such as diabetes, rely on needles for treatment and monitoring purposes. However, individuals with needle phobia are more likely to experience difficulties complying with interventions, resulting in adverse health outcomes. There has been limited research into the effects of needle phobia in chronic disease, particularly for adults. As chronic disease becomes increasingly common and COVID-19 vaccinations are required regularly, the issue of needle phobia urgently requires greater attention. This research aims to explore the lived experience of adults who are regularly exposed to needles due to chronic disease. A qualitative approach was selected to allow a deeper look into this population's daily experience. Eight adults with various health conditions were recruited using Facebook community groups. Online semi-structured interviews were conducted, and thematic analysis was used as an analytical approach for the data. Thematic analysis identified: 1) the power imbalance between patients and healthcare professionals, 2) regaining power as a patient, 3) the desire to be understood, and 4) the tension between rationality and phobia. Results highlight the need for reciprocal relationships between clinician and patient and greater education on the distinction between dislike and phobia. Results also support the conception of pain as a complex process that can be highly emotional. Future research is needed to explore how the desire for control contributes to the experience of managing disease and phobia, as this is a unique finding of the study. Results have implications for healthcare professionals, psychologists, and public health measures.

INTRODUCTION

Needle phobia has become a current and topical issue due to the vital role it has in public health, particularly concerning the vaccination uptake for COVID-19. Freeman et al. (2021) estimate that 10% of nonvaccinated individuals in the UK result from needle phobia. This has consequences for wider society, affecting the ability of countries to achieve “herd immunity”, and personal impacts such as the risk of serious illness from COVID-19 (Ashworth et al., 2021). Furthermore, avoiding needle-related procedures means individuals forego necessary and sometimes life-saving medical procedures such as cancer treatment (Jenkins, 2014).

Trypanophobia, or needle phobia, as it is more commonly known, is a recognised anxiety disorder marked by an extreme fear of needles (ICD-11, 2022). Needle phobia is a clinically impacting disorder with wide-ranging implications and is distinct from a normative behavioural dislike that most individuals express (Abado et al., 2021). Needle phobia affects approximately 3.5% to 10% of adults and up to 60% of children (Anxiety UK, 2010).

The relationship between those with chronic illness and the associated risk of experiencing needle phobia is complex and has attracted limited research attention (Duncanson et al., 2021). Chronic illness is defined as an incurable physical or mental health condition that has lasted longer than one year, such as diabetes, schizophrenia, and kidney disease (CDC, 2021).

Advances in medicine and science since the mid-20th century has meant chronic illness is more prevalent than ever, according to Holman (2020). The World Health Organisation (2017) stated that 71% of deaths worldwide could be attributed to chronic diseases. Risk factors for chronic disease are similar to needle phobia and can include adverse childhood experiences, age, and family history (Cockerham et al., 2017).

Several treatment regimens for chronic disease involve drugs being administered via injection, or monitoring must be done via intravenous blood work. For example, one method of managing diabetes is through insulin injections that are not suited to oral delivery. This is due to the medication being destroyed by stomach acids (Shah et al., 2016). Additionally, diseases such as arthritis and inflammatory bowel disease can require regular injections to control the disease (Schiff et al., 2017). For example, some types of arthritis can be treated with steroid injections, or patients may be required to self-inject biologic drugs (Rein and Mueller, 2017). Self-injectable drugs are viewed favourably due to the independence they offer patients, decreasing the need for frequent hospital visits (van den Bemt et al., 2019).

However, needle phobia presents a challenge in adhering to this type of treatment, as highlighted by McMurty et al. (2016), who argues that individuals with a needle phobia are at a heightened risk of experiencing difficulties in the management of their condition. This ranges from lower compliance to self-management and poor physical and mental health outcomes than those with no needle phobia. For example, a qualitative study by Abu Hassan et al. (2013) used questionnaires and semi-structured interviews to explore the facilitators and barriers to beginning insulin treatment. Thematic analysis revealed reasons for non-compliance with treatment such as needle phobia, pain with injections and fear of self-injections. This study demonstrates the multitude of factors influencing treatment adherence, notably highlighting that participants who used insulin for three years still struggled with injection. Additionally, work by Sharma et al. (2020) found that 35% of participants delayed treatment for diabetes due to needle phobia, despite adverse health consequences.

Rationale for the study

A literature review by Duncanson et al. (2021) illustrates that there is limited information on adults who experience both needle phobia and chronic illness, as most research focuses on paediatric patients. Most research has been quantitative, examining if needle phobia exists and is a problem for treatment, not exploring cause or the experience of needle phobias. In addition, adults are most likely to experience a chronic condition, further compounding the issue and exacerbating the need for research into this population. Furthermore, most of the existing literature on needle phobia has been centred on one-off experiences such as vaccines, at the expense of research for individuals exposed to needles regularly due to chronic disease. This study sought to address this gap in the literature and spotlight the experiences of an adult population for whom needles are a regular part of treatment.

Furthermore, it is important to understand the effects of needle phobia on treatment for chronic disease due to the harmful effects non-compliance can have on health, life expectancy and general well-being. Additionally, having a deeper insight into the experience of individuals dealing with chronic disease and needle phobia can be helpful in providing a framework for patients to express wishes that can be used to inform healthcare practices (Guha et al., 2021).

This research explores the lived experience of individuals with a chronic health condition and how this is affected by a needle phobia, aiming to unpack the origins of needle phobia, coping mechanisms and how these influence treatment for chronic disease.

METHODOLOGY

Study design & Recruitment

A qualitative design was used in order to explore the thoughts, feelings and hopes held by individuals with needle phobia. Participants were recruited using an advertisement on Facebook community groups that provided needle phobia support. Advertisements were posted in November and December 2021. Facebook was chosen due to the low cost and time friendly method of recruitment that is suited to research concerning uncommon diseases (Thornton et al., 2016).

Participants

Eight (N = 8) participants took part in the study, aged between 21-68 years old (M = 43). Most participants identified as female (N = 7) and one as non-binary (N = 1). Half of the participants were from the United Kingdom (N = 4) and half from the United States (N = 4). All participants were currently experiencing needle phobia, and seven were presently experiencing chronic disease, with one speaking from experience. Participants were asked to confirm their chronic health condition and needle phobia, and a time frame of more than one year was considered for selection. For inclusivity purposes, self-report was used for both conditions so as not to exclude any participant who did not have the means for a formal diagnosis. Furthermore, due to the nature of needle phobia, some participants were undiagnosed due to not being able to have the blood test which would confirm their condition.

Procedure

Semi-structured interviews were conducted to understand the phenomenological experience of chronic illness and needle phobia. Interviews were used to allow for comprehensive discussion of possibly sensitive and personal issues (Manera et al., 2018). Furthermore, they enabled spontaneous issues to be discussed and close contact with the participant, which was suited to a research project that sought to understand an individual's holistic experience.

Table 1: Descriptive information of participants

Participant demographics	N
Gender	
Female	7
Non-binary	1
Residence	
United Kingdom	4
United States	4
Status of needle phobia	
Present	8
Past	0
Status of health condition	
Present	7
Past	1
Type of health condition	
Arthritis	2
Graves' disease	2
Chronic pain	1
Chronic mental illness	1
Gestational diabetes	1

The interviews took place between 15th December 2021 and 24th January 2022 and were conducted online on Zoom and Microsoft Teams due to the COVID-19 pandemic. The interviews lasted between 45 minutes to 1 hour.

Ethics

Ethical approval was granted by the Ethics Committee at the University of Glasgow. An ethical concern that I noted and addressed in this study was that the population was a vulnerable group, dealing with chronic health conditions. To minimise harm, I included contact information for chronic health and needle phobia organisations on the participant information sheet for support after the interview. Additionally, participants were encouraged to bring another individual with them for support. Ethical concerns about internet use and video conferencing were also considered. Although this method was physically accessible for a population with potential mobility issues, virtual accessibility was a possible barrier pertaining to technical ability and access. To counter this, participants were offered a range of options such as telephone calls or their preferred video conferencing platform.

Data Analysis

Transcripts were edited using the verbatim transcription method to correct mistakes and reflect the spoken interview. This was used as it is most suited to gaining an account of what was said and how it was said, picking up on emotions and capturing the interaction between interviewer and participant (Azevedo et al., 2017).

To uncover the experiential account of managing needle phobia and chronic illness, Thematic analysis (Braun and Clarke, 2006) was used. Thematic analysis affords a flexible and robust process to uncover recurring meanings within qualitative data and was chosen for this reason (Kiger and Vapio, 2020). Analysis followed the six-step process outlined by Braun and Clarke (2006) where initial codes were identified in the transcripts and used to generate themes that were indicative of

the dataset. This was conducted on the software Nvivo as it offered increased transparency and a coherent synthesis of the data (Houghton et al., 2016).

RESULTS AND ANALYSIS

Thematic analysis identified four themes which categorise the experience of living with needle phobia and chronic illness: 1) the power imbalance between patients and healthcare professionals, 2) regaining power as a patient, 3) the desire to be understood and 4) the tension between rationality and phobia.

Theme 1: The power imbalance between patients and healthcare professionals

This theme captured how participants felt about attending appointments for their chronic disease and encountering needles. They reported feeling that they lacked agency when negotiating situations with clinicians concerning injections. The natural power structure between doctor and patient was amplified regarding needle phobia and can be divided into two subthemes: lack of control and childhood experiences.

Sub-theme 1.1. Lack of control

The power imbalance resulted in individuals lacking control in aspects concerning chronic health and needle phobia. This influenced their thoughts, feelings and how likely they were to comply with treatment. When asked about their future hopes and anxieties managing needle phobia and chronic health conditions, Olivia, who described having a needle phobia 'forever', replied with:

'There is always the thought of tomorrow or later today I could be rushed to an emergency room, and they don't give a damn what you're feeling. They want to get you better you know, whatever they have to do.'

Olivia shared her anxiety about possible scenarios where her health condition would require urgent admission to the hospital. The word choice of 'rushed' indicates the lack of control over the situation, possibly alluding to the fact that there would not be time to implement her coping strategies. This thought is 'always' on her mind, further underscoring how much this troubles her. She also alluded to the inherent tension between doctors who want to help and how this is made difficult by patients who refuse treatment.

The lack of control that participants experience is also illustrated by Maxine, who has dealt with Graves' disease for 4 years. She explains her thought process before a hospital appointment:

'I start playing it over in my head ... particularly if it's somewhere new... I'm like what's it going to be like? Are they going to believe me goes through my head. How am I going to deal with this?... Will there be a bed for me to lie down or are they going to make you sit in a chair? ... The key consideration I'm always thinking, who's the person who's going to do it and are they going to be sympathetic towards me?'

Maxine's spiral of thoughts indicated her anxiety at the lack of control and unknown element of the situation. Her lack of control was evident in her thoughts surrounding 'are they going to make you sit in a chair?'. This implies she anticipated being forced to obey instructions from a clinician, demonstrating a lack of autonomy on her part. This also suggests that accommodating individual preferences such as lying down would help the patient feel more in control of the situation, dialling down the level of anxiety they feel beforehand.

Sub-theme 1.2. Childhood experiences

A lack of control was also present when participants were asked if they could recall the origins of their phobia, and all of them discussed adverse childhood experiences. The power imbalance between healthcare professionals and children was apparent when participants detailed how they were forced to have injections.

Alice has had arthritis for three years and has struggled with needle phobia since childhood. She illustrated how her experience as a child led to the development of her phobia, stating:

'When I was about six or seven I actually fell off the doctor's wall and I had a big cut ... this was 50 years ago and all I remember is being... I called it an ironing board because that's what it seemed as a young girl and there's doctors and stuff leaning over me. My mum wasn't in the room at all. They were obviously trying to wrestle and fight with me down on the bed.'

In this extract, Alice described her mum's absence as contributing to her anxiety, especially when surrounded by unknown healthcare professionals which Maxine discussed in the subtheme lack of control. Her lack of agency is summarised in her comparison of the hospital bed to an 'ironing board', suggesting she is confined and restricted. Overall, the situation was out of her control, and a power imbalance is evident.

Theme 2: Regaining power as a patient

Participants detailed numerous ways in which they challenge the power disparity they were confronted with when exposed to needles as part of their chronic illness treatment. Two ways in which this was achieved was through: being proactive and choice.

Sub-theme 2.1. Being proactive

Being proactive captures the different methods employed before participants were exposed to the needle. When asked if she had any advice for individuals managing both chronic illness and a needle phobia, Jenny replied:

'I think, be honest with your healthcare provider... saying things like "oh, I'm not too good with needles", it's very different to "I require a huge level of support in order to receive an injection."'

Jenny had found a way to regain control by being upfront about her needle phobia. By being direct and proactive, she outlined her needs from the beginning and ultimately challenged the power dynamic. She was not ashamed but instead suggested that individuals share the extent of their phobia with their health care professional. This is a way for individuals to take back control, advocating for themselves and adopting an unapologetic stance when discussing their care with their doctors.

Sub-theme 2.2. Choice

Individuals also negotiated power structures using choice. For example, Taylor, who deals with chronic pain, discussed how she could get a tattoo whilst having a needle phobia. When asked what it is about needles that caused her distress, she replied:

'It's definitely not the pain ... I'm covered in tattoos and I've had piercings ... I do freak out with the piercings; that's why I've had quite a few because, in a way, I feel like it's helping me get over that.'

The fact that Taylor stated that her needle phobia is not about pain is illuminating. It could point to the presence of pain as a constant in the lives of individuals with some chronic illnesses,

suggesting they are used to pain and that it is not a factor in their phobia. She explained that choosing to get piercings and tattoos is a way to help her overcome her phobia, ultimately taking that power away from the needle. Having the choice of what needles to be exposed to also gives power back to Taylor, allowing her to make decisions about her body which can be challenging to achieve when living with a chronic disease.

Theme 3: The desire to be understood

As participants discussed their experiences navigating needle phobia and chronic illness, their desire to be understood by healthcare professionals and the people in their lives was evident. They mentioned times where they felt validation of their phobia and times where it had been disregarded.

Sub-theme 3.1. Disregard for feelings and phobia

Participants discussed experiences where their phobia has not been validated by clinicians and how they felt about being disregarded:

Maxine illustrates how she has been invalidated, stating:

‘You go to a medical professional and say “I’ve got a needle phobia” and they say “yeah, yeah you’ll be fine love” and it’s like “no, I really do have a needle phobia”. It’s like they don’t tend to take you at face value.’

Maxine had attempted to be honest about her phobia, but a lack of understanding on the part of the clinician left her feeling invalidated and dismissed. She explained that she said, ‘I really do’ suggesting that she was trying to prove her fear, possibly due to individuals loosely using the term ‘phobia’, resulting in its meaning being diminished. She also quoted the medical professional as saying, ‘yeah, yeah’ which is dismissive language suggesting she is not being taken seriously.

Jenny also spoke about her experience as a young girl when she attempted to get a blood test:

‘And this nurse was just kind of like “Oh for goodness’ sake, you know, we’re not going to be able to do it today are we?” And she said something along the lines of “well you can’t be that poorly you know, if you’re not willing to have the blood test.” It’s that kind of thing.’

The nurse was evidently frustrated by Jenny’s inability to go through with the blood test and not only invalidated her needle phobia but also invalidated her disease, stating, ‘you can’t be that poorly’. This suggests a lack of understanding on the nurse’s part that the patient’s feelings towards the needle were a barometer for how unwell they were.

Sub-theme 3.2. Validation

On the other hand, Olivia described her experience of being validated by doctors whom she called ‘earth angels’. When asked how she felt about the treatment she received from them, she stated:

‘Great! It empowers me. I just hope this doctor never leaves. I hope that she doesn’t get promoted ... and abandons me because I don’t know if another would do that for me. Same thing with my ENT doctor ... I hope to God he never retires ... Those doctors I can trust and they understand me.’

Olivia had found doctors who were willing to listen to her and go the extra step to sedate her for procedures that patients were commonly awake for. She spoke of trust and understanding, highlighting how important this is to her by her anxiety that these doctors will be promoted or retire. This validation is so important to her that she is worried about what would happen without them and spoke of ‘abandon’, suggesting that she

would take their leaving personally and feel entirely lost without them.

Jenny also highlighted how the desire to be understood was rooted in the participant’s need for validation by describing her ideal experience of a blood test:

‘If you’re a GP and ... a set of symptoms in front of you requires a blood test ... explain the treatment ... gain that consent ... When we’re dealing with other health concerns, the focus is on the physiological ... they forget that there’s other stuff going on for that person ... asking “how can I make this a more comfortable situation for you?” can be the difference between whether you get it done or not.’

Jenny outlined her desire for GPs to take the time to anticipate the needs of their patient and not assume that everyone is comfortable with a blood test. Asking the patient for their consent would challenge the power imbalance and place control back in their hands, allowing them to make decisions about their healthcare. Jenny also discussed the disproportionate attention that physiological health receives, especially in a chronic illness context, at the expense of mental health. She sought validation of the phobia equal to that she received for Graves’ disease, suggesting that one is not more important than the other. This understanding from a clinician would empower the patient to keep working on their phobia.

Theme 4: The tension between rationality and phobia

As participants discussed their needle phobia and chronic disease, there was a sense of rationality and awareness of the situation. They were aware that their phobia was irrational, they longed for different, and they knew the adverse effects it could have on their health.

Nicole explained how she was able to laugh at herself during a situation when she was struggling to complete her finger-prick blood test:

‘I was like hyperventilating ... I wouldn’t laugh at other people but to, like, see this adult person that has a rational brain yeah, and at least got a partially intact working frontal lobe ... there still is just this like hyperarousal around ... this tiny little thing and it, you know ... it’s this temporary pain ...’

Nicole was cognisant that the potential pain she would experience is momentary, and the needle itself is small; however, this knowledge did not make the situation any easier. She used phrases such as ‘frontal lobe’ and ‘hyperarousal’, suggesting she is familiar with the psychological mechanisms at work within a phobia. This did not translate into being able to cope, which she found ironic and somewhat entertaining. She also used the phrase ‘adult person’, again suggesting that as an adult, she expected herself to be able to deal with finger pricks and was frustrated by the fact she could not.

Additionally, Taylor described how her needle phobia had prevented her from getting potentially life-saving surgery, stating:

‘With the ovaries now like I’ve kind of had to come to terms with the fact that I could literally die ... the cyst is so large that it only takes like kind of one attack where it’s particularly tense, my entire ovary could twist and turn necrotic and that that’s how bad the phobia is, I’ve been told the facts, and I still can’t have the surgery.’

Taylor demonstrated that she was aware of the life-threatening consequences of her phobia, yet there was a tension between knowing this and being unable to act on it. The phobia was particularly counterintuitive in this case because it could result

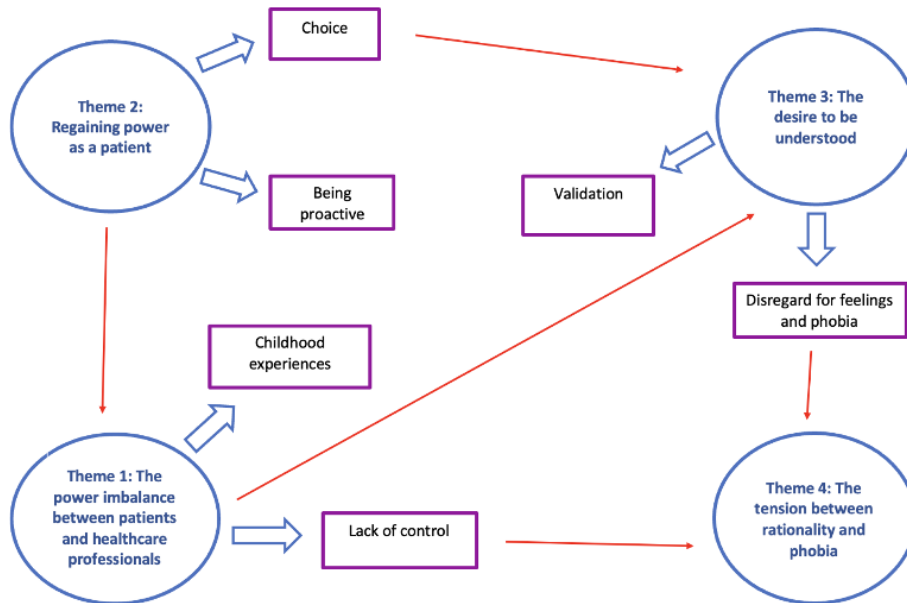


Figure 1: Mind map illustrating connections between themes.

in death. When dealing with a chronic illness, as Taylor is, experiencing fleeting pain from a needle would generally be preferable to end the chronic pain. Therefore, this is where the tension lies between rationality and needle phobia, particularly for those with chronic disease.

Whilst these themes are distinct, they do inform each other (see Figure 1). For example, theme 1, *the power imbalance between patients and healthcare professionals*, is connected to theme 3, *the desire to be understood*. In both themes, participants recounted experiences where they felt their clinicians had dismissed their phobia and left them feeling overlooked. The subtheme of *choice* in theme 2, *regaining power as a patient*, is also connected to theme 3, *the desire to be understood*. Participants described how they can choose get tattoos as a somewhat contradictory way of taking back control. This is illustrated in theme 1, *the power imbalance between patients and healthcare professionals*, which also informs theme 4, *the tension between rationality and phobia*. The lack of control that categorised the participants' reactions to needles was noted as irrational by the participants' themselves, further emphasising the difference between feelings and phobia (theme 3).

DISCUSSION

This qualitative project aimed to explore the lived experience of adults who are managing a chronic illness in the context of needle phobia. Subsidiary research questions involved: examining the origins of needle phobia and how this influences treatment, as well as exploring what coping mechanisms exist for individuals dealing with chronic disease and needle phobia, and their effectiveness. This was achieved using thematic analysis, which identified four main themes that encapsulate the experience of needle phobia and chronic illness: 1) the power imbalance between doctors and patients, 2) regaining power as a patient, 3) the desire to be understood and 4) the tension between rationality and phobia.

The Power imbalance between patients and healthcare professionals

The power imbalance between patients and doctors was implied as participants discussed their experiences, particularly from childhood, where they spoke of being physically restrained

which contributed to their fear. The impact of adverse childhood experiences on the development of needle phobia is supported in the literature, particularly by Noel et al. (2017), who state that painful encounters with needles, even as an infant with no conscious memory, can stay with children and influence how likely they are to manage injections in the future. The current findings support this as participants were able to recall experiences, in some cases from over fifty years ago, recounting the lack of consent given on their part and the physical and mental scars they were left with. It can be suggested that the lack of power they felt as children has manifested into a desire for control as a patient and informs their feelings toward injections as an adult.

The lack of power they held as children carried through to experiences as adults navigating chronic illness and needle phobia, where they grappled with a feeling of being out of control. This was reflected in the fear that participants had of being rushed to hospital. Work by Stern (2018) elaborates on the power imbalance, explaining that control lies with the clinician who considers themselves the authority on the organic and medical side of the disease. However, they argue that participants also have a valuable contribution concerning their lived experience of the disease, which should be valued. The desire for control participants felt as individuals with chronic illness in the context of needle phobia explicitly, is something unique which this study adds to the literature and has not been discussed to my knowledge.

Regaining power as a patient

Participants did find ways to regain power through several different coping mechanisms such as advocating for themselves and choosing which pain to subject themselves to. Participants spoke of how they were able to get tattoos yet unable to face injections as part of their chronic health regimen. Bolme et al. (2021) also observed this in participants with severe dental phobia who had been able to get tattoos and piercings. This dichotomy supports Gate Control Theory by Melzack and Wall (1965) which proposed that the spine contains a neural gate that either opens or closes, sending signals to the brain, influencing the perception of pain. This study highlights how the emotions surrounding pain and injection procedures are complex and multifactorial. This can be examined through the framework of

the biopsychosocial model of health which conceptualises health as biological, psychological, and social (Wade and Halligan, 2017). This study would argue even more so in the context of needle phobia, which is a psychological disorder impacting physical disease. Participants also discussed how they were more comfortable with pain due to their chronic illness rather than injection pain, which again supports the idea that this is a way to take back agency and is psychological.

Furthermore, participants felt that advocacy helped regain power by being proactive about their needs and wants. This is supported in the literature by Kristjansdottir et al. (2018), who used qualitative interviews to examine the personal strengths of individuals with chronic illness, concluding that tenacity was among the most positive qualities. However, this study only looked at strengths through the lens of chronic illness, and without the additional element of needle phobia, it is not wholly applicable to the current study. Nevertheless, participants in this study did find ways to regain agency, showcasing their resilience and efficacy despite the setbacks they faced.

The desire to be understood

The desire to be understood emerged as an important theme in the analysis, as participants discussed how they had been both validated and disregarded by clinicians. Having their feelings validated included understanding and accommodation from clinicians. Furthermore, participants longed for others to understand the differences between phobia and dislike, which is discussed in literature by Abado et al. (2021), who refer to needle phobia as the 'neglected one' as it is under-researched and misunderstood.

Participants' desire for understanding and validation is also reflected in literature by Schiff et al. (2017), who conducted individual and group interviews to uncover how individuals coped with self-injection. Although this was not in the context of needle phobia, themes such as patient empowerment, compassion and communication were discussed to optimise self-injection for patients with chronic illness. In addition, Nafradi et al. (2018) conducted interviews with individuals with chronic pain and, using thematic analysis, discovered that positive, reciprocal relationships with doctors empowered and validated the participants. This is supported in the analysis where participants discussed how important it was to obtain doctors understanding of their phobia. Especially with the added challenge of needle phobia, patients with chronic disease require empathy and understanding from their clinicians to maximise treatment outcomes.

As for not being validated, participants discussed how when they confided in clinicians that they had a needle phobia, they had their feelings dismissed. In some cases, it was suggested that they could not be unwell enough if they were unwilling to comply with treatment. The invalidation of needle phobia in chronic disease requires further examination to uncover why it is not taken seriously in this context and to find strategies to mitigate it. Despite this, there is literature on general dismissal within chronic illness which is somewhat applicable to the current findings. Jeffrey (2018) discussed the 'empathy gap' patients experience in their interactions with doctors. They argue that the lack of empathy dates to poor clinical training and a general custom of prioritising scientific progress above the patient's cognitive wellbeing. Jeffrey (2018) advocates for adopting a diverse framework that is centred on empathy and incorporates aspects such as concern, attention, and communication. The current analysis supports this view as participants spoke in-depth about clinicians lacking empathy for their needle phobia in the context of chronic illness, thus making them feel invalidated and left seeking understanding.

The tension between rationality and phobia

The tension between rationality and phobia was also uncovered in analysis, encompassing the hard reality that participants understand the adverse and, in some cases, fatal consequences of their needle phobia yet cannot comply with treatment. Participants were aware that it was not rational to go without treatment for chronic disease because of a needle and wished that they could cooperate with their clinicians. The 'rational patient' concept has been discussed in the literature as an individual who complies with treatment. Therefore, by default, the "irrational patient" is the one who does not adhere (Buetow, 2007). Corrigan et al. (2014) maintain that instead of being purposefully difficult and calculating, the patient's reasons for non-adherence are usually implicit and often emotional. This has been reflected in the analysis where participants recalled trauma from previous experiences and described doctors rolling their eyes or believing them to be purposefully troublesome. The perception that needle phobia is something that the patient can get over by weighing up the costs and benefits is related to the model of the rational patient. The rational chronic disease patient would be able to see the price of not having the procedure and therefore employ a coping strategy. However, as Corrigan et al. (2014) illustrate, this is an outdated way of thinking and does not empathise with the patient's needs, especially one with needle phobia. Participants' accounts reflected this tension between rationality and phobia and the subsequent lack of understanding from clinicians.

CONCLUSION

Overall, this study explored the under-researched experience of adults with both chronic illness and needle phobia, examining how individuals coped and how their phobia developed. This study advances the literature on chronic illness and needle phobia management by emphasising the need for control on behalf of patients and outlining the importance of reciprocal relationships with clinicians. Building on these findings, future research should investigate more thoroughly the essential role of control in power dynamics between those with chronic disease and needle phobia and their clinicians. Although there is literature on control and the inherent power structure generally for individuals with chronic disease, the additional element of needle phobia has not been investigated and is a unique contribution warranting future examination. The feeling of being out of control was present in their recent experiences of needle phobia and childhood recollections, and a desire for control over the environment was evident. Additional research is needed to fully understand the psychological mechanisms behind the desire for control and ways to empower patients. The painful experience of clinicians invalidating and misunderstanding needle phobia in patients with chronic illness also came up in this exploratory study and is a further direction for research. From a practical viewpoint, the scope for population size was limited due to having to fit a specific criterion of both needle phobia and chronic illness. Additionally, the population was difficult to reach due to Facebook community guidelines preventing recruitment and time constraints on the research project. Future research could also consider these methodological limitations.

Nevertheless, this study highlights how chronic illness and needle phobia are multifactorial and underscores the role that adverse childhood experiences play in developing a phobia. Moreover, it is clear from listening to participants that greater education is needed on the differences between normative dislike and phobia. Additionally, a patient-centred, empathetic approach to healthcare is necessary, accounting for physical and mental health. Overall, participants demonstrated their resilience and persistence, finding ways to empower themselves as they managed chronic illness and needle phobia.

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