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“I could do it in my own time and when I really needed it”: perceptions of online pain coping skills training for people with knee osteoarthritis

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Abstract

Objective To qualitatively explore the perceptions and experiences of people with knee osteoarthritis (OA) who used an online automated pain coping skills training program (PCST).

Methods A descriptive qualitative study (based on interpretivist methodology) embedded within a randomised controlled trial. Individual semi-structured interviews were conducted with 12 people with knee OA who had participated in an 8-week automated online PCST program while also receiving exercise advice and support from a physiotherapist via Skype™. Interviews in this study focused specifically on the online PCST program, rather than the physiotherapy component. Interviews were audio recorded, transcribed verbatim, and thematically analysed.

Results Five themes arose: 1) easy to understand and follow (clearly explained; presented well); 2) better able to cope with pain (controlling pain; helping relax; pacing self; incorporating skills into exercise program); 3) anonymity and flexibility (no judgement by clinician; work at own pace; accessibility); 4) not always relatable or engaging (some techniques not useful; Americanisation of the program; annoying character examples; time consuming and slow-paced); 5) support from clinician desirable (follow-up from a clinician would be beneficial; worked in tandem with physiotherapist-prescribed exercise; desire referral to the program by trusted source).

Conclusions People with knee OA had generally positive experiences using an online PCST program, suggesting that online PCST is a broadly acceptable and accessible way to help people with OA to manage their pain. User engagement may be enhanced by redesigning some aspects of the program, and provision of support from a clinician.

Significance and Innovations

- There is some evidence that online pain coping skills training (PCST) can improve pain, function, and psychological health in people with osteoarthritis, yet little is known about user perceptions of such programs.
- People with knee osteoarthritis who completed an automated online PCST program had generally positive experiences, suggesting that it is a broadly acceptable and accessible way to help people with OA to manage their pain.
- Findings suggest user engagement may be enhanced by redesigning some aspects of the program, such as making some aspects optional and ensuring the program is delivered in a context-specific way that is relevant to the local culture or patient group.
- Having support from a clinician was highlighted as being important and the program was perceived to work effectively in tandem with a physiotherapist-prescribed exercise program, suggesting that physiotherapists and other clinicians should consider incorporating online PCST programs as an adjunct to recommended core management approaches like exercise.

Introduction

Knee osteoarthritis (OA) is highly prevalent, affecting around 24% of the adult population [1] and incurring enormous direct and indirect healthcare costs [2]. All current clinical guidelines recommend education and advice, exercise, and, if appropriate, weight loss for management of OA [3, 4]. Pain is the most common and debilitating symptom experienced by people with OA [5], and difficulty coping with pain has been associated with increased pain severity and greater emotional distress, muscle and joint tenderness, and pain-related disability, as well as poorer outcomes from treatment [6]. People with OA may also reduce their physical activity because they fear that movement will exacerbate their pain [7, 8]. As such, the development of effective and accessible psychological interventions that help people with OA cope with their pain is important [9, 10].

One such psychological intervention is pain coping skills training (PCST), a form of skills training informed by cognitive behavioural principles. PCST helps patients reconceptualise

how thoughts, feelings, and behaviours influence pain and systematically trains them in skills such as relaxation, goal setting, and the use of positive coping thoughts to reduce pain catastrophizing [11]. Studies have shown that PCST leads to improvements in pain, physical function, and psychological distress in people with OA and rheumatoid arthritis [11]. Although PCST is generally delivered by a psychologist specialising in pain management, there is more recent evidence that a combined exercise and PCST intervention delivered by physiotherapists significantly improves pain and function in people with knee OA to a greater extent than either exercise or PCST alone [12].

Healthcare clinicians trained in the delivery of PCST, such as psychologists, may be difficult for some people with OA to access. For example, in Australia in 2016, there were only 23.8 and 14.8 psychologists per 100,000 population in remote and very remote areas, compared to 74.5 per 100,000 in major cities [13]. As such, delivering PCST remotely via the internet is one potential way to increase accessibility. An online self-guided PCST program was developed by our team in the USA to provide an accessible, low-cost option for people with OA who may be unable or unwilling to visit an appropriately trained clinician in-person [14]. One study investigated the efficacy and acceptability of that program in a 2-arm randomised controlled trial, finding that online PCST led to improvements in pain and self-efficacy for pain management amongst people with hip and/or knee OA [15]. Another more recent study investigated the effectiveness of delivering that same online PCST program before a home exercise program for people with hip OA, compared to the home exercise program alone [16]. Participants in the PCST group experienced improvements in pain coping as well as pain and function immediately after completing the program. However, although improvements in pain coping were sustained, there were no significant differences in pain and function between groups after the exercise program [16].

While there is emerging evidence supporting the efficacy of online PCST for people with OA, little is known about user perceptions of such programs, including whether they are perceived to be safe, effective, or useful. There is some evidence that patients with mental health issues [17] and people with bulimia [18] who have undergone internet-based psychological interventions (including cognitive behavioural therapy) valued the flexibility and accessibility, but expressed concerns about privacy, lack of face-to-face support, and the requirement for computer literacy. Cancer patients with bone pain who completed an online PCST program did not express similar concerns [19], reporting generally positive responses

to the program's content, length, and function as well as the ability to use the program at home. To our knowledge, no previous studies have explored the perceptions people with OA have towards online PCST. Thus, the aim of this study was to qualitatively explore the perceptions and experiences of people with knee OA who participated in a randomised controlled trial (RCT) involving an online PCST program.

Methods

Design

A qualitative design based on interpretivist paradigm [20] was used to explore participants' experiences of our online PCST program. According to this paradigm, knowledge about a phenomenon is developed by gathering perceptions of participants who experience it [20]. This qualitative study was nested within the IMPACT randomised controlled trial [21] which evaluated the effectiveness of an intervention combining internet-delivered physiotherapist-prescribed home exercise and online PCST. The Consolidated Criteria for Reporting Qualitative Research checklist was used to ensure complete and transparent reporting of this qualitative study [22].

Participants

A subset of participants from the intervention arm of the trial were invited via purposive sampling to participate in this nested qualitative study 3-6 months after completing the 3-month intervention. This involved inviting a mix genders, a range of ages, and people from metropolitan and rural areas. Inclusion criteria for trial participants have been described in detail elsewhere [23] and briefly included being aged ≥ 50 years, having persistent knee pain for more than three months and for most days of the past month, self-reporting a minimum average knee pain intensity walking score of 4 on an 11-point numerical rating scale and at least mild-moderate physical dysfunction (score > 20 on the Western Ontario McMaster Universities (WOMAC) physical function subscale), and having access to a computer with internet connection. Participants were recruited Australia-wide via media campaigns and advertisements (e.g. in newspapers, university websites, and on Facebook and Twitter), and using our research volunteer database.

The final sample of 12 participants was dictated by the principle of theoretical saturation, where data were analysed in an ongoing manner after each interview and, when no new categories or themes emerged, no new participants were invited [24]. All participants

provided written informed consent prior to participation and the institutional ethics committee approved the study.

Intervention

The intervention has been described in detail elsewhere [23]. Briefly, participants randomised to the intervention group received seven consultations with a physiotherapist delivered via Skype™, where they were prescribed an individualised home-based exercise program to be performed three times per week. Participants also simultaneously received login access to the PCST program, which was previously developed for research purposes and is guided by social cognitive theory and adult learning theories to ensure skill mastery [14]. Physiotherapy sessions generally occurred in week 2, 3, 4, 6, 8, 10, and 12 of the 3-month intervention, with participants asked to complete PCST modules in week 1-8, with a booster session at week 11 (involving an email encouraging participants to revisit the modules they found most useful). The PCST program involved eight 35-45-minute online modules to be completed at a rate of one session per week (described in Table 1). The first module provided an overview of the program, a therapeutic rationale involving a simplified version of gate control theory, and an introduction to progressive muscle relaxation as the first pain coping skill. The second to seventh modules taught: i) brief relaxation practices (“mini-practices”); ii) activity-rest cycling; iii) pleasant activity scheduling; iv) cognitive restructuring (developing “coping thoughts”); v) pleasant imagery, and; vi) problem solving. The final module taught strategies to enhance long-term use of pain coping skills.

Participants were led through the program by a female virtual coach who provided verbal descriptions and instructions of each pain coping skill, walked users through interactive exercises that allowed them to try a skill and review their experience with it, and followed up with feedback and encouragement to practice the skills. Instruction was mainly provided in audio format, with important points emphasised with onscreen text or graphics. Modules began with a review of the previous weeks’ skill, including a review of the number of practice sessions the participant completed between modules. If participants had trouble completing practice sessions, the program gave prompts to help them identify why they did not practice, problem solve obstacles and challenges to practice, and develop solutions so they could improve next time. The new skill for that module was then introduced, after which participants were given a chance to practice using it and asked to evaluate their experience by, for example, rating how relaxed or calm they felt afterwards. At times throughout

modules, characters modelled after OA patients appeared and spoke about their own experience using the skill, how it helped their pain, and how they dealt with challenges of applying the skill. At the end of the session, participants were asked to select practice goals for using their new skills in the coming week. Participants were able to go back to review previously-completed modules at any time.

The PCST program also included three optional modules to assist practice and enhance engagement: i) a module to help participants self-monitor their progress by setting goals, recording number of practice sessions completed, rating self-efficacy, and managing automated email reminders to practice; ii) a module that allowed participants to read about other people's experiences using the pain coping skills and write about their own experiences, and; iii) a module that provided participants with information about the program and actions to take in a medical or mental health emergency. The home page of the program also displayed reminders and badges that could be earned by completing practice sessions and tasks.

Prior to starting the intervention, participants were mailed an instructional manual and workbook which included information on each session, as well as password access to the program. Participants also received monthly email reminders from the trial coordinator during the 6-months following the intervention to encourage them to continue their exercises and practice their pain coping skills. Physiotherapists were asked to encourage participants to complete the pain coping skills modules.

Interviews

Individual semi-structured interviews were conducted over the telephone by RKN, the coordinator of the IMPACT trial, who had phone screened and enrolled all trial participants and who is also a physiotherapist. The interview guide is displayed in Table 2. Interviews were audio recorded and transcribed verbatim by an external transcription service. Pseudonyms were assigned to each participant for confidentiality. Data were de-identified and stored in digital format on a password-protected university server.

Data analysis

Data analysis was based on a thematic approach [25]. Transcripts were read through by RKN soon after transcription to check for accuracy. BJL, a researcher trained and experienced in qualitative research methods, performed coding of transcripts. This involved reading through

each transcript in detail and identifying topics and initial patterns of emerging ideas. Once each transcript had been coded, similar topics or ideas were grouped into categories, before being organised into broader themes and sub-themes. RKN, who performed all interviews, reviewed initial drafts of developing codes and themes to ensure that they reflected interview data. Final themes were reviewed and deliberated by all members of the analysis team (BJL, RKN, RSH, KLB). Disagreements were resolved through discussion until consensus was reached.

Results

Participants

Table 3 describes the twelve participants who were interviewed. The majority were female (58%), living in metropolitan areas of Australia (58%), had graduated from university/polytechnic or had postgraduate qualifications (58%), and half were employed either full- or part-time (50%).

Themes

Five themes arose (Table 4): i) easy to understand and follow; ii) better able to cope with pain; iii) anonymity and flexibility; iv) not always relatable or engaging, and; v) support from clinician desirable.

The first theme was: “easy to understand and follow”. Participants found that the concepts and techniques presented in the PCST program were clearly explained in simple language that was easy to understand: “it made sense, you know I must say the whole program was very good in explaining the whys and [what] fors” Bob (Table 3 and 4). Participants also believed that the program was presented well by the main female virtual coach, in that it was not too “clinical” and that her voice was “calming” and “clear”.

The second theme was: “better able to cope with pain”. Most participants believed that the pain coping techniques that they learned helped them better control their pain and that they no longer felt overwhelmed by it. Participants had different perceptions about which techniques were most useful for them. Many found that the relaxation techniques (progressive relaxation and mini relaxation practices) helped them alleviate muscle tension and reduce stress. Participants valued the activity-pacing technique, finding that it helped them avoid flares in pain and break activities into smaller more manageable segments. The

pain coping skills also helped participants control any pain experienced during the exercise program that was prescribed by the physiotherapists in the overarching IMPACT trial.

The third theme was: “anonymity and flexibility”. One perceived advantage of the program being online was that it provided anonymity, in that participants felt that they were not being judged by a “smart” clinician. For example, participants felt more comfortable being able to go back into previous modules to clarify or review concepts themselves without feeling embarrassed by having to ask a clinician to do so in-person: “if I didn’t understand something I could just replay it without feeling like I was a ditz” Alice (Table 3 and 4). The flexibility of the program was also an advantage, where participants found that they could progress at their own pace and at a time and place (e.g. home, work) that was convenient to them: “I liked the fact that I could do it in my own time when I was ready to do it and when I really needed it. I didn’t have to worry about going somewhere having appointments.” Sandra (Table 3 and 4).

The fourth theme was: “not always relatable or engaging”. Many participants found that some of the techniques were not useful or applicable to them, in that they were “not finding the benefit” or that they “don’t really think it added much value”. However, there was no clear consensus on which techniques were the least helpful, and each participant had different preferences: “there are other strategies that might be appropriate for other people...I struggled with some of the techniques that they were trying to convince me to do and use. And even though I tried them it was just not [for] me” Melanie (Table 3 and 4). The “Americanisation” of the program (i.e. American accent of the virtual coach and characters) was perceived to be a negative aspect by some, and most believed that they would have liked the program more if it were presented by people with local Australian accents. The character examples, where two or three people appeared onscreen to speak about their own experiences using the techniques, were described as “annoying”, in that they felt “fake” and “scripted” and broke the momentum of the program for some participants. Some participants found the program to be slow paced and time-consuming, and many would have liked an option to skip ahead at points where they felt they had already grasped the concept and were ready to move on.

The fifth and final theme was: “support from clinician desirable”. Although participants valued the anonymity and convenience of the online PCST program, they expressed some desire for some kind of follow-up from a clinician either via email or telephone to “touch

base” and see how they are progressing, and to reinforce key PCST principles. Participants also believed that the PCST program worked in “tandem” with the home exercise program prescribed by the physiotherapists via Skype™ in the trial, and that the program would not have been so effective in isolation: “it was like a whole package and I really thought that was really good. If I would have had the physio and then the [online PCST program] or the other way round I don’t think it would have worked so well....it’s like a tandem thing, like a thing that works together” Sandra (Table 3 and 4). For referral to the PCST program in the future, participants believed that it would be most acceptable and trustworthy for referral to come from a health professional, such as their general practitioner, rather than the program being generically available on the internet or social media (e.g. Facebook).

Discussion

The aim of this study was to explore the perceptions and experiences of people with OA who completed an online PCST program. We found that participants generally described positive experiences using the program, valuing its anonymity and flexibility and believing that it helped them better manage their pain. However, at times, some participants found that the program was difficult to engage with or relate to, and that it could be time-consuming and slow-paced. Collectively, findings suggest that an online PCST is a broadly acceptable and accessible way in which people with OA can manage their pain, particularly if the program can maintain user engagement and involves support from a clinician.

One perceived advantage of the PCST program was the anonymity and flexibility that it offered participants by being online, rather than delivered in-person by a clinician. This reflects the findings of previous studies investigating perceptions of internet-based psychological programs [17-19]. For example, one study used a survey to evaluate preferences for internet-based psychological interventions, compared to face-to-face, for use of mental health treatment [17]. Participants in that study believed that the main advantages of internet-based interventions were flexibility, accessibility, and anonymity. Another qualitative study explored the perceptions of nine people with bulimia nervosa or related eating disorders who used an internet-based cognitive behavioural program [18]. Those participants found that the program was easy to fit into their lives and they valued the privacy and confidentiality of online delivery. Collectively, these findings suggest that the convenience and accessibility of online delivery has the potential to address barriers to

cognitive behavioural interventions, such as lack of access to trained therapists as well as the inconvenience of travelling to attend a clinic in-person at a set time [26, 27]. In addition, the self-directed nature and anonymity of online PCST programs may help patients feel more comfortable addressing their pain than if they were to speak to a clinician in-person [28], which may also help people feel more empowered and in control of their condition [17].

Although participants valued the anonymity and privacy of the PCST program, most also believed that having support from a clinician was important, and that it would not have been as effective if not done in conjunction with the physiotherapist-prescribed exercise program. To our knowledge, no previous studies have explored the perceptions of participants who completed an online PCST program (or similar) in addition to receiving care from a clinician. However, previous research does suggest that people who complete online psychological programs also desire some kind of follow-up support from a clinician [17-19]. For example, interviews with people with bulimia nervosa who used an online cognitive behavioural program revealed that receiving email support from clinicians during the intervention was vital to help participants feel more supported and make the experience more personal, as well as provide motivation to complete sessions [18]. Similarly, patients with cancer pain who completed the same online PCST program as in our study [19], required phone calls by study staff to encourage completion of the program. These findings suggest that, although online PCST programs have the potential to be a low cost and accessible way in which people can manage their pain, including some kind of support from a clinician may help improve adherence to, and the effectiveness of, such care [29]. Further research is required to determine how best to combine online self-directed programs with clinician support without compromising the potential cost-effectiveness and convenience of online delivery [30].

Participants in our study believed that, to improve the credibility of the PCST program, it should be recommended to patients by a clinician, rather than being freely available on the internet or advertised on social media. The qualitative study by Rini and colleagues [19] involved focus group interviews with physicians or advanced practice providers who had experience providing care for people with cancer pain. Those clinicians believed that online PCST would be useful, however thought they would have difficulty finding time or remembering to discuss such a program with their patients. They recommended that nurses or pharmacists might be better able to support use of the program because they would have more time to address symptom management and to check patients' progress over time. In

addition to time pressures, clinicians such as physiotherapists and general practitioners tend to adopt “biomedical” approaches to care (i.e. focus on biological aspects of pain or injury) and are not traditionally trained to provide psychologically informed care to their patients [31, 32], and they may not acknowledge, or be aware of, the benefits of doing so. Further investigation is required to determine the best way of directing people with chronic pain to online PCST programs, and whether clinicians believe that they are best-placed to do so.

At times, participants experienced difficulty relating to, and/or engaging with, aspects of the online PCST program. Some participants found that some techniques were not useful for them, and the program was described as often being slow paced. Many believed that they would have liked to have been allowed to skip certain modules that they perceived to be ineffective. Participants with bulimia nervosa also found that some of the content of their online cognitive behavioural therapy program was irrelevant and became repetitive at times [18]. However, those participants also acknowledged that including a range of techniques in the program was important to make it applicable to a broad spectrum of people, and also allowed participants to gain a general understanding of all concepts involved. Similarly, in our study, different participants found different techniques to be useful, suggesting that providing patients with a range of different techniques to try is important. Whether the number of modules can be reduced, or some could be made optional rather than mandatory, without making disengaging participants and sacrificing the potential efficacy of the program is worth consideration.

Our study was conducted in Australia and participants disliked the fact that the program was delivered by people with American accents. This is consistent with evidence that people can have more negative perceptions of people who speak with non-native accents, and believe they are less pleasant to listen to [33, 34]. These perceptions are likely linked to local culture and a sense of familiarity or similarity, which may influence the perceived trustworthiness and likability of the speaker [35]. Similarly, participants in our study overwhelmingly disliked the character examples presented throughout the program, believing that they “weren’t real people” and were difficult to identify with or relate to. People with persistent cancer pain who completed the same online PCST program similarly believed that it should include cancer-relevant examples and depictions of younger people like themselves [19]. Collectively, these findings suggest that online PCST programs will be more acceptable to

users if they are context-specific and relevant to the local culture and/or the particular patient group.

Our study had a number of strengths and weaknesses. A strength of our study is that we interviewed a range of participants, including males and females of varying ages and occupational status who lived in metropolitan and regional areas across Australia. Our study also had some limitations. Only one researcher (BJL) performed coding and initial organising of data into themes, thus findings may be influenced by her individual beliefs or perceptions. Participants volunteered to participate in the trial and an interview, and as such our data may be biased towards those who have a greater interest in online interventions and who are willing to share their thoughts and experiences. In addition, more than 75% of our sample had at least some tertiary education, and thus our data may not be generalisable to those with a lower level of education. In fact, there is some evidence that level of education moderates the effects of PCST in people with hip and knee OA, with those who have a higher level of education experiencing greater improvements in outcomes, including pain, fatigue, self-efficacy, and quality of life [36].

In summary, people with knee OA had generally positive experiences using an online PCST program, suggesting that an online PCST is a broadly acceptable and accessible way to help people with OA to manage their pain. User engagement may be enhanced by redesigning some aspects of the program, such as making some aspects optional and ensuring the program is delivered in a context-specific way that is relevant to the local culture or patient group. A revised version of the PCST program used in this study is now freely available (www.paintrainer.org). In addition, provision of support from a clinician was highlighted as being important, and that the program worked effectively in tandem with the physiotherapist-prescribed exercise program. Findings add to existing evidence [12] suggesting that physiotherapists and other clinicians should consider incorporating online PCST programs as an adjunct to recommended core management approaches like exercise.

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Table 1. Summary of the online pain coping skills training program content

	Name of technique/skill	Content of module
1	Progressive muscle relaxation	<ul style="list-style-type: none"> - Introduce program and concept of pain coping skills - Teach gate control theory - Introduce progressive muscle relaxation and lead practice session - Evaluate feelings of relaxation after practice - Identify strategies to overcome obstacles to use of skill - Set goal for practice sessions over next week
2	Mini-practices (brief relaxation skills)	<ul style="list-style-type: none"> - Review progressive muscle relaxation and completed practice sessions - Introduce “mini-practices” and lead practice session - Evaluate pain after practice - Identify strategies to overcome obstacles to use of skill - Set goal for practice sessions over next week
3	Activity/rest cycling	<ul style="list-style-type: none"> - Review mini-practices and completed practice sessions - Introduce activity/rest cycling and identify activities that participant may overdo - Show examples to demonstrate how to change overdone activities - Create plan to incorporate plan into daily routine - Set goal for practice sessions over next week
4	Pleasant activity scheduling and identify negative automatic thoughts	<ul style="list-style-type: none"> - Review activity/rest cycling and completed practice sessions - Introduce pleasant activity scheduling and demonstrate example of how to select and add pleasant activities to routine - Schedule pleasant activities for week and problem-solve barriers - Introduce negative automatic thoughts and demonstrate how to identify them - Set goal for practice sessions over next week
5	Identify/change negative automatic thoughts and coping thoughts	<ul style="list-style-type: none"> - Review pleasant activity scheduling and completed practice sessions - Introduce coping thoughts and lead example creating coping thoughts - Identify strategies to overcome obstacles to use of skill - Set goal for practice sessions over next week
6	Pleasant imagery and distraction techniques	<ul style="list-style-type: none"> - Review coping thoughts and completed practice sessions - Introduce pleasant imagery and provide opportunity to practice - Set goal for practice sessions over next week
7	Problem Solving	<ul style="list-style-type: none"> - Review pleasant imagery and completed practice sessions - Introduce concept of problem solving and demonstrate use of skill - Practice selecting skills for different situations - Set goal for practice sessions over next week

-
- Review all sessions
 - Evaluate skill use, helpfulness, and comparison to other user experiences
 - Develop plan for maintenance of skills
 - Motivate further practice and skill development
 - Review practice goals
-

Adapted from Rini, Porter [15]

Table 2. Semi-structured interview guide

1. Think back to when you first started the online PCST program, what were your initial thoughts about the program?

What were your expectations of using the online PCST program for your knee problems at the start of the program?

2. What did you learn from the [online PCST] program?

What did you learn about how thoughts, feelings, or behaviours can affect your pain?

Was this new information for you or was it a “refresher” for knowledge you already had? if the latter, where did you get this information/knowledge previously?

3. In what ways did or didn't the online PCST program help you become more aware of how your thoughts, feelings or behaviours affect your pain?

What was helpful about the online PCST program?

What about the program did you find less helpful if anything in helping you understand the role of feelings thoughts and behaviours?

4. What is your impression of learning these skills like you did, on the computer without face to face contact from any professional?

What did you like about the program /what didn't you like?

What stands out as different from the skills training in the online PCST program from the way you have learned things face to face with a health professional before?

What do you think is the best way to learn a new skill?

5. What particular pain coping skills stand out as most useful to you in your daily life?

How are you using them? How do they help?

What was least useful?

What else, if anything, would you have liked the program to do that would have addressed any difficulties you had when you were practicing the skills?

6. So what specifically about the online PCST program helped you learn the skills to be able to use them in your daily life?

Thoughts on presenter dialogue/ interactive exercises/ability to reflect or stories told by characters? What did you do if you didn't understand something initially?

7. How did you feel doing the physiotherapy exercise at the same time as the online PCST sessions?

What role did the physiotherapist play (if any) in helping you understand the skills and how they could be useful? How did you find the time commitment?

8. Since having had the experience of the online PCST program how have things changed for you (positive or negative) – regarding your knee pain or how you feel physically or emotionally?

How have you changed? What would you say is the most lasting impact of the program?

9. What additional advice do you have for us about the online PCST program and the information it contains as we begin to improve this program to use with people suffering from knee symptoms in the wider Australian community?

Thoughts on length - currently is 8 weeks long. Was that too long, too short, or just about right?

How best to access ie referred to the website by a health professional, just something you find in a google

search ie on arthritis advocacy websites.

10. Is there anything else you would like to add about your experience with the online PCST program?

PCST: pain coping skills training

Questions in italics were used as prompts if necessary.

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Table 3. Participant details (n = 12)

Pseudonym	Age	Gender	Geographic location#	Level of education	Employment status	Knee pain (NRS)	Physical function (WOMAC)	Pain catastrophizing (PCS)
Bob	68	Male	Regional	Graduated from university/polytechnic	Retired (not due to health reasons)	7	31	1
Sandra	67	Female	Regional	Graduated from university/polytechnic	Retired (not due to health reasons)	5	35	13
Andrew	56	Male	Metropolitan	Three years or more of high school	Work full-time	6	25	8
Alice	62	Female	Metropolitan	Some tertiary training	Work part-time	6	26	5
Jane	69	Female	Regional	Three years or more of high school	Retired (not due to health reasons)	5	36	0
Olivia	65	Female	Metropolitan	Graduated from university/polytechnic	Work part-time	8	45	9
Caroline	57	Female	Metropolitan	Graduated from university/polytechnic	Work part-time	7	44	8
Melanie	58	Female	Metropolitan	Any postgraduate study	Retired (not due to health reasons)	7	32	8
Simon	65	Male	Regional	Some tertiary training	Permanently unable to work due to health	8	34	13
John	55	Male	Metropolitan	Graduated from university/polytechnic	Unemployed	5	35	10
Adam	52	Male	Regional	Graduated from university/polytechnic	Work full-time	3	23	4
Lauren	58	Female	Metropolitan	Some tertiary training	Work part-time	5	32	0
Mean (SD)	61 (6)					6 (2)	33 (7)	7 (5)

#Defined according to The Australian Statistical Geography Standard Remoteness Structure (<http://www.abs.gov.au/websitedbs/d3310114.nsf/home/remoteness+structure>)

NRS: numeric rating scale; ranges from 0 to 10 where lower scores indicate less pain

WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index – physical function sub-scale; ranges from 0 to 68, where lower scores indicate better function

PCS: Pain Catastrophizing Scale; ranges from 0 to 52, higher scores indicate greater catastrophizing

Table 4. Themes, sub-themes, and exemplary quotes

Sub-theme	Exemplary quote
Theme 1: Easy to understand and follow	
Clearly explained	<p>Bob “it made sense, you know I must say the whole program was very good in explaining the whys and [what] fors...I think the whole program is very well set up and it certainly does, I mean it teaches you the skills and then through the follow ups and the program right through to the end, just keeps reinforcing what you need to do to improve it. I thought it was very good.”</p> <p>John “The introductory section about, you know, pain and how its transmitted to the brain...It sort of did it in a very basic way. It wasn’t really complicated in terms of the, the human anatomy but and how that works but I thought that was really useful”</p> <p>Sandra “It was very well explained and put together and I found it easy...you understood exactly what was meant with the exercises”</p>
Presented well	<p>Alice “I found that I really liked the way the lady talked. I really, really did. I liked her accent and I liked the way she explained things...I just liked the way that she worded it. It wasn’t over long that what she was trying to tell you. She was very clear about what she was saying.”</p> <p>Olivia “I think [the presenter] was excellent she was very good, she was very straight forward with what she said. Everything was very easy to follow.”</p> <p>Jane “listening to the presenter, she’s really good the way they put that presenter on and her voice and everything is all very calming and enlightening. I find that very helpful”</p> <p>Adam “the dialogue ... Just the ease of kind of it didn’t actually sound very clinical at all. It sounded very basic, very generic, very user adaptable and easy to understand and quite relevant”</p>
Theme 2: Better able to cope with pain	
Controlling pain	<p>Sandra “I have I think learnt from [the online PCST program] that you can actually ride the pain out as it where, you can actually deal</p>

with it, whereas, before that it was always you were scared of pain because you thought you couldn't deal with it but now I know you can actually deal with it in some way, you have some control. I mean you can't get rid of it but you can deal with it"

Caroline "I learnt so much...the pain - I can control it. I know I can control it. It's also taught me to control my mental side of the pain, which has been huge...It put me in control. It put me in the driver's seat"

Olivia "I can control the pain a bit more... A few minutes to sit down and stop and do one of the practices for the [online PCST program] just changes things for you... they're very positive thing to get me through the days"

Helping relax

Jane "[progressive relaxation] is particularly helpful and I was able even to drop off sometimes during it, it was really calming and soothing and it really helps you relax. I found it very, very good."

Andrew "I used to like doing pleasant imagery distractions where you can go and relax and just go and pretend you're somewhere else...you could sit back and just with the progressive relaxation you just sit back and listen to your body and really focus in on to the part that was on your knee that was annoying you"

John "the relaxation techniques were really good, not just for pain, but it's just to - to get you back down into a calm state. I really enjoyed that. I really, I really thought that was really good"

Pacing self

Adam "the other things that I kind of fully got out of the [online PCST program] was also spacing out jobs and actually taking a break every so often...[normally] I'll just keep on going until I collapse...[now] I'll spend an hour doing work or whatever and then I will actually have a, you know, a ten minute cut off break or whatever."

Sandra "I think the one about pacing yourself was really good. I thought that stood out for me in my daily life because I wasn't doing that before...saying "I can do that later, my knee is now bad I'm going to sit down and do that later" or give myself a break for 10 minutes and then keep going"

Caroline "my biggest thing is that the work-rest cycle - I can plan, and I now know that if I need to do something, I can do it, but I just

	break it down into smaller amounts...I will rest it, and then I'll go back and I'll go back to where I need to be and do things in smaller amounts."
Incorporating skills into exercise program	<p>Bob "if you're doing the exercises, you start to get pain or whatever, you can stop and take a few deep breaths and sort of re-focus before you get back to it...taking a break, a rest cycle, doing some of the other stuff, the pleasant imagery or whatever to help them get through the exercise program."</p> <p>Jane "it was helpful when you're doing the exercises because you might, when you're feeling in pain you can go to your [online PCST program] and learn how to cope with that and do your relaxation techniques as well to help you if you're feeling any pain from your exercises or from what you're doing around the house. So it is helpful to have them in conjunction"</p>
Theme 3: Anonymity and flexibility	
No judgement by a clinician	<p>Alice "if I didn't understand something I could just replay it without feeling like I was a ditz...You haven't got anybody judging you. I like that. I like the fact that you know sometimes I didn't do a really good job that week for one reason or another but I was never judged. So you don't have that person looking at you. I loved it."</p> <p>Jane "I liked the presenter even though she wasn't there with me...sometimes [a clinician] might be a bit smart, they're very knowledgeable and they are making out they are so you might be thinking well they're a bit smart sort of thing so you don't feel as comfortable with them. So it was good on the computer the way that woman presented herself."</p>
Work at own pace	<p>Sandra "It's just something you can go back anytime you want to, you can think "oh, what did they mean with that" and you go back and you just see it again. If you're talking to someone in an office you can't go back and say "what did you mean by that?", you know what I mean? It was for me it was perfect"</p> <p>Jane "on the computer being able to go in there and be able to replay if you wanted to listen to the segment over and over again. I thought that was very helpful as a lot of us tend to forget very easily and I find it's better, myself, to see it on the computer like that, interact with it"</p>
Accessibility	Andrew "you could do it at your time when you had the time...if you didn't feel like doing it today you do it tomorrow or something. If

you only want to do half of it you could do half of it and go back another day”

Sandra “I liked the fact that I could do it in my own time when I was ready to do it and when I really needed it. I didn’t have to worry about going somewhere having appointments.”

Adam “The fact that you can just access it at any point in time. It was online like, you know, there were a few times when I did it while my son was doing soccer training in the evenings and there were a view times like on a Sunday morning when I just sort of log in quietly while I was chilling up in bed and I’d watch it.”

Theme 4: Not always relatable or engaging

Some techniques not useful

Melanie “if you were able to pull off and say look, I like the look of this technique and that one and so customise the delivery a bit. I think that probably would have been better for me...you get to a point and you go I can’t be bothered. I’m not finding the benefit that it’s asking me to do. Not the [techniques] I felt comfortable with, it asked me to do those other ones and I was thinking “I don’t want to do that”; sit there and think about being on a beach. I don’t want to think about that”

Lauren “[the online PCST program] wasn’t my cup of tea, so to speak, that’s all, and sure, it might help for some people but, you know - like on some of the tapings on there, you know, I’m sure maybe it helped some people but I don’t know, I didn’t find it all that beneficial”

John “the pleasant activity scheduling and all that sort of stuff, you’ve really got to try and, you know, program something in your life, get some spare time in your life to do all of that. So that’s a little more difficult to do and as I said before I didn’t really think that that added much value to me personally”

Americanisation of the program

Andrew “the only thing I didn’t like the American accent...get rid of those American accents”

Olivia “I don’t particularly like the Americanisation it was very American...it would be a problem for some people I think... it would be better with a program more based in Australia”

Melanie “I think the American accents with the American examples, if there is any way you can get an Australian example or Australian

	presenters to do it, I think that would work.”
Character examples were annoying	<p>Sandra “These people that come on and say what their experiences were like, I find them the least useful... it’s almost was to me as if I was doing the [online PCST training] and I was right into it and then these people come on and it’s like, “oh God, okay, I’ll listen to you because I have to but I don’t really want to”. I was on a roll as it were and I thought “oh, well, now here they go, yes, I know, I know”.”</p> <p>Caroline “[the character examples] felt like they were actors. They weren’t real people. So, I turned off pretty quick...if I could have skipped past that, possibly yeah, that would have been – maybe not more helpful, because everything that I was doing I was finding helpful – but for me, personally, I didn’t find that necessary”</p> <p>John “The ‘next’ button very important for people who don’t want to listen to that through the [character] examples in particular because I didn’t really think the examples were much good either way. They sounded fake to me, you know, they sounded like they were scripted”</p>
Time consuming and slow paced	<p>Lauren “I don’t know, maybe it was a bit too time consuming for me...it took a heck of a lot of time, for me, and, like I said, some days I just couldn’t do it”</p> <p>Melanie “I thought “yes, yes, yes, I got what you’re trying to get me to do but do I have to listen to all of this?” You can’t skip ahead and move on. You’re forced to sit there and listen to it all as well”</p> <p>Sandra “I think it was a little bit longwinded...to me it was almost like, “oh, come on get on with it”. For me personally it was too slow, I know that some other people who are elderly and have these problems and whatever probably need the slowness of it, but to me it was almost a bit longwinded.”</p> <p>John “It was a bit drawn out with some of the examples. So, you know, you sort of like - it was a bit slow paced I guess, ... “yeah I did this, yes keep going, hurry up”.”</p>
Theme 5: Support from clinician desirable	

Follow-up from a clinician would be beneficial	<p>Bob “I guess maybe some follow up would be beneficial. There are times when you sort of, you experience kind of mini break throughs, where you thought this is terrific, I feel great and you want to share that in a way... as a telephone call or whatever, just to touch base and assess you know how the person’s going and how they’re coping”</p> <p>Caroline “maybe once a week if someone could just touch base and just say, are you okay? Because sometimes, if people aren’t coping well, it is difficult to take that step to pick up the phone to ring. But if someone rings you, it can make a big difference”</p> <p>Olivia “when I was seeing the physiotherapist every couple of weeks or whatever that was good because that gave added support to the [PCST program]... being able to speak to someone would be an advantage rather than just having something online even if you speak to someone about the pain that say it face to face even on Skype would be good rather than just an animated character”</p>
Worked in tandem with physiotherapist-prescribed exercise	<p>Sandra “it was like a whole package and I really thought that was really good. If I would have had the physio and then the [online PCST program] or the other way round I don’t think it would have worked so well....it’s like a tandem thing, like a thing that works together”</p> <p>Caroline “[the online PCST plus the physio consults] incorporated it into a whole program...doing physio with the rest of the [online PCST program], I think it’s needed as a whole package. One without the other wouldn’t have worked”</p> <p>John “the physio was all about building up your muscle strength around your knees and your back and the [online PCST program] was all about training your mind to manage the pain. So I think they were linked, I think it’s good that they were linked together. Doing it one, just doing one and not the other probably lessens the impact of the outcomes I guess. So, you know, the outcomes were, I think anyway, the outcome for me was more enhanced because I did both together”</p> <p>Melanie “I think having the physio well and truly aware of what stage a person should be at within the Pain Coach, it actually helps reinforce it rather than have it presented as two separate things.”</p>
Desire referral to the program	<p>Sandra “I think it’s probably best if you get given [referral to the online PCST program] by a health professional because overall I think a</p>

by trusted source

lot of people don't use computers very much in that sense, they don't go and Google it... the doctor can say "look, there is this program" and I'm sure people would access it."

Olivia "if a health professional referred you there maybe you're more inclined to take notice of it. Then an arthritis website you're more inclined to take notice of it."

John "if a health professional told me to do something, I know that the health professional is saying you need to do this because its going be beneficial to you. So I think you get more impact from a health professional telling you to do that or suggesting that as part of your treatment"

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