

Ten Footsteps 2021. An Online course to support self-management of pain

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Abstract

Objective

To describe an online self-management course that was piloted as part of Footsteps 2021, an online festival provided on a voluntary basis by a team of health care professionals and experts by experience with the intention of supporting people to live well with pain.

Design

A feasibility study to assess who would engage with the course and potential areas of benefit. The Ten Footsteps Course mirrors a multidisciplinary pain management programme and was offered to anybody who identified that they would find it helpful to attend the sessions.

Results

A pre-course survey indicated that people who signed up were familiar with the idea of self-management and were largely in alignment with its ethos. Scores completed on a range of questionnaires were in alignment with those reported from formal pain management services. Thirty-two people completed the pre-course questionnaire. Only nine people completed a follow-up questionnaire at the end of the course. At the end of the course average reported levels of self-efficacy were higher and catastrophizing were lower compared to at the beginning while pain intensity and overall wellbeing did not differ at the two timepoints.

Conclusions

Pain self-management support co-produced and delivered in an open access format is of interest to people living with pain and some appear to benefit. There is a need to explore how this intervention can be made more accessible, including the use of different formats of delivery.

Contributions of the paper

- A pain self-management group can be delivered online and is of interest and value to people living with pain.
- There is a need to explore further alternative formats and to consider how to make the intervention more widely accessible.
- An illustration of a model of co-production and delivery where the voices of professionals and experts by experience are considered equally.
- Representation of factors that were important to people who wished to engage with an online programme to support self-management.

Keywords

Self-management, digital delivery, co-production, pain management.

Introduction

Footsteps 2021 is an online 'festival' that is co-produced by people who live with pain and professionals. It is run on an entirely voluntary basis and aims to provide accessible help and support for self-management for people who are living with pain and their families and friends. The festival (<https://my.livewellwithpain.co.uk/festival/explore-the-festival/>) was originally conceptualised as a way to ensure that people living

with pain could continue to access support during the first national lockdown in March 2020. Events are co-produced, always including a lived experience volunteer and often a pain management professional. To date the festival has included a variety of live and recorded content including sessions on understanding pain, relaxation, sleep, exercise, and mindfulness. A particular hallmark of the festival is the emphasis also on enjoyable and meaningful activities.

These have included cookery, creative writing, zentangling, therapeutic knitting and singing as well as more informal meetings over a cup of coffee or craft activity which are entirely run by lived experience volunteers.

Within the context of this festival, the aim of this paper is to describe the development, initial delivery and feedback of a supported self-management course, Ten Footsteps. The aim of this course was to introduce or reinforce strategies that are generally acknowledged to be important for the self-management of pain [1] and to make this delivery as accessible as possible. Session content is intended to be suitable both to those new to self-management and also people who might previously have attended a pain management programme and need a refresher. This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

The Ten Footsteps Course

Ten Footsteps (<https://my.livewellwithpain.co.uk/resources/ten-footsteps/>) is an interactive resource for people living with pain which was developed in a collaboration between Live Well with Pain, a well-known and trusted website that provides resources to support self-management of pain, and researchers from Durham University. In this resource people can read online about different skills that are important for self-management and access supporting materials. The Ten Footsteps programme was based on these trusted resources and developed and delivered by a multidisciplinary team including a Clinical Psychologist, Physiotherapist, GP, and people with lived experience of pain. The programme was offered freely to anybody who was living with pain or supporting people to live with pain. No assessment was required to access the programme. To further increase accessibility sessions were recorded and made available after each session. The programme was promoted on internet and social media sites.

The aim of the Ten Footsteps course was to build on the written resource with live, interactive sessions. Each session linked to materials that are available on the Ten Footsteps course. The course was planned as a series of six sessions of 90 minutes each which were co-delivered and loosely followed the Ten Footsteps structure. Sessions were delivered in a webinar style including the use of interaction using the chat function. A summary of session content is shown in Table 1. Sessions were recorded, and recordings of four of the six sessions were made publicly available as part of the Footsteps Festival.

Table 1

Session	Footsteps
1	Pain and the Brain, Goal Setting
2	Pacing, Getting Active, Goal Setting
3	Acceptance, Anxious Mood
4	Low Mood, Setbacks
5	Sleep, Relationships
6	Setbacks, Kindness to Self

Methods

The Ten Footsteps course was advertised online on social media and through word of mouth (many of the organisers are in contact with pain support organisations). People living with pain were invited to sign up. There was no pre-course assessment and numbers were not limited. Participants joined each session using a zoom link which was emailed out in the week preceding the session.

Data

Participants completed demographic information and a range of validated psychometric tests. Free text responses were also collected before and after the course. Responses were collected using JISC online surveys and analysed using Stata v16. All participants gave online informed consent as part of the questionnaires for the use of their data.

Measures

Pain

Pain was measured on two numerical rating scales ranging from 0 (no pain) to 10 (the worse pain I can imagine). Participants were asked to choose a number for the average pain experienced over the past 7 days and the worst pain in the last 7 days. Numerical rating scales are commonly used for pain and have been shown to have acceptable reliability and validity [2].

Wellbeing

The WHO-5 wellbeing index is a widely used questionnaire of 5 items measuring subjective well-being. Each item is scored on a scale of 0 to 5 with total scores ranging from 0 to 25 which are then multiplied by 4 for a final score out of 100. It has good psychometric properties [3] and has also been used as a screening instrument for depression, with cut off scores of <50 for depression and <28 for severe depression [4].

Catastrophizing

The brief, 3-item version of the Pain Catastrophizing Scale [5] was used to minimise response burden. Good psychometric properties of the scale have been demonstrated in a range of pain populations. Questions as to what extent an individual keeps thinking about how much it hurts, feels overwhelmed

by pain and feels it will never get better and are rated on a 6-point numerical scale. Recommended cut-off scores are not available for this scale. For this study, we estimated a clinically relevant score to be 7 by referring to the recommended clinically significant score of 30 for the 13- item scale [6] and adjusting according to the number of items included.

Self-Efficacy

The Pain Self-Efficacy Questionnaire-2 [7] is 2-item measure which includes questions about confidence in the ability to work and lead a normal life despite pain. It has been shown to be psychometrically robust. Each question is scored on a 6-point numerical scale. The authors of the scale suggest that a score of 5 or less is likely to indicate the need for help

Table 2: Self-management median responses at intake and completion

Item	Importance		Confidence	
	Before (n=32)	After (n=9)	Before (n=32)	After (n=9)
take steps to maintain a healthy lifestyle	6	5	3	4
plan goals based on what is realistic now	5	5	3	4
prioritise things that are important to you	5	5	4	4
understand that factors other than physical damage can affect pain	5	5	5	4
do some activity, exercise or movement daily	5	5	4	5
communicate well with healthcare providers	5	5	4.5	4
express your needs to family and friends	4	5	3	4
challenge yourself	4.5	4	3.5	4
plan and do something that stretches you	4	5	3	4
maintain or develop positive relationships (with friends, partners or family)	6	6	4	5
express your needs to family and friends	4	5	3	4
manage emotional ups and downs	5	5	3	4
relax your body	6	6	3	4
rest your mind	5.5	6	3	4
recognise and manage unhelpful thoughts	5.5	6	3	4
be kind to yourself	6	6	3	4
be active without exhausting yourself	6	5	2	4
deal with setbacks	5	5	3	4

in increasing confidence in the ability to carry out functional behaviours and that a score of 8 or above is likely to indicate reasonable functional outcomes such as the ability to work.

Self-Management

Questions about self-management were designed for this survey. A list was generated by the study team which includes both pain clinicians and people who live with pain. This included seventeen items that the team believed to be important for self-management of pain. These ranged from broad items such as remaining healthy to more specific abilities such as resting the mind and managing thoughts. A list of the items is included in table 2. For each item participants were asked on a 7-point scale how important they believed it was and how confident they were in their ability to do it.

Results

A total of 49 people signed up for the course. Of these, 32 completed the pre-course survey. 30 people attended the first session. There was significant attrition during the course and 13 were present at the final session, having completed most or all of the sessions offered. Nine people completed the post-course survey.

Of the 32 people who completed the pre-course survey, 29 identified as female and 3 male. Twenty- nine were White, 2 Asian and 1 Black. Age was 21 to 40 (6), 41 to 60 (19) or 61 to 80 (7). All respondents had had pain for over a year and 23 reported having had pain for over 5 years. Of the 9 people who completed the post-course evaluation, 6 had attended informal coffee and chat sessions offered alongside the course, 5 had attended a separate session focused on understanding pain, 4 had attended a mindfulness course

and 3 had attended at least one gentle exercise session. Only one person had attended all the ten footsteps' sessions live, two had completed all the sessions either live or by catching up with the recordings and six had attended some of the sessions.

Results of psychometric questionnaires are shown in table 3. Independent measure t-tests were selected for each pair of results to test whether scores differed significantly between questionnaires filled in at each timepoint. Independent measures were selected because of the different number completing at each timepoint and due to there being no ability to match questionnaires – self-generated unique identification numbers collected for this purpose only provided reliable matches for three individuals. No significant difference was identified between average or worst pain intensity or wellbeing at each of the timepoints. Differences were identified for self-efficacy ($t=-161.3.9279$, $df=8$, $p=.0044$) and catastrophizing ($t=3.0327$, $df=8$, $t=.0162$).

Using the recommended cut off on the brief self-efficacy scale [7] to represent meaningful functional outcomes the mean fell above this for the 9 participants who completed the follow-up questionnaire (8.56) compared to 7.06 for the 32 participants who completed the initial questionnaire. The mean PCS score was 9.91 for the first questionnaire and 8.11 for the second, both of which fall above our estimated clinically relevant value of 7 for this measure.

Responses to the items on the self-management scale are shown in Table 2. Median scores for each of the skills were at least 4 on a 6-point scale, suggesting that they were all considered to be important by participants both before and after the course. Ratings of confidence in having the skills

Table 3: Psychometric Measures at intake and completion

Scale	Before (n=32)		After (n=9)	
	mean	sd	mean	sd
Average Pain 7 days	6.91	1.53	7	1.32
Worst Pain 7 days	8.66	1.56	8.56	0.72
Self-efficacy	7.06	3.24	8.56	2.78
Catastrophizing	9.91	2.54	8.11	2.52
Wellbeing	53.12	19.12	52.44	14.88

were somewhat lower.

Qualitative Feedback

All respondents filled in a free text section asking about the reason they wanted to do the course. After the course respondents were asked for feedback about their experience of the course. The prompts stop, start and continue were used to elicit further feedback about elements of the course that were seen as unnecessary, those that were well received and any suggestions for additional content. Qualitative responses were analysed using thematic analysis [8]. A sample of 20% of the full responses were coded individually by two of the authors (CP and JA), representing perspectives from clinical psychology and lived experience. Both authors followed a series of steps, initially becoming familiar with the data, assigning individual codes and assigning codes to groups and themes. Differences were resolved with regular discussions. The remaining responses were coded by the first author (CP). Once coding was complete themes were generated through a series of discussions between CP and JA which continued until both authors agreed that themes were a complete and fair representation of the data collected. Themes that were generated from this process are described below.

A central theme for most respondents was 'Living Well with Pain'. This was described by respondents along a continuum which we assigned to two subthemes, taking back life, and not wanting to give in. For example, one person said, 'to inspire me and keep me motivated in my journey of learning to live with pain', while another said, 'to keep me out of using a wheelchair'. A related theme mentioned by several patients was the importance of understanding pain. Again, this was linked to subthemes of science (e.g., 'pick up new tips based on up-to-date research') and perspective (e.g., 'understanding how to better support myself when I am in pain'). Respondents also referred to the importance of Tools ('Learn coping strategies and how to sleep better'), Self-care ('to remind me of looking after myself'), Expert guidance ('Made a difference that presenters had a clear understanding of chronic pain') and Trust ('Felt we were all in it together'). A visual representation of the themes is shown in Figure 1.

Discussion

Guidelines published by the British Pain Society recommend that pain management programmes delivered by multidisciplinary teams are offered to people living with pain [1]. It is further recommended that suitability for a PMP is based on the impact of pain, with no grounds for discrimination based on age, literacy, litigation, or judgement of motivation, and that more rapid access to all forms of PMP

is desirable. During the national lockdown in England access to all forms of pain management support was limited. This provided part of the motivation of providing a high-quality online programme that was widely accessible to support people living with pain who could not otherwise access multidisciplinary pain management.

The results of this feasibility study present interesting findings in terms of accessibility. The first is in relation to the demographics of people who signed up and attended. Our data show that attendees were overwhelmingly White women and mostly middle-aged. To fulfil our aim of accessibility it will be important in future to work to reach out to a more diverse range of people living with pain to find out what needs to change to better meet their needs. Comments in the pre-group survey and responses to questions about self-management skills also suggested that people interested in attending were already engaged in managing their pain, familiar with commonly recommended methods of pain management and closely aligned with the attitudes and values of living well with pain. This may reflect the platform on which the Festival is hosted, a well-known national website of resources for supporting self-management of pain. It may also reflect the possibility that staff working in pain management services are signposting patients to the Ten Footsteps program for support if they have already completed a pain management programme.

This could indeed be an important function of a resource such as Footsteps Festival. Pain may change over time and with life circumstances and it is common for patients to have times when they need extra support to help them continue to manage their pain. Making lifestyle changes and developing self-management skills when living with a challenging long-term condition also does not happen quickly. Even if a patient has completed an 'intensive' residential programme that may have run for 3-4 weeks, by the time they have finished they are only at the start of their journey with the process of self-management. Most pain management programmes do not collect long term outcomes and there is some evidence that treatment gains tend to reduce over time [9].

Having access to a resource such as the Footsteps programme may help patients to embed what they have learned as they move forward with their life and try out new self-management skills. In doing so there is the potential that a freely accessible programme such as Ten Footsteps could fill a gap that is often left following discharge from a pain management service, potentially providing the support and resources that a patient may need and reducing alternative strategies for support-seeking such as increased GP

appointments and treatment-seeking. Our feedback indicates that several patients who attended the sessions were using the programme in this way.

The course could also be used as an introduction to self-management or an alternative to current provision. Advantages of this would be the availability of a range of ongoing sessions within the Festival and easier accessibility compared to traditional pain services. It may also de-medicalise pain treatment by locating it within the voluntary or third sector. However, this would have resource implications that would need to be considered carefully. It would be useful in future to explore whether the structure of six 90-minute sessions is the best way to provide this support or if a more flexible arrangement would be more appropriate.

Our data also highlight the challenge of how to broaden access to reach and appeal to people who are not currently aware of self-management but could benefit from it.

Initial data collected suggest that people who engaged with this programme had similar levels of pain to those who attend hospital-based pain management programmes. A comparison of patients attending pain management programmes [10] reported average pain intensity of 7.4 in a highly disabled group and 6.8 in a standard pain management group, receiving an intensive residential pain management programme for four full days a week over 3 weeks. The mean in our study of 6.9 is in keeping with these figures.

The level of attrition also needs careful consideration. Approximately a third of people who signed up completed the programme and the post course evaluation. This low rate of completion is nevertheless in keeping with reports of other online self-management programmes. Even in established pain management services with patients assessed by a multidisciplinary team uptake of an online pain management programme to support self-management was low, with 14 patients attending programmes across 3 cycles from a waiting list of 61 [11]. Although reasons for this are unclear, beliefs about the relative benefits of online versus face-to-face treatment delivery may be of relevance. A qualitative study of 25 patients highlighted that most respondents believed face to face sessions would be more desirable for self-management support and more likely to be effective than online provision [12].

It seems important to consider whether non-completion of an online self-management course is because the course is not meeting people's needs, or whether many might have been able to benefit from the course in a different way that

was not structured around regular attendance. Nearly all the nine who did complete the post-course evaluation had also engaged in other events offered through the Footsteps Festival. Possibly for some people accessibility means the ability to dip in and out of relevant content in a more flexible way that fits their lifestyle and what is important to them at the time. Indeed, if pain services have similar issues a low intensity open access course may be a useful first step to set expectations about what an online programme to support self-management might involve. Alternatively, different formats of delivery and engagement may be required. A recent review has highlighted that there is very little evidence at present to guide the development of online programmes that are designed to support self-management [13]. A point of learning for the team however is that in aiming to make the ten footsteps course accessible we may have omitted to stress the nature of the course and the importance of attending all sessions if possible. The nature of the course offered without formal assessment or links to local pain or health services removes any sense of pressure or obligation to complete it and this may have been a factor that contributed to the low completion rate. Having said that, four of the six sessions (where confidentiality allowed) were recorded and posted to the website. Within the first six months this content has been accessed on 118 separate occasions indicating that people are continuing to find it helpful.

It was not possible to compare any type of pre to post outcome of the course, given the difference in responses between the pre and post course survey and not being able to match up individual responses. Nevertheless, some comparison between the surveys is interesting. It appears that there was very little difference between pre and post course in pain intensity or overall wellbeing. Measures of self-efficacy and catastrophizing however differed at the different timepoints. Self-efficacy scores at post-course evaluation fell within the range associated with 'meaningful functional outcomes' [7]. Similarly, catastrophizing scores were lower at follow-up, although they remained within a range that might be considered clinically significant [5]. The possibilities that people who completed the course might have benefitted on these measures, or that higher initial levels of self-efficacy and catastrophizing differentiated people who were more likely to complete the course are 288 both worthy of further exploration.

Conclusion

The Footsteps Festival represents an innovative and widely accessible way of supporting people to live well with pain and complements existing provision, much of which may be inaccessible to people who are unable to travel or commit to

attend intensive pain management programmes. As part of this, the delivery and evaluation of the ten footsteps course has thrown up a number of questions that deserve further consideration. It remains unclear whether it is important for people to commit to and attend regular sessions, and if so whether in the current format it would be possible to identify people who are more likely to be able to do this. It will also be important to consider how we can reach out and make pain management more accessible to people who do not currently engage with it.

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Fig 1: Thematic Representation of Qualitative Comments about hopes, expectations and learning from the Ten Footsteps Course.

