

Clinical Pain Research

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Acceptability of psychologically-based pain management and online delivery for people living with HIV and chronic neuropathic pain: a qualitative study

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Abstract

Objectives: Chronic neuropathic pain is common in people living with HIV. Psychological treatments can improve quality of life for people with chronic pain in general, and online delivery can increase access to these treatments. However, the acceptability of psychological treatment and online delivery have not been investigated in-depth in people living with HIV and chronic neuropathic pain. Therefore, a qualitative study was undertaken to explore views about a psychological treatment for pain management in this population and to investigate the acceptability of online treatment delivery.

Methods: Qualitative interviews were conducted and analysed using inductive thematic analysis, adopting a critical realist perspective. Twenty-six people living with HIV and

chronic neuropathic pain completed semi-structured interviews. Their views about a psychological treatment for pain management and online delivery were explored in-depth.

Results: Three themes and 12 subthemes were identified. Theme one represents a desire for a broader approach to pain management, including not wanting to take more pills and having multidimensional goals that were not just focussed on pain relief. Theme two includes barriers to online psychologically-based pain management, including concerns about using the Internet and confidentiality. Theme three describes treatment facilitators, including accessibility, therapist support, social connection, and experiencing success.

Conclusions: A psychological treatment for chronic neuropathic pain management appears acceptable for people living with HIV. Therapist-supported online delivery of cognitive-behavioural pain management may be acceptable for people living with HIV given appropriate development of the treatment to address identified barriers to engagement. These data can inform developments to enhance engagement in online psychologically-informed pain management in people living with HIV and more broadly in remote delivery of psychological treatments.

Keywords: acceptability; cognitive-behavioural therapy; HIV; Internet; neuropathic pain.

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Introduction

With the UNAIDS 90-90-90 targets, more people living with HIV (PLWH) are in long-term care [1]. The targets specify that by 2020, 90% of PLWH should know their status, 90% of these should be on antiretroviral therapy (ART), and 90% of these should show viral suppression [2]. The United Kingdom achieved these targets in 2017 [3]. Calls have been made for a “fourth 90” whereby 90 percent of people with viral suppression experience good health-related quality of life [4].

In the era of highly effective ART, chronic conditions and HIV-associated complications have a greater quality of life impact than AIDS-related illnesses [5]. In particular, chronic pain is a major threat to quality of life in PLWH [6]. Estimates suggest that 54–83% of PLWH experience pain of any aetiology [6, 7]. Chronic neuropathic pain caused by a lesion or disease of the peripheral somatosensory nervous system [8] is common in PLWH. In particular, painful distal symmetrical polyneuropathy affects 22–44% of this population and is strongly associated with reduced quality of life [9–11]. Pharmacological treatments appear ineffective for chronic neuropathic pain in PLWH [12, 13]. Additionally, 40–73% of PLWH with pain receive no pain treatment [6]. Considering challenges with polypharmacy [14], there is a clear need to improve pain management in this population.

Psychological treatments, such as cognitive-behavioural therapy (CBT), improve pain-related quality of life using relaxation, pacing, cognitive restructuring, and goal-setting [15]. Acceptance and commitment therapy (ACT), a form of CBT, helps people to engage in personally-meaningful activities alongside pain, using metaphors, experiential exercises, mindfulness, and values-based goal setting [16]. ACT may be well-suited for pain management in PLWH as it can foster successful living with a range of physical and mental health symptoms that may be comorbid with pain in PLWH [4, 17–19].

Meta-analyses of 42 randomised-controlled trials (RCTs) showed that CBT for chronic pain is associated with small to moderate improvements in pain severity, disability, and mood [20]. Meta-analyses of 25 RCTs showed that acceptance and mindfulness-based treatments are similarly associated with small to moderate improvements in pain, disability, and mood [21]. There is emerging evidence that CBT and ACT can be delivered online which may address pain management access barriers, including limited availability outside of speciality clinics and transportation challenges [22, 23].

Most studies investigating psychological treatments for pain have focused on musculoskeletal pain or samples with mixed aetiology [20]. A 2015 systematic review concluded there is a lack of methodologically robust RCTs to determine the efficacy of psychological treatments for neuropathic pain [24]. A 2003 RCT investigated CBT versus supportive psychotherapy in 61 PLWH and neuropathic pain; only 33 participants completed the protocol, suggesting limited acceptability [25]. Anecdotally, the authors suggested that participants were seeking medically-focussed pain management [25]. The episodic nature of disability among PLWH may also create challenges for treatment completion [26]. More recently, two pilot RCTs of

cognitive-behavioural treatments have shown promise for pain management in PLWH; however, these did not focus specifically on chronic neuropathic pain [27, 28].

Considering limited research on psychological treatments for chronic neuropathic pain in PLWH, further research is needed to examine the acceptability of this approach. Qualitative methods can explore in-depth people's views about treatment and can identify strategies to optimise engagement [29]. This can inform tailoring of treatment to the needs of PLWH and chronic neuropathic pain, in line with complex intervention guidance [30, 31]. Therefore, a qualitative study was undertaken to explore views about a psychological treatment for pain management in this population and to investigate the acceptability of online treatment delivery.

Methods

Data in this paper are from a qualitative interview study exploring the experience and impact of chronic neuropathic pain in PLWH and the acceptability of a website-based version of ACT for pain. Participants completed a single semi-structured interview investigating both topics. Themes reflecting the experience and impact of pain from these interviews have been published [32]. To ensure adequate interpretation of themes, the current paper details the analysis of the acceptability of ACT and online delivery. A comprehensive description of the methods is provided in [32]; these are briefly summarised below. The study was approved by the National Research Ethics Service (16/YH/0367). All participants provided written informed consent.

Eligibility criteria

Participants were adults (≥ 18 years) living with HIV who screened positive for painful peripheral sensory neuropathy (bilateral, symmetrical foot pain) [33] and neuropathic pain in the feet (Douleur Neuropathique 4 Questions Interview (DN4i)—patient-reported outcomes) [34, 35]. Participants had pain for at least three months with an average intensity and interference of ≥ 4 on a 0–10 scale on two items adapted from the Brief Pain Inventory [36]. Excessive alcohol consumption (>30 units/week) or a history of neuropathy due to a cause other than HIV (e.g. diabetes) or ART were exclusion criteria [37, 38]. Inability to provide consent or to conduct the interview in English was also exclusion criteria.

Recruitment

Participants were purposively sampled to include a demographically diverse sample in terms of gender and ethnic background. Clinicians at HIV clinics at a major London, UK hospital referred participants. Poster advertisements were also placed in these clinics. PLWH and painful peripheral neuropathy from a previous study by our group (HIV-POGO Study; <https://clinicaltrials.gov/ct2/show/NCT02555930>) who consented to be re-contacted were approached. Lastly,

participants were recruited through community HIV organizations across London, social media, and chain referral sampling [39]. The target sample size was approximately 30 participants to achieve a diverse sample. Data analysis was conducted alongside data collection. Recruitment stopped when the researchers felt that a diversity of perspectives was captured which was sufficient to address the research questions [40].

Procedure

Participants completed questionnaires before the interview for the purpose of describing the sample. Self-report questionnaires assessed demographics (e.g. age, gender), medical history (e.g. HIV and pain duration), and Internet use (e.g. device type and frequency of use). Questionnaires also included the Brief Pain Inventory (BPI) and Patient Health Questionnaire-9 (PHQ-9) to assess pain intensity and interference and depression symptoms, respectively [41, 42].

Interview appointment

The first author conducted all semi-structured interviews individually face-to-face in a hospital setting. The interviewer was a clinical psychologist with expertise in psychological treatments for chronic pain; participants were aware of this during recruitment. The interviewer conducted the eligibility screening which facilitated rapport with participants during the interview. The first author made notes after each interview to record impressions and identify potential themes/sub-themes. All interviews were audio recorded and transcribed verbatim. Participants consented for anonymous quotations to be used.

An interview schedule was developed from previous qualitative studies on psychological factors and treatments for chronic pain and feedback from PLWH [43, 44]. The interview consisted of two parts. The first part asked participants to discuss the impact of pain and their pain management strategies [32]. Part two explored participants' views about the acceptability of ACT and online delivery for pain management. They were given brief information about the treatment rationale and possible practical aspects, such as the frequency and duration of sessions and therapist support. Participants also viewed two brief video clips of exemplar psychological exercises from ACT for pain demonstrated by human actors. Video one guided participants through a present-moment awareness exercise ("Notice Five Things"), while video two guided them through an exercise on committing to values-based actions ("Small Steps"); these are two key processes within ACT [45]. The videos came from a previously developed version of online ACT for chronic pain (not specific to PLWH) [23]. After watching these videos, participants discussed the acceptability of this approach for pain management.

Lastly, participants viewed a brief, illustrated video summarising "BeYou+", an mHealth application to support self-management strategies for PLWH [46]. This video (access: <https://vimeo.com/162059872>) summarises the content and functionalities of BeYou+. This video was presented to provide a contrast of presentation formats (e.g. human actors vs. graphic illustrations) to generate discussion around preferences for how information is conveyed. Questions from the second part of the interview are in the Supplemental Material.

Data analysis

Inductive thematic analysis was conducted according to the recommendations of Braun and Clark [47], using NVivo 12.0 (QSR International, London, UK). This study drew on a critical realist paradigm. Briefly, this approach acknowledges that while there is an objective reality, knowledge is subjectively constructed [48]. This paradigm allowed for the identification and interpretation of multiple perspectives and meanings surrounding the acceptability of the proposed treatment among participants.

A reflexive stance was adopted to consider the role of the researchers' background and experiences in the interpretation of the data. The transcripts were independently analysed in full by two researchers: a doctorally-trained clinical psychologist with significant experience providing psychological treatments, including ACT, for people with chronic pain (WS) and an MSc-level health psychology student interested in psychological aspects of long-term health conditions (MGCMS). Nineteen of the transcripts were also independently analysed by a third researcher, a medical student completing an intercalated neuroscience and psychology degree with interest in mindfulness-based therapies (JB). Throughout the analytic process, developing themes and sub-themes were discussed by the three researchers and refined to ensure the analysis was not related to the perspective of one researcher, ensuring the trustworthiness of the results [49]. Additionally, participant accounts that were contrary to the predominant pattern and the analysts' own views were actively searched for and incorporated into the analysis [50].

Each transcript was read several times for familiarity. Transcripts were coded line by line to identify first-level descriptive codes. First level codes were combined into second level codes indicating sub-themes. Finally, themes that integrated subthemes were described by third-level codes. Subthemes are illustrated with quotations [47]. The transcripts were regularly reviewed to ensure (sub) themes adequately represented the data.

Results

Table 1 summarises characteristics of the 26 participants. The sample was diverse with respect to gender, ethnicity, age, and HIV and pain duration. Most participants (85%) had at least one device to connect to the Internet and had regular Internet access (77%). Interviews ranged from 37 to 80 minutes. Three inter-related themes and 12 subthemes were identified related to the acceptability of ACT and online delivery (Figure 1).

Theme 1: desire for a broader approach to pain management

This theme represents participants' views about the limitations of an entirely medical approach to pain management and their willingness to engage in a broader, psychologically-informed approach.

Table 1: Characteristics of the sample.

Variable	Mean (SD) or n, %
Gender	Men: 14 (54%) Women: 12 (46%)
Age, years	53.7 (SD: 9.7; range: 40–78)
Ethnicity	White British/European: 17 (65%) Black British/African: 9 (35%)
Self-reported HIV duration, years	Median: 17 (range: 3–32)
Prescribed antiretroviral therapy	24 (92%)
Self-reported viral suppression	23 (88%)
Self-reported neuropathic pain duration, years	Median: 5 (range: 1–24)
Pain intensity (BPI; rated from 0 (no pain) to 10 (pain as bad as you can imagine))	6.2 (1.7)
Pain interference (BPI; rated from 0 (does not interfere) to 10 (completely interferes))	6.9 (2.0)
Depression symptoms (PHQ-9; total score from 0–27, where 0 is none/minimal and 27 is severe depression)	14.5 (6.6)
PHQ-9 score at least moderate (>10)	19 (73%)
Devices used to access Internet (not mutually exclusive)	
Smartphone	19 (73.1)
Laptop/desktop	16 (61.5)
Tablet	10 (38.5)
Internet access ≥ 5 days per week	
Yes	20 (76.9)
No	5 (19.2)
Missing	1 (3.9)
Internet use per day, hours	Median: 3.3 (range: 0–13)

BPI, Brief Pain Inventory; PHQ-9, Patient Health Questionnaire Depression. Mean BPI and PHQ-9 scores indicate moderate levels of pain intensity and interference and depression symptoms [36, 41].

Not wanting to take more pills

Participants felt that there is not enough support to help them manage pain. Many expressed a wish not to take more analgesic medications. This was important in the context of taking daily ART. Many had tried numerous analgesic medications and experienced limited benefit or problematic side effects.

“...you know so many pills in my life which I really don’t want any more, less is possible, I always tell doctor [name] please no more pills, no more pills.” (P12)

The cost of over-the-counter analgesics was also a barrier for some.

“...I have to buy it [ibuprofen]...at times I don’t have money” (P18).

Understanding of the mind-body connection

Participants provided many examples to illustrate their understanding of the mind-body connection. In addition to articulating links between pain, low mood and anxiety (detailed in [32]), many described the attention-grabbing nature of pain.

“Because you are unable to, you know, stop thinking about the pain that you have.” (P3)

At the same time, participants provided examples of how pain was less intense or overwhelming when they were focused on certain activities. The role of psychotherapy for pain management made sense to participants in the context of this understanding of the mind-body link in pain.

“Certainly with my feet you know, sometimes if I’m really busy at work, or I’m, or I’m doing something that keeps me occupied then I don’t think about it [the pain] but it’s then when you know when I’m just sitting or whatever that or, obviously when I’m walking it’s, I’m more conscious of it.” (P17)

Previous experiences of psychotherapy

Many participants disclosed that they had previously received psychotherapy or counselling. This was primarily in the context of adjusting to life with HIV or to manage a range of mental health difficulties. Participants reported previous exposure to aspects of cognitive-behavioural therapy, mindfulness, psychodynamic therapy, and hypnotherapy. The format of past treatments ranged from self-directed learning to individual, group, and online therapy. Participants saw how

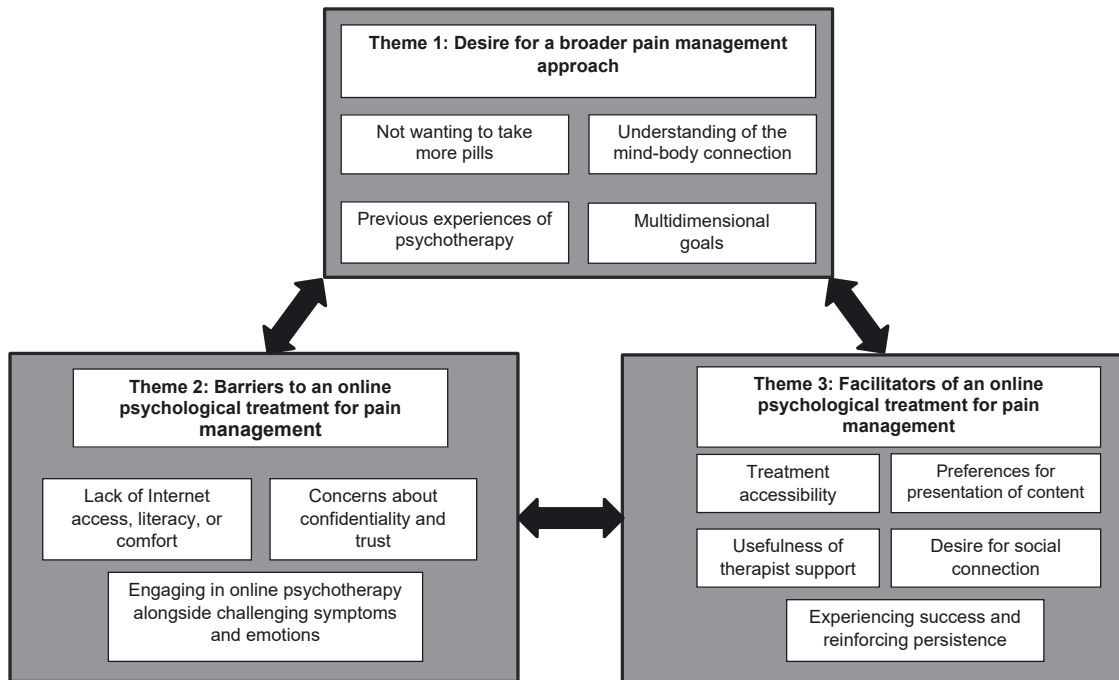


Figure 1: Associations between themes and subthemes.

strategies learnt from past psychotherapy could be adapted to help manage pain, although pain management had not been a focus of past psychotherapy for most.

“...I know with my psychologist because I suffer from anxiety, that when I...occupy myself in a specific direction of doing something **productive***, the anxiety falls away and then it’s a similar process I suppose with the pain.” (P14)

In contrast, however, some participants did not see the potential role of psychotherapy in pain management, specifically for reducing the pain. A few expressed negative experiences during past engagement with psychological/psychiatric services.

“I don’t know, I don’t know, for pain? I don’t know, I mean, I suppose I’d give it a go, but it’s like...trying to teach an old dog new tricks, you know what I mean? I have certain strategies and I...uhm...and it’s like mindfulness, like I said, there was some things [in the mindfulness course] that I found...uhm...I had already been doing but there were some things I just didn’t get.” (P26)

*Words in bold and italics demonstrate emphasis by participant when speaking.

Multidimensional goals

While some participants hoped for pain relief, they also identified a broad range of goals that they might wish to pursue if they engaged in a psychologically-based pain

management treatment. Goals included learning new skills, leaving the house more, having a healthier lifestyle, strengthening relationships, improving mood and confidence, contributing to the community, hobbies, and having more control over their life. At the same time, some participants appeared focused on obtaining pain relief, while others hoped to control the impact of a broad range of physical symptoms on their lives. Many participants connected with an approach that focused on taking small steps to achieve their goals and building up progress over time; some had already been successful doing this in the past.

“I realised I have to start doing something, you know, and I picked up my sewing again. So I started to do stuff at home myself, maybe just flick through my sewing. I collect, I’m a collector, so...I look through my collection of quilts or something umm and then sort of maybe design, so I say okay, today I’m going to think up a quilt, what, you know, the pattern, do that on a day...” (P26)

Goal setting brought up difficult thoughts and feelings for one participant in particular; this person identified that treatment materials should communicate that participants are free to choose to set manageable goals if and when they are ready. For some, focussing on goals was difficult in the presence of other HIV-related challenges.

“At the very...very baseline level that it is okay...just to be. What we are giving you is a space to be and to breathe with all that pain and all that sh*t and all the rest of it that you have to deal with

that there is this that we can move on when you are ready if you want to, if not stay there for a bit...and then...you know what I mean?" (P6)

One participant identified the need for cultural sensitivity when discussing values-based goals:

"I noticed when the gentleman [in the video] uses the word values...culturally there can be misinterpretation. It is wide, values, or African values or they can be different." (P21)

Theme 2: barriers to an online psychological treatment for pain management

This theme represents barriers to engaging in psychological pain management delivered online. Demonstrating the heterogeneity of treatment preferences, some participants identified specific treatment components as barriers, while others identified these as potential facilitators of a psychological treatment and/or online delivery. This theme also incorporates solutions offered by participants to address some treatment barriers.

Lack of Internet access, literacy, or comfort

Many participants had Internet access and said they would be willing and able to use a treatment website. However, some did not have reliable Internet access or worried about their ability to navigate a treatment website. Notably, some had been making efforts to use community resources to enhance their computer literacy. Some said they would be willing to use an online treatment if shown how to use the website or if they were provided with a device with Internet access. Participants generally agreed that a simple website with few external links that did not have multiple layers of pages would be most helpful.

"That [being given access to a device with Internet] would be helpful because I must tell you there are a lot of people out there who have interest in doing things but because, especially the Internet, you will tell them, give them advice you know if you go online, you can check this and that and they would say but I don't have a smartphone." (P25)

A few participants explained that they did not feel the Internet was an appropriate means to deliver a psychological treatment for pain as it is too impersonal, and preferred face-to-face therapy.

"...everything's online and distant from you as a person and I think that has become a frustration, that when you just, I mean the thing is now you are just one in millions [...] yeah it's very impersonal services and everything done automated and so

there is a slight [hesitates] frustration but [sighs], you know, we live in a modern world with technology, I use technology. I'm not against technology at all but the thing, it...[hesitates] personal contact and caring...uh...does help a lot more than an app does." (P4)

Concerns about confidentiality and trust

Data security and confidentiality were very important to participants, particularly due to HIV stigma.

"Well data, I don't care what anyone says. Putting all that stuff on the phone I would not do. Specially [sic] with what's just happened with...you know... [recent high profile data breach] nothing is secure anymore, you have to sort of start with the premise that everyone's going to eventually have everything." (P6)

It was important for participants to know who had access to their data and to choose how much data they provided online. Participants also wanted to know that online health information came from a reputable, trustworthy source.

"Uhhh email for me is fine [hesitates] but it it I-I-I'd be reluctant I think about...the amount of information or if I believe for me is confidential then I might be cautiously putting it in an email." (P2)

In contrast, one participant felt that completing an online programme would enhance privacy over a face-to-face pain management group, where HIV status might be disclosed.

"That [online treatment] for me, for me personally, sounds better because I, because of, there's so much around my HIV etcetera, I wouldn't probably want to do a group. Whereas that [online treatment] I could do at home, privately, and it's more like one to one...I'm better with one to one." (P24)

Engaging in online psychotherapy alongside challenging symptoms and emotions

Several participants worried that they would struggle to complete an online psychological treatment when pain, other HIV-related symptoms, or mental health problems worsen, as these symptoms affect their concentration and motivation. They felt that they would be more motivated to engage in face-to-face psychotherapy when they experienced an exacerbation of these problems. Other participants felt they would be willing to do the online treatment even when pain was worse, especially as they felt that was the time treatment would be more helpful.

A few participants initially described how experiencing strong emotions like sadness, fear, or frustration

would limit their willingness to complete a psychological treatment online. However, after watching the exemplar online ACT videos, their reactions shifted and they subsequently indicated more willingness than they initially thought to do the treatment with these challenges.

“Sorry...but being at home over the Internet I don’t think it will help because think about you wake up in the morning with the pain and your mood will be low and you don’t want to do anything to go to the Internet, it’s, I don’t know if it will work. Especially for people that live with depression like me, you know.” (P13 before watching videos)

“...the video said you must make a decision why something you have to do today is like, for me it’s like wow...the message is really really powerful, and that, especially for me when I get depression, the pain makes my mood very low and I don’t want to do nothing, so when they say make a decision is a *little* step...small step to do today. And my mind said, okay, this is big encouragement...it just said small steps, no big, small...it could be stand up and walk, could be...I don’t know...this could be dress yourself go out.” (P13 after watching “Small Steps” video)

Theme 3: facilitators of an online psychological treatment for pain management

The final theme represents facilitators of engaging with an online psychological pain management treatment. As mentioned in theme 2, some aspects of treatment that were barriers for some participants were facilitators for others. This theme also represents treatment delivery and design features perceived as having the potential to mitigate against barriers and to optimise treatment engagement and outcomes.

Treatment accessibility

Many participants identified that the potential flexibility of online treatment delivery was advantageous, especially if it could be accessed on a range of devices (e.g. smartphone, tablet and/or computer). Some felt burdened by having to attend many medical appointments already for HIV and other health problems.

“That sounds quite promising because often it is difficult to get to appointments, and when you have to go to an appointment again it can create an even bigger umm bigger scenario with a problem in your head, because again you are going to another appointment...uh...so I think that that could take a lot of that stress.” (P15)

Additionally, some felt remote delivery could increase continuity in care, especially as it could be used ‘on demand’ in times of need.

“Yes, the continuity, the continued support and you are able to access it at regular times, at any time, that is important in managing.” (P16)

Preferences for presentation of online content

Many participants expressed that they connected with the information and psychological exercises presented in the videos. However, participants varied in their preferences for the style of videos; namely, whether they should be presented by human actors (as in the first two) or by graphic illustrations (like the BeYou+ video). Some felt cartoon graphics minimised the gravity of their experience of life with HIV and that human actors provided the human connection needed in a technology-driven programme.

“and I thought the ummm...the HIV one [BeYou+ video], the ugh, the animation...ummm...that that that was okay [hesitates]...a little frivolous I thought. Ya know, because ugh...I think it’s a little more serious than what I felt was coming out [of the video].” (P14)

In contrast, others preferred the graphics in the BeYou+ video, which they experienced as more engaging and optimistic. Most preferred a mixture of presentation styles. Participants appreciated that their peers had varying levels of English proficiency and there was consensus that language needed to be simple, direct, and free from jargon. Participants generally did not want to read lots of text. However, some indicated that a hard copy book would help them to follow the online materials more effectively, or could be used to provide more in-depth explanations of material on the website for people who wanted this.

“I think I am one of those people that like a mix of everything, umm, and not drawn specifically to, drastically to one area, uhm I like the visuals, the colour, very visual [referring to BeYou+ video]. Umm, but also...the thing with apps I miss the kind of human interaction, like the first [videos] you showed me with the real person talking and you could see them, which uhm, yeah I miss, so I quite like that as well.” (P5)

Experiencing success and reinforcing persistence

Participants indicated they would be willing to stick with an online pain management programme if they experienced early benefits. They identified that frequently repeating key messages, tracking progress, prompts, and built-in rewards could help them to stick with the treatment and their goals. Setting realistic expectations for treatment outcomes and emphasising the need to actively practise new strategies were identified as ways to keep people

motivated. This was demonstrated by one participant in particular who had previously completed courses of online CBT and mindfulness:

“And it it’s **so** important to allow people to understand it will work, but you have to repeat, and repeat, and repeat information to go, for people to take it in. And the big repeat is, you’ve got to do it...It’s not like swallow this tablet and your pain goes. This is keep doing it. It **will** take, you know... Very explicit to say umm you will probably find **some** benefit immediately, but it will only really kick in in like two, three weeks or four weeks. And the longer you do it the better it will be. (P3)

Usefulness of therapist support

Most participants felt having some form of therapist support would help them benefit from an online psychological treatment. They felt that having a therapist would hold them accountable for completing treatment, help to manage challenging experiences if they arose, and help them progress.

“They can help you actually ugh stick with the programme because one of the relations is...there is a positive and a negative. The positive is gives encouragement...contrary to that also is might be sort of like some people will say ‘oh okay, well I’m going to get a phone call anyway so I better watch it.” (P21)

There was also a feeling that therapist support would enhance the ‘human element’ of an online treatment.

“And you know that you’re not just sat there clicking boxes and not knowing if anybody is going to read it.” (P23)

Participants varied in their preferences for therapist support to be delivered by telephone, face-to-face, or online messaging. Only a few felt that they would not need therapist support to complete an online programme. One participant worried that therapist support might open “Pandora’s box” of other problems that could be difficult to manage, especially if a person was not receiving more intensive psychological support elsewhere.

“I am not so sure if you have someone to check into, I think that is something quite...that is opening up...uh...could be opening up Pandora’s box there [...] unless they, they really are going to be there, I am without support and if the door opens [...] I am going to jump on it.” (P6)

Desire for social connection

There was a strong desire to connect with other PLWH and pain. This was particularly important as many felt they did not have adequate social support in their lives. A key

perceived benefit of this was a sense of shared understanding and learning successful pain management strategies from others. Knowing that a trusted peer with similar problems completed a similar online programme would motivate one to do so. Many felt that a support or chat group alongside the online treatment could be beneficial. Several participants hoped to learn new pain management skills so that they could share these with others in their community.

“The improvement that I hope to see is just uh...like I mentioned it’s not for myself, I would really like to be like an ambassador to most of those who have pains and the, umm, I would really like to work with them, you know.” (P25)

However, a few expressed a strong wish to not attend another “sick group”.

“I am just quite, I am quite desperate to...not be ill and not belong to another sick group.” (P15)

Discussion

This study explored the acceptability of a psychological treatment and online delivery for managing chronic neuropathic pain in PLWH. Key themes were the desire for a broader approach to pain management, and barriers and facilitators to engaging in online ACT. Although interviews explored ACT and online delivery as a specific form of treatment and provision, the results can inform other psychologically-based pain management treatments and delivery methods. The data can also inform developments to enhance engagement in online psychotherapy, an area which is rapidly developing for persistent pain and physical symptoms more broadly.

Participants’ desire for a broader, more whole-person approach to pain management is notable given the predominant focus on and limited efficacy of analgesic medication for managing pain in PLWH to date [13, 51]. Given the nature of the early HIV/AIDS epidemic, pain management in this population has historically been approached from a palliative care perspective focused heavily on opioids [52]. Thus, a longer-term pain management approach where patients play a more active role in improving their function and quality of life represents a shift of focus. This parallels developments in other health conditions, such as cancer, where pain management has shifted from palliative to longer-term models emphasising quality of life [53]. Based particularly on theme one from this study, an approach that does not focus solely on medical management appears to be acceptable for PLWH in the current treatment era.

It is widely acknowledged that the biopsychosocial model is a useful heuristic to understand pain [54]. Although many participants identified a specific pathophysiological explanation for their chronic neuropathic pain (i.e. nerve damage due to HIV or ART), they described their experiences of pain in broader biopsychosocial terms. For example, many descriptions of how participants experienced the attention-grabbing quality of pain were consistent with attentional models of pain [55]. Some described how focussing on specific activities reduced the pain or helped to manage its impact. This point requires some clarification, however. While distraction may be useful for acute pain, a recent meta-analysis demonstrates that distraction is not effective for chronic pain [56]. Thus, rather than fostering better distraction per se, CBT and ACT-based approaches help people to direct focus toward meaningful activities so that life can be “bigger” than the pain, through methods such as behavioural activation, goal-setting, and values clarification [15, 16]. Some participants expressed an entirely understandable wish to reduce the pain. This is a common occurrence in ACT, is relevant and addressable, and is not a contradiction to this treatment [16]. At the same time, many easily identified a broad range of goals to improve their physical, psychological, occupational and social functioning. Thus, participants’ desired outcomes align with the pragmatic focus on improving functioning and quality of life within current psychological treatments for chronic pain, and within rehabilitation approaches more broadly [57].

Although a psychological treatment for pain management was generally acceptable to participants, their views about online delivery were more mixed. Accessibility and flexibility were viewed as key strengths of online delivery. Important barriers included concerns about data security, lack of Internet access or literacy and difficulties completing treatment when symptoms worsen. These barriers have previously been identified in relation to digital technology for managing a range of health problems, including HIV [58–61]. Thus, they are important factors to address in the development of digital pain management interventions to improve participant engagement.

For context, data collection for the current study occurred several months after two widely publicised UK data breaches, including a major email breach at a National Health Service HIV clinic in London [62]. To build trust, digitally-based treatments need to ensure data security and robust data protection procedures, compliant with relevant legislation, and these procedures need to be effectively communicated to potential participants. Involving patients in the development of data management

policies for an online treatment and allowing them to decide how much personal information to share may further increase trust in this regard.

While some participants lacked Internet access or literacy, there was generally willingness to use an online approach under certain circumstances. As part of treatment costing, budgeting to provide a basic Internet-enabled device may minimise the likelihood of excluding some potential participants by design. The inclusion of an initial digital literacy session prior to the online pain management programme may likewise facilitate broader inclusion and may represent an important goal itself. Indeed, the provision of digital literacy training may help mitigate against disparities caused by the “digital divide” in healthcare [63–65].

The relationship between online treatment barriers and facilitators in the current study provides further insight into how engagement in online pain management can be optimised. For example, some participants felt that using an Internet-delivered treatment would be especially challenging when they experienced exacerbations of pain or depression symptoms (barrier). Notably, these challenges may also interfere with engagement in face-to-face treatment [66]. In the context of online delivery, having therapist support to manage these challenges and reinforce persistence was identified as a motivating factor to continue treatment (facilitator). This is consistent with research showing therapist support is a key component of online CBT/ACT [67, 68]. Therefore, a system which regularly tracks participants’ functioning and mood may help identify periods when more intensive therapist support is needed (e.g. a phone call versus messaging) to motivate participants to respond more helpfully to these challenges. The capacity to provide more tailored therapist support when needed, rather than rigidly following a protocol for the number and timing of therapist contacts may improve treatment completion.

Participants expressed a desire for social connection (facilitator), which they felt might counteract the isolation of living with pain and the lack of human contact in an Internet-based treatment. One strategy to facilitate social connection might be to embed online pain management within existing HIV peer support services in the voluntary sector. Peer support was successfully integrated in a pilot trial of a face-to-face behavioural intervention for people with pain and HIV [28]. Alternately, providing case examples of peer’s effectively managing pain within online materials may provide a social learning function. Of course, treatment can still foster social participation and engagement with important relationships even if the delivery format does not involve extensive social support.

Digital technology holds promise for improving the accessibility of cognitive-behavioural treatments [69]. However, the current data suggest that digital technology should not be viewed as a panacea for all challenges related to cognitive-behavioural pain management in PLWH. Rather, it may be a useful tool in a continuum of care which includes face-to-face delivery formats. Rather than a one size fits all approach, models of pain management delivery should flexibly address the varying range of complexity present within a diverse group of patients. These models should incorporate patients' preferences for how they receive care and enable varying levels of treatment intensity and clinician input depending on need. Idiographic methods [70] rather than group-level designs may be better suited to tailor and evaluate cognitive-behavioural approaches for pain management in diverse samples of people living with (or without) HIV.

Several limitations must be considered. First and foremost, participants were aware of the interviewer's professional background and of the intention for the data to be used to inform the development of online ACT for chronic neuropathic pain in PLWH. This may have influenced participants' expression of positive views about the proposed treatment. The fact that many participants openly discussed barriers to engaging in a psychological treatment and online delivery for pain suggest that they felt willing and able to provide negative and constructive feedback about the treatment. Relatedly, potential participants were made aware of the specific purpose of the study and the treatment approach being explored. This may have created a selection bias whereby patients who were not interested in a psychological approach or online delivery chose not to participate, and thus the views of these patients may not be adequately reflected in the data. Our study was conducted in England, a high resource setting with a universal healthcare system and a well-established third sector that provides support for PLWH. Participants' past exposure to psychotherapy and peer support and their willingness to engage in a psychological pain management treatment may have been influenced by this context. The extent to which such an approach is acceptable to patients and feasible to implement in lower resource healthcare settings is unclear and requires investigation.

To conclude, this study supports the acceptability of a psychologically-informed treatment to manage chronic neuropathic pain in PLWH. Therapist-supported online delivery of cognitive-behavioural pain management may be acceptable given appropriate development of the treatment package to address identified barriers to engagement. Further research is needed to test the efficacy of online ACT for pain management in PLWH. A focus on holistic person-centred

treatment delivery is vital to achieve the "fourth 90" target for quality of life in PLWH in the current treatment era.

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Informed consent: Informed consent was obtained from all individuals included in this study.

Ethical approval: The research complies with all the relevant national regulations, institutional policies and was performed in accordance with the tenets of the Helsinki Declaration, and was approved by the National Research Ethics Service (16/YH/0367).

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