


Patient experiences of remote care in a pain service during a pandemic

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Cathy Willcocks¹, Deborah LA Joy¹ , Joseph Seward², Samantha Mills², Mark Heywood² and Cathy Price¹ 

Abstract

Background: In March 2020, Pain Management Services were obliged to cease face-to-face consultations. This abrupt change, in line with recommendations from the British Pain Society, aimed to protect patients and staff and allowed resource re-allocation. Pain services were obliged to switch to remote consultations using Video Tele-Conferencing Technology (VTC) and Remote Consultations (RC) either through telephone or video calls using a variety of media and software applications. Little is known about the patient experience of remotely delivered pain care especially when alternatives are removed. The aim of this work was to understand the patient experience of this necessary switch regarding pain self-management interventions during the initial stages of the COVID-19 pandemic.

Methods: A mixed-methods evaluation of the patient experience from three pain self-management interventions, taking place in a large community-based pain rehabilitation service along the South Coast of England, was performed. Experience-Based Design (EBD) methods were used to map patient experience at touch points through two interventions that were delivered in a structured format. Semi-structured recorded interviews were transcribed and analysed using thematic analysis for the third.

Findings: Fifty-eight patients took part covering the scope of the service. In general, educational and psychological sessions were well received, with physical rehabilitation components being less easy to convey remotely. Attrition rates were high for the pain management programme. Group pain education worked particularly well in an online format with hope being the predominant emotion experienced. Clear limitations were technical failures and the lack of ability to form relationships in a virtual world.

Conclusions: Remote digitalised interventions were acceptable to most patients. Attention should be paid to access and improving social aspects of delivery when considering such interventions. Physiotherapy may require more face-to-face necessitating a hybrid model and needs further investigation. EBD proved a highly suitable approach.

Keywords

Chronic pain, pain management, pain, pain clinics, Intractable pain

Introduction

Prior to the COVID-19 pandemic, the majority of NHS Pain Centres in the UK provided a variety of interventions to support self-management of pain. Individual pain sessions, group pain education and Pain Management Programmes were delivered largely face-to-face.¹ In March 2020, Pain Management Services were obliged to cease face-to-face consultations. This abrupt change, in line with recommendations from the British Pain Society,² aimed to protect patients and staff

and allowed resource re-allocation. When people with chronic pain are denied assessment and treatment, their condition can significantly worsen.^{3,4} To assess, treat

¹Pain Clinic, Solent NHS Trust, Southampton, UK

²University of Southampton Faculty of Medicine, Southampton, UK

Corresponding author:

Cathy Price, Pain Clinic, Solent NHS Trust, Western Community Campus, Southampton SO16, UK.

Email: c.m.price@soton.ac.uk

and support service users with chronic pain at a distance became imperative.

Pain services were obliged to switch to remote consultations using Video Tele-Conferencing Technology (VTC) and Remote Consultations (RC) either through telephone or video calls using a variety of media and software applications. Group sessions were termed VTC (Video-Teleconferencing Consultations), individual consultation RC (Remote Consultations). Eccleston et al. provided guidance for delivery of RC for pain management at the outset of the pandemic.⁵ Remote care is not a new concept. Wilson et al. have suggested that remotely delivered PMPs may increase access to Pain Management care.⁶ Evidence-based, low-cost approaches delivered through telehealth may provide a low-burden, effective alternative to traditional pain management care.⁷ However, opportunities for social learning may be lost with no opportunity for friendships to form and modelling of behaviours.⁸ Walumbe et al. found little evidence to guide practice in delivery of VTC delivered pain management programmes.⁹ Little is known about the patient experience of remotely delivered pain care especially when alternatives are removed.

The aim of this work was to increase understanding of patient experience of the necessary switch to RC and VTC for pain self-management interventions during the initial stages of the COVID-19 pandemic.

Methods

Study design

A mixed-methods evaluation of a suite of pain management interventions – group Pain Education (PAINEDU), group Pain Management Programmes (PMP) and individual Pain Management (PI) sessions aimed at supporting self-management using a variety of psychologically based interventions delivered remotely over a three-month period in 2020 when strict social distancing rules were in place.

Setting

The service serves a population of 1 million falling predominantly within the Office of National Statistics cluster of larger University towns and Cities with significant levels of deprivation due the presence of two large ports.¹⁰ Pain rehabilitation is delivered via a single, large, community NHS Trust through locality-based specialist, multi-disciplinary pain teams from medical, nursing, psychological and physiotherapy backgrounds. Approximately 620 patients p.a. undergo pain rehabilitation. The mean age of attendees is 51 years, male: female 1:2, 37% are not working due to

pain. Eighty per cent have musculoskeletal pain (majority in the back or widespread), 15% neuropathic pain and 5% visceral pain.

Participants

All patients, over the age of 18 years old, receiving care with Solent NHS Pain Service and attending one of three elements (PAINEDU, PMP, PI) of the self-management pathway were eligible. Patients needed to speak English. Exclusions were people following an interventional pain medicine pathway and those without the technology to do remote consultations. Those undergoing medical investigations or treatment are routinely excluded from PMP.

For PAINEDU and PMP, participants were invited during VTC group sessions. Participants who did not wish to be contacted indicated this via the ‘chat’ function. For PI, participants were identified through searches of self-management pathway lists stored on SystemOne, the electronic patient record system database used by the trust. Contact was first made via email and followed up 5 days later by telephone.

Intervention

PAINEDU consisted of a 2 h information giving group session held on Zoom. This consisted of pain neuroscience^{11,12} discussion of the pain cycle¹³ and an explanation of how the service delivers care. PMP consisted of 10 weekly 3 h sessions of Acceptance and Commitment based Therapy (ACT) for pain,¹⁴ through either telephone, or video using commercial software. Individual pain sessions (PI) consisted of a blend of rehabilitation and psychological sessions based upon individual need, utilising both ACT and CBT approaches for pain as needed. The number of sessions delivered varied widely ranging from 1 to 12 with a mean of 6 sessions.

Evaluation

A range of differing methods, both qualitative and quantitative were deployed to understand the patient experience of remote consultations. The researchers were three third-year medical students completing their research methods module. During this time, they received training via the University of Southampton in qualitative methods and the ethics of research. Pain clinic staff with additional academic qualifications acted as supervisors. Academic staff within Solent NHS Trust Academy of Research and Improvement provided additional input and supervision. The epistemological stance taken was interpretive as the researchers were primarily interested in the views and

opinions of the patients¹⁵ although some hypotheses were developed based on the literature reviews in the area and explored during the interview process.

Modified Experience-Based Design (EBD) methods¹⁶ were used to capture, understand and make recommendations on improving the experience of the emotional journey through PI and PMP as interventions are delivered according to a set treatment protocol. The standard emotive words suggested in the EBD toolkit:¹⁷ happy, supported, safe, good, comfortable, in pain, worried, lonely and sad were reviewed in consultation with pain team clinicians and revised to match the patient journey. The questionnaires were then tailored to explore specific 'touch points', that is, key emotionally significant moments during sessions. Touch points were identified during review of the videos as being themes that particularly seemed to resonate with attendees of the group sessions. Potential touch points were identified through observation of the sessions by the researcher and then discussed in more detail with their supervisor. Refined touch points were then tested against the refined emotive word list in a structured questionnaire. To mine patient experience as far as possible a box for free text was also left to make comments and patients were also invited to an additional semi-structured interview.

For PAINEDU, touch points within the session were identified as information provided prior to joining the session, use of the chat function or interacting during the session. Consenting patients were then interviewed by telephone. For PMP a tailored EBD questionnaire was administered looking at multiple touch points during the course with further questions about the general environment. Key touch points were participant initial views on the offering of VTC-PMP, experiences of attending VTC-mindfulness and movement sessions, technical difficulties, experience of interpersonal interaction and attendance. Additional questions were added about the use of online communication and what people liked and managed well throughout the sessions. Space was provided for free text comments. Patients filled out the patient experience questionnaire in their own time either online or on paper after the last PMP session and were encouraged to provide as much detail as possible. Microsoft Forms compiled the responses automatically into a spreadsheet, to which the paper copy responses were added manually. All responses were anonymised.

Due to the heterogenous nature of PI, in-depth individual, semi-structured patient interviews were carried out by the researcher using heterogeneous, purposive sampling in order to gain maximum insight into the range of patients choosing to attend clinics on a one-to-one basis for supported self-management.¹⁸ Sampling was based upon the case-mix of patients

attending the clinic in respect to the commonest diagnoses, presence of neuropathic pain, level of anxiety, depression, self-efficacy to try to capture the range of care pathways available on an individual basis as the number and range of clinics differs by condition and level of psychological difficulty. Questionnaires used were General Anxiety Disorder (GAD) 7, Patient Health Questionnaire (PHQ) 9, Pain Self efficacy Questionnaire (PSEQ) and PainDetect.^{19–23} For example, the researcher, in conjunction with the supervisor ensured that patients were selected with severe and mild depression and there were people with differing pain diagnoses. Questions included in the interviews were based upon a literature review conducted by the student of barriers to the online experience. Interviews ceased when code saturation was reached, that is, no new codes appeared to be emerging from the interviews.²⁴ All interviews were recorded using a dictaphone or using the recording facility on the video interview which was transcribed verbatim.

Data analysis

For PAINEDU and PMP, the EBD element was mapped according to the number experiencing a specific emotion at each touch point. Qualitative responses were analysed using thematic analysis, with interview transcripts and free text questionnaire responses being analysed on NVivo. Interview and questionnaire free text responses were merged for thematic analysis due to the small number of interviews conducted and the similarity of themes in both. Experiential thematic analysis from an interpretive epistemological stance was used – focussing on the participants standpoint – 'how they experience and make sense of the world'¹⁷ and was felt to link well to the principles of experience-based design. Steps included reading and familiarisation with the data, generating initial codes, searching for themes, reviewing potential themes and defining and naming themes.¹⁸

For PI, which was entirely qualitative in approach, recordings were checked for anomalies, uploaded into NVivo software then analysed using inductive thematic analysis.²⁵ This method is a widely used analytical approach to systematically identify, organise and provide insight into patterns and themes across qualitative data.²⁶ (Braun and Clarke) It allows researchers to gather ideas from collective or shared meanings. The researcher immersed and familiarized themselves with the transcribed data and initial codes were identified. Codes were then shared and discussed with a second researcher until a consensus was reached. These codes were used to identify when code saturation had been reached. Common codes were then grouped together into categories to identify and pull out the themes from

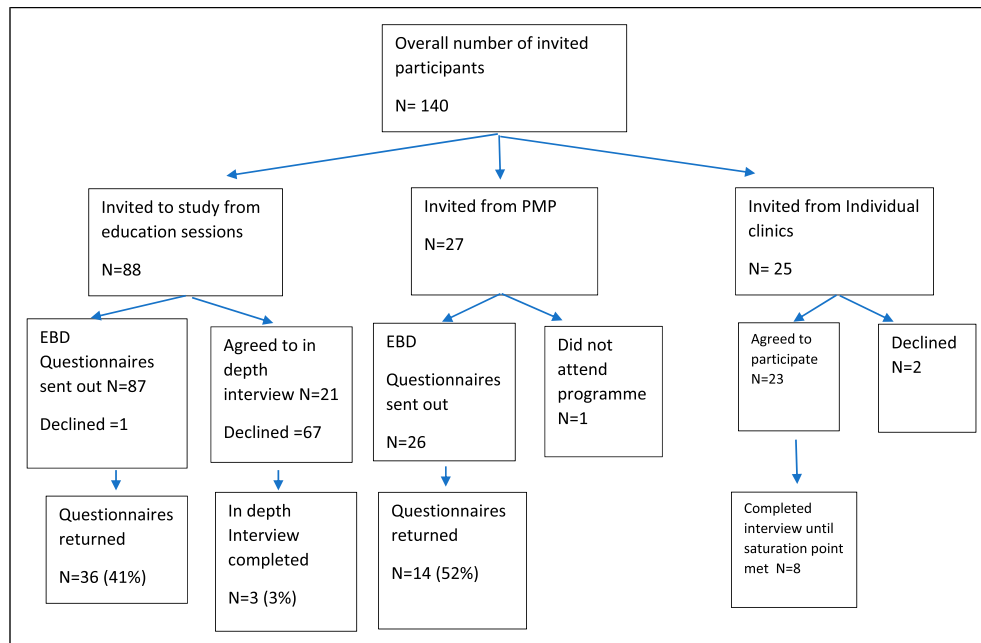


Figure 1. Flow through the Study.

the data set. A log of initial thoughts/feelings and analysis decisions was kept to account for and keep track of emergent themes and minimise the effects of researcher bias.

Ethics and governance

Ethical approval to conduct the study was received from the University of Southampton Faculty of Medicine Ethics Committee and Solent NHS Research and Improvement Team. Consent was given electronically. Audio recordings were discarded after use and transcripts were anonymised to protect participant identities. As a result of the need to obtain remote consent there was a specific request to completely anonymise the group patients which meant that linkage to case-mix details was not feasible.

Results

General information

Figure 1 describes entry and flow through the study. The total number of participants approached in all three arms was 140 with 58 completing the study. Response rates for the questionnaires were 41% and 52% for PAINEDU and PMP, respectively. Saturation point was reached at 8 patients for PI with no further themes elicited. Only three patients wished to complete a more in-depth interview with PAINEDU as indicated on their completed questionnaires. The reasons for this

were not ascertained. There were no follow-up interviews undertaken with PMP patients. Demographic details and case-mix for those who were interviewed are found in Table 1 and Table 2, respectively – questionnaires for PAINEDU were completely anonymised and so linkage was not possible to the usual clinical psychological questionnaires. Psychological questionnaires for PMP and PI broadly matched the clinics usual case-mix for face-to-face contacts with average scores for self-efficacy, anxiety and depression being in the moderate range and standard deviation being similar. Overall PMP attendance was excellent with only one patient out of 27 missing one session.

Emotions at touch points for PAINEDU

Overall, 36 returned the EBD questionnaire describing emotions at key touch points. Figure 2 illustrates frequently identified emotions at different touch points – before, during and after the VTC pain education session. The feeling of hopefulness was the predominant emotion expressed throughout the session and afterwards. Other predominant emotional experiences were of feeling nervous prior to the session, feeling safe and calm during it and afterwards supported and positive.

Patient experience of PAINEDU

Key themes identified were those of feeling hopeful, participants found the session positive and that remote

Table 1. Demographic details of participants.

	Total	Mean Age (y) (range)	M:F	Years of pain	Site of pain	Employment status
Educational session*	36	43	1:2	n/k	n/k	n/k
Pain management programme*	14	53	n/k	n/k	n/k	n/k
Individual clinics	8	50 (36–65)	5:3	<2 years 2 >2 years 6	Low back 4 Others 4	Not working due to pain 4

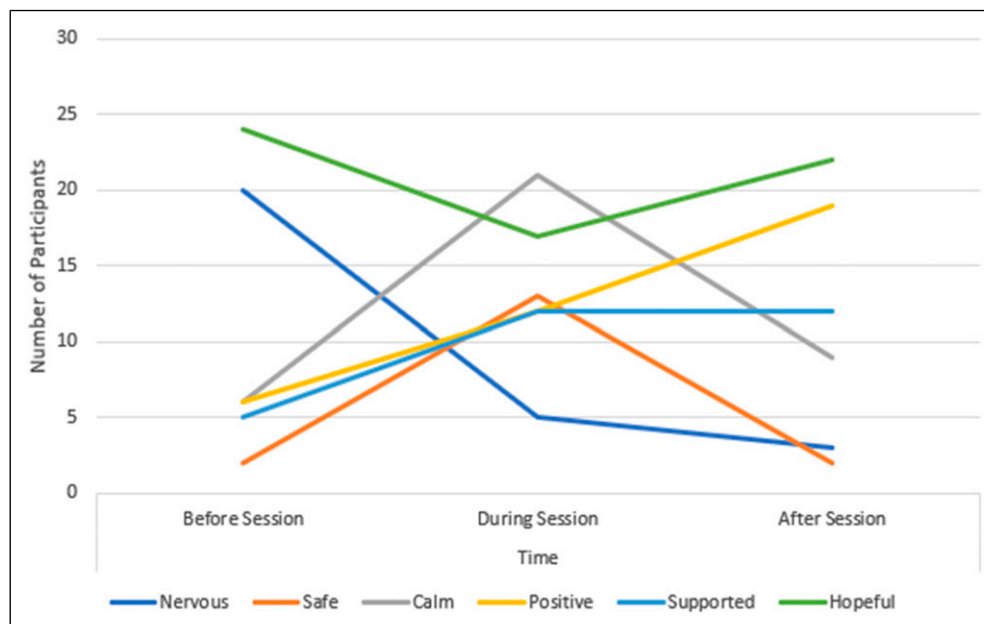
*EBD questionnaires anonymised

**those who agreed to interview N = 21.

Table 2: Profile of sample for pain Management Programmes and individual Pain Management against previous clinic data from psychological questionnaires. N = 22.

Questionnaire	Mean (SD) of F2F population N = 210	Mean (SD) of Video tele-conferencing technology sample N = 27	Mean (SD) of individual Pain Management sample N = 8
General anxiety disorder 7	11.98 (5.39)	10.8 (5.36)	12.37 (5.99)
Patient health questionnaire 9	15.69 (6.36)	11.50 (6.83)	15.25 (6.49)
Pain self efficacy questionnaire	22.67 (11.95)	22.6 (12.32)	20.37 (14.22)

Abbreviations: N = Number; F2F =Face to Face; SD = Standard Deviation.

**Figure 2.** Outcomes from experience-based design questionnaire: feelings at key touch points during the education session. N = 36.

access clearly had benefits. However, they also highlighted the lack of peer support (Table 3). When asked how the service may be best delivered in the future a majority opted for a remote session – either for a live

remote session (44%), or by accessing a pre-recorded session on the website (19%). A significant minority of those who attended the remote session would have preferred face-to-face (37%).

Table 3. Pain Education Session – Key themes that emerged from the experience-based design free text questionnaire and interviews.

Key themes	Subthemes	Examples (‘..’direct quotes)
Feeling hopeful	<ul style="list-style-type: none"> To learn Having pain accepted and acknowledged 	<ul style="list-style-type: none"> Gaining more information about the service, to understand more about their pain To move forwards with their pain, be understood and have help in managing
Positive staff interaction	<ul style="list-style-type: none"> Supportive of participants emotions throughout the session Professional and clear delivery of content 	<ul style="list-style-type: none"> Staff put participants at ease, were calming and informative, were professional and sympathetic ‘Clear explanations were given’
Benefits of remote access	<ul style="list-style-type: none"> VTC reduced flare ups happening Less personal cost 	<ul style="list-style-type: none"> Able to be more relaxed, no travel reduced risk of flare ups More convenient, ‘less confronting’
Lack of access to peer support	<ul style="list-style-type: none"> Lack of non verbal communication Lack of sense of community Minimal participant interaction 	<ul style="list-style-type: none"> ‘unable to see or feel other participants’ ‘Missing general chit-chat’, felt impersonal No eye to eye contact, limited times for interaction

Emotions at touch points – PMP

Overall, 14 patients returned EBD questionnaires for PMP. Figure 3 illustrates the emotions experienced by patients during the VTC pain management programme at touchpoints. Patients initially identified feeling worried and confused, which was gradually replaced by feeling more confident and supported.

Patient experience – PMP

Participants’ views on the offering of a VTC-PMP format were mixed including ambivalence within individual participant responses (N = 14). Whilst face-to-face appeared to be favoured in principle by many attendees, many were pleased to receive a PMP in this format as opposed to none. Comments yielded mixed thoughts on VTC delivery format prior to VTC-PMP with themes of worry about using Zoom (29%), relief after a long wait for PMP (29%), fear VTC would be inferior (36%) and being glad PMP was available despite Covid-19 (29%). However, only 14% identified being generally comfortable with it. Overall, participants reported feeling safe online, most felt they now had a helpful toolkit to manage pain although some felt they still needed more support.

Participation in VTC-mindfulness sessions was rated as ‘easy’ or ‘very easy’ to engage with by 78% of participants:

‘the one area where Zoom was better than physically meeting’

Participation in VTC-movement and exercise sessions was rated as ‘easy’ or ‘very easy’ by only 36% with a lack of confidence over VTC a significant issue:

‘It would have been good to gain reassurance that I was moving as I should be as things hurt in weird places’

‘better when demonstrated in person rather than playing the video’

Technical difficulty was experienced at least once during the course by 10 (71%) participants. Patients were asked ‘how was your experience using Zoom?’ and responded in three main ways: it was awkward (14%), better than expected (35%) and they gained in confidence over time (21%).

Between the first two sessions worry was identified more:

‘I was conscious of how I was presenting myself and my home’.

Participants were asked to compare discussions over Zoom with 42% reporting communication challenges such as stilted conversation, the impersonal nature of VTC:

‘often results in people starting to talk over each other or the opposite where people don’t talk at all’

‘a wall of faces and blank boxes’

‘Lacking. It isn’t natural to discuss- in fact that is not possible over zoom. Only one person at a time and the emotion and important points are missed. The 2 guys said very little and may have said more face to face, even their expressions would have been visible’.

Some additional methods were suggested to increase group bonding such as support sessions and more chat time with other attendees. Four made positive

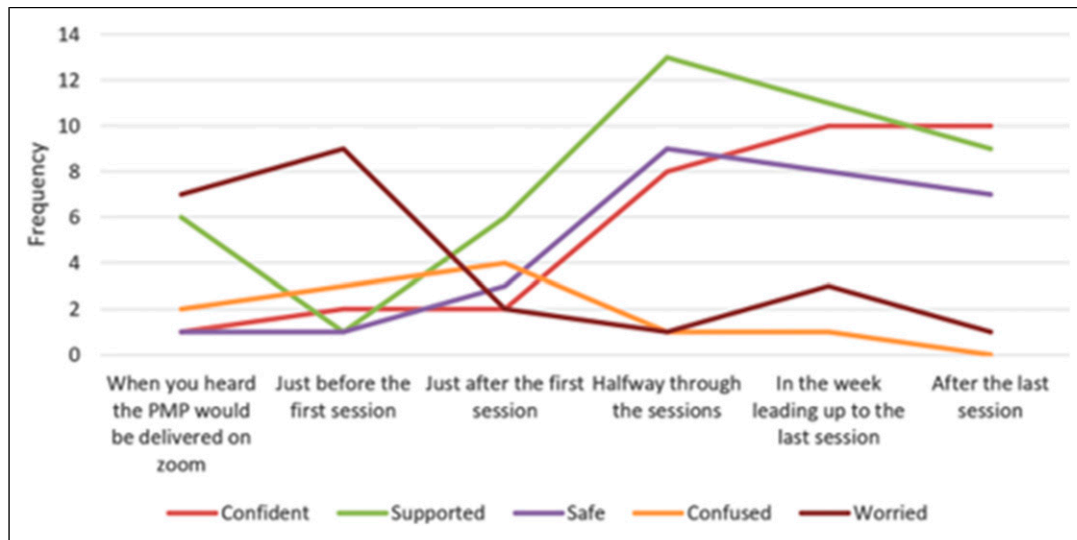


Figure 3. Outcomes from experience-based design questionnaire at touch points throughout the Pain Management Programme. $N = 14$.

comments about the format. Only one very strongly wished it had been face-to-face.

Two patients stated that, irrespective of the pandemic, they could only attend VTC. An increase in loneliness was observed in four participants halfway through the programme.

Individual pain management

Eight patients attended in-depth interviews over VTC facilities. There were several positive themes: flexibility with the ability to fit in around work, no travel time and the usefulness of video consultations in terms of maintaining visibility. Three key themes identified regarding patient difficulties – access to resources, technical difficulties and rapport building.

With access to resources

‘It was over the internet, and I am not on the internet.... I only just got my phone and it only has so many GB’s a month’

One reflected on how the positive impact of meeting staff face-to-face before the National lockdown impacted the rest of her treatment.

‘I managed to meet ... before lockdown which was great....I think if I had started my psychotherapy over the phone I’m not sure how easy it would have been’

Discussion

This study looked at patient experiences of VTC and RC during the COVID-19 pandemic to understand the

strengths, limitations and what can be learnt moving forwards for various methods and components of delivery of supported self-management of pain. Attrition was greater for VTC-PMP than the service’s standard PMP (33% versus 18% Face to Face (F2F)). However, the percentage of complete data sets received out of the possible number of treatment completers was similar across each condition (VTC, 65% versus F2F 70%). Physical rehabilitation components on PMP seemed less easy to convey remotely. Group pain education worked particularly well in an online format. Clear limitations were technical difficulties and the ability to form relationships in a virtual world.

In line with Eccleston et al., our results confirm minimal requirements for remote consultation include apps and videoconference programs installed on patients’ devices in addition to having highspeed internet connection.⁵ We also confirmed the importance of methods to build rapport in the absence of non-verbal cues such as silences, open posturing and empathetic touch. The virtual environment itself poses challenges to traditional patient-provider relationships and HCPs may need training to provide high-quality telemedicine care that builds up relationships.²⁷ Many participants identified positive support from staff in all three elements of the service. This helped participants feel calm and safe during sessions.²⁸ The option of remote consultations was better than no option and was certainly acceptable to many. However, there is little research available on the content, delivery and acceptability to patients and staff currently, particularly with group work. A study in general practice of group consultations highlighted the need for patients to be co-

producers of the service and care delivery would need to be substantially re-configured for the service to be successful.²⁹ The complexities of tele-psychiatry have been highlighted.³⁰ Use of the PERCS framework (Planning and Evaluating Remote Consultation Services), which covers system, organisational, technology and staff domains, may assist with development of remote services.³¹ A study of Swedish physiotherapists reported that most did not take up remote consultations readily, but felt there were potential significant benefits, for example, use of the chat function, SMS messages, online surveys and sending treatment plans via the internet.³²

The use of EBD methods highlighted some important elements to delivering group-based pain education and rehabilitation. The importance of 'hope' as a concept in relation to PAINEDU was raised and maintained throughout the session. Hope is known to have positive impact on patients with chronic pain,³³ building the likelihood of being able to participate in pain rehabilitation.³⁴ Patient responses to the EBD questionnaire highlighted the importance of delivering these PMPs in any way possible, rather than offering nothing or anxiety-provoking treatment delays. However, half of participants attending PMP said they did not feel there were opportunities for impromptu one-to-one conversations that help friendships to form. This is consistent with research on social learning⁸ and the limits of online group therapy.³⁵⁻³⁷ The lack of group cohesion may have contributed to the longer time it took for patients to feel comfortable and to feel that they were benefitting from the sessions. Use of the EBD model for both questionnaire and interview provided useful feedback on touchpoints throughout the intervention being delivered and allowed us to gain invaluable, rich information that may have not been collected using other methods.

PAINEDU was very positively received online and for some it was the only option. A proportion of the PMP could be safely delivered online. Inability to socialise and some difficulty with physical rehabilitation need to be considered and balanced against the low attrition rate. Access to the technology needed was a significant concern, especially as chronic pain tends to be concentrated in the more deprived populations³⁸ and services should consider whether loans of equipment and a training session would be useful to both patients and staff.

There were some limitations to this study. Researchers had limited access to resources due to COVID, time was limited to 3 months of data collection and numbers were thus small. We wished, however, to be rapidly assured that remote provision was safe; time was of the essence in doing this. This

means that the question 'how does remote self-management care for pain compare to more traditional face to face options?' cannot be answered. We simply know that it was an acceptable format for those who could access it. We do not know very much about those who had no access. Saturation was described as reached when no more themes could be coded (i.e. 'code saturation point'). This may have limitations in that a researcher may have 'heard it all' but may not have 'understood it all'.²⁴ It is possible that further interviews would have gained greater insight into the experiences. Gaining consent was challenging, due to the need to grapple with remote consent for the first time, with methods needing to be reworked several times to be ethically sound. The consequence was that the questionnaires returned were anonymised and so only group conclusions could be drawn from PMP and it was not possible to review the case-mix of PAINEDU. The response rate for EBD questionnaires was 44% – the self-selecting nature of the respondents may have thus skewed the results. Without direct comparisons available it is hard to know. Free text comments in questionnaires were broadly the same as interview responses in PAINEDU meaning that integrating the responses did not overly weigh the results in any direction although a greater number of people directly interviewed would have increased confidence in the findings. However, very few consented to further in-depth interviews and methods may need to change to increase this. EBD has not been widely used in pain management despite it being a recommended way to improve services¹⁶ meaning that there was no clear comparison of its use in other pain research.

In summary, the findings from our qualitative evaluation of the forced shift to Remote Care during the pandemic found it to be safe and acceptable to many patients. However, significant difficulties were reported by patients in terms of accessibility and technical concerns. A once-off Pain education session was particularly acceptable as were the Pain Management Programme mindfulness sessions. However, the need to run both face-to-face and remote sessions may limit its use. It may improve access for some. A framework for doing this is available and we would recommend this is followed.³⁰

This work could be repeated on a much larger scale to confirm our findings and identify potential subgroups who may benefit most from this approach. A lengthier, more in-depth set of interviews reaching 'meaning saturation' would likely enrich information in the area. The strong theme of hope is poorly investigated in the pain literature and appears of significant importance to patients. Further qualitative work

exploring this theme and how best to harness it may be beneficial, given its fundamental importance in engaging people in rehabilitation.



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ORCID iDs

Deborah LA Joy  <https://orcid.org/0000-0001-7318-5227>
Cathy Price  <https://orcid.org/0000-0003-0111-9364>

Supplemental Material

Supplemental material for this article is available online.

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