



City Research Online

City, University of London Institutional Repository

Citation: Booth, G., Di Rosa, A., Corcoran, P., Hallisey, C., Lucas, A. & Zarnegar, R. (2024). Patient perspectives on the unwanted effects of multidisciplinary pain management programmes: A qualitative study. *Clinical Rehabilitation*, 38(8), pp. 1118-1129. doi: 10.1177/02692155241254250

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/33273/>

Link to published version: <https://doi.org/10.1177/02692155241254250>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Title: **Patient perspectives on the unwanted effects of multidisciplinary pain management programmes: a qualitative study**

Authors: Gregory Booth¹, Amanda Di Rosa², Paula Corcoran³, Charlotte Hallisey¹, Andrew Lucas⁴, Roxaneh Zarnegar⁵

Affiliations:

¹Therapies Department, Royal National Orthopaedic Hospital NHS Trust

²Institute for Global Health and Development, Queen Margaret University

³Department of Psychology, City University

⁴Department of Clinical Health Psychology, Royal National Orthopaedic Hospital NHS Trust

⁵Pain Clinic, Royal National Orthopaedic Hospital NHS Trust

Corresponding author:

Mr Gregory Booth, Therapies Department, Royal National Orthopaedic Hospital, Brockley Hill, Stanmore, Middlesex, United Kingdom, HA7 4LP. Email: Gregory.booth@nhs.net

Other author contact details:

Dr Amanda Di Rosa, mandy.dirosa@gmail.com

Dr Paula Corcoran, paula.corcoran.1@city.ac.uk

Ms Charlotte Hallisey, charlotte.hallisey100@gmail.com

Dr Andrew Lucas, Andrew.lucas3@nhs.net

Dr Roxaneh Zarnegar, r.zarnegar@nhs.net

Abstract

Objective

This study aimed to understand the impact of pain management programmes, focusing on the unwanted effects and their influence on patients' long-term use of self-management strategies.

Design

Qualitative study.

Setting

Specialist musculoskeletal hospital in North London, England.

Participants

Patients with chronic musculoskeletal pain that have completed a pain management programme.

Intervention

Multidisciplinary pain management programmes.

Main measures

Data were collected regarding patients' experiences and unwanted effects from the pain management programme using semi-structured interviews. Data were analysed using thematic analysis.

Results

Fourteen participant interviews were included in the analysis (median age 54 years, 12 females). Four themes were generated from the data: Benefits and burdens, Pain management programme and real life, Social support and Healthcare interventions. Unwanted effects included heightened anxiety related to negative interactions with peers, being in a new environment, worries about ability to cope with the programme, social anxiety from being in a group, the strain on families due to participants being away from home and a sense of abandonment at end of the programme. Burdens associated

with implementing pain management strategies were identified, including the emotional burden of imposing their self-management on close family and competing demands with time and energy spent on self-management at the expense of work or home commitments.

Conclusions

Pain management programmes have an important role in helping patients to learn how to self-manage chronic pain. Their unwanted effects and the treatment burdens associated with long-term self-management may be an important consideration in improving the longevity of their beneficial effects.

Key words:

Chronic pain, pain management programmes, burdens, unwanted effects, patient perspectives, self-management

Introduction

Chronic musculoskeletal pain conditions are leading causes of disability,¹ and substantially limit the quality of life of people experiencing them.² People with musculoskeletal pain have the highest need for rehabilitation globally.³

Services for people with musculoskeletal pain commonly provide pain management programmes. The core objectives of pain management programmes are to improve patients' participation in daily activities and enhance their quality of life. This may involve improving mobility, self-care, work, leisure participation and other social activities, and reducing reliance on medication and healthcare professionals. Pain management programmes are interdisciplinary, group-based programmes, and can include 1:1 elements to enable individualised care.⁴

Although outcomes from pain management programmes in terms of reducing physical disability and improving psychological wellbeing are overall favourable,^{5, 6} there are many patients in whom the long-term uptake of pain management programme principles is low. The reasons for abandoning the principles that lead to self-management in favour of revisiting medical and surgical treatments are poorly understood. Current evidence shows that simply repeating the principles of self-management is ineffective.⁷ To date, qualitative research relating to pain management programmes has focused on the factors that matter to people in the pain management process,⁸ the impact of programmes⁹ and barriers and facilitators to ongoing use of self-management strategies.^{9, 10}

In pharmacological and invasive intervention research, the recording of adverse events, defined as anything unfavourable or harmful that happens during and after an intervention,¹¹ is well established and in medical practice, side effects of treatment are discussed with

patients. In contrast, much of the literature on multidisciplinary pain management programmes ignores the possible occurrence of unwanted effects.⁶ This may reflect uncertainty among researchers and multidisciplinary teams about what these effects may be and therefore, how they could be assessed. This study was designed to better understand the impact of pain management programmes, focusing especially on the unwanted effects reported by programme participants and the influence of these on patients' long-term use of self-management strategies.

Methods

This study was conducted in a specialist musculoskeletal hospital in North London that runs a three-week intensive residential pain management programme. Follow-ups are conducted at three months and one year after completion. This programme consists of group and individual therapy sessions and is delivered by a multidisciplinary group of physiotherapists, occupational therapists, therapy technicians, psychologists and nurses. It includes all the components recommended in the British Pain Society's pain management programme guidelines.⁴ Example timetables for the programme are displayed in the supplementary material.

Eligible patients were those who had completed the host institution's pain management programme at least six months prior to interview, were able to participate in a telephone interview (e.g. had no hearing impairment that made them unable to speak on the phone) and were able to understand and speak in English.

Potential participants were recruited in two ways: (1) patients who had completed the pain management programme at the host institution 1-2 years prior to study recruitment were identified consecutively from electronic patient record systems at the study site and sent information about the study weekly, in groups of five, by post or e-mail accompanied by a consent form, and (2) patients attending the second follow up were given the same written information and consent form. All patients were given a stamped addressed envelope and asked to sign and return their consent forms by post if they wished to participate. A reminder phone call was made 7-14 days later to ensure they had received and read the information. This was also an opportunity for participants to ask questions about the study and its conduct. Participants were invited to a telephone interview once they had returned the consent forms. This recruitment process continued until enough participants had been recruited.

There is no quantitative power calculation method to determine sample size in qualitative studies. Considering the paucity of knowledge on the unwanted effects of pain management programmes, we used the empirical evidence presented by Guest et al. that saturation of themes is reached by the twelfth interview when research aims are focused and the sample is relatively homogeneous.¹² We therefore expected to interview at least 12 participants. It is recognised that the concept of power in qualitative research is more complex than just sample size; it is also tied into the richness of the data generated during the interviews.¹³ In order to be more certain that the sample size is appropriate, we planned interim analysis by the interviewing researchers, initially after six interviews, to generate codes. The researchers would then do a further three interviews and determine whether any new codes were added. This process would continue until there were no new codes, taking this as the point of saturation.¹⁴ We agreed that if a saturation point was not reached, we would not interview

more than 50 participants due to limitations in being able to reliably manage the analysis task.¹⁵

Data were collected using semi-structured interviews. The interviews were conducted by telephone to enhance participation and reduce travel burden. Two researchers each conducted 50% of the interviews. The interviewers, undertaking Masters degrees in psychology and health, had no relationship with the participants prior to interviews.

Patients were aware at the time of consent for participation that the interviewers were from an academic institution, independent of the clinical team involved in the programme or its subsequent follow up. This information was repeated at the time of the interview. Participants were therefore aware that their therapists and clinicians would not have access to specific identifiable interviews and their comments would remain anonymous.

Participants were involved in scheduling their interview to ensure it was at a convenient time for them. They were also given the options of doing the interview in two parts or asking for short breaks.

An interview guide with open questions was developed prior to the interviews (see supplementary material). To help the interviewing researcher understand the participants' views of their chronic pain problem and establish their level of engagement with self-management, the interviews started by exploring the pain history and treatment experiences, followed by expectations of the pain management programme. The participants were asked general questions about the programme to trigger memories, allowing a free flow of conversation. In the second part of the interview, participants were asked open-ended questions to determine whether there were any unwanted effects or anything that the

participants interpreted as harmful, including anything that they found surprising, struggled with or were disappointed with.

All interviews were done in a closed office, audio recorded and then transcribed verbatim. Participant personal data were not included on the audio-recordings. The anonymised audio-recordings and transcripts were kept on password protected computer systems. Participants were made aware that the recordings and transcripts would be anonymised and would not be included in medical notes or other reports.

The qualitative data were analysed using inductive thematic analysis.¹⁶ Analysis was undertaken by three of the authors who were not involved in data collection. These authors are all experienced healthcare professionals that work on the pain management programme with backgrounds in physiotherapy and pain medicine. Interview transcripts were uploaded into QRS NVivo (version 12) software¹⁷ to support the analysis. Three transcripts were independently coded by two authors who then met to discuss the coding. The remaining transcripts were then coded and organised into themes and subthemes. All authors reviewed and agreed on the final themes and subthemes. Non-parametric statistics were used for describing quantitative data.

Our reporting of the results is in line with the consolidated criteria for reporting qualitative research (COREQ) checklist¹⁸ Ethical approval was received from East Midlands-Leicester Central Research Ethics Committee (IRAS ID: 202089; REC Reference: 16/EM/0250).

Results

Sixty-two people who had completed the pain management programme were invited to participate; 31 did not reply, nine wrote back and formally opted out, and seven said that they intended to participate but did not send in a consent form. All 15 participants who returned a consent form completed an interview.

After 12 interviews, interim coding of the transcriptions, as described in the method section, indicated that saturation had been reached. Therefore, recruitment to the study was closed. At this time, another three participants had returned their consent forms and the decision was made to give these responders the opportunity to contribute to the study, which would also help confirm data saturation.

Participant characteristics are summarised in Table 1. The median age of the participants was 54 years (IQR 12, range 46-77), with a sex ratio of 12 females to two males. The median time from pain management programme completion to the time of interview was 74 weeks (IQR 24, range 50-87). The median length of interviews was 36 minutes (IQR 12, range 22 - 76). The interviews were conducted between August and November 2016. The voice file of one participant was accidentally deleted prior to transcription and was therefore not included in the analysis. Fourteen transcribed interviews were available for analysis.

We generated four themes from the data with 2-3 subthemes in each. These are summarised in Table 2.

Theme 1: Benefits and Burdens

Perceived benefits

The participants described treatments they had prior to attending the pain management programme. These included medications, pain interventional treatments and surgery. Some of these had been beneficial in reducing pain intensity but overall, the benefits did not last and in this sense were disappointing. Medication use was often limited by side effects. For one participant, surgery had worsened pain and function. Exercise regimes had had mixed effects, and some self-management strategies such as healthy eating, walking aids and home adaptations had been tried.

“I had tried several things, had the injections, and tried the nerve burning, but nothing worked... medication wise, I’d tried all sorts, but I’m very, very sensitive to medication, ... they didn’t help the pain, they made me feel woozey, and very muddle-headed.” [Participant 2].

All the participants felt that the pain management programme was helpful, enjoyed the programme and would recommend it to others. The pain management programme enhanced the participants’ ability to cope with living with chronic pain, improved the understanding of their condition, facilitated acceptance and shifted focus from looking for medical solutions to learning to live with pain as a long-term condition. Participants described how they learnt strategies such as pacing, relaxation, adjustments to activities of daily living, communication techniques and managing flare-ups.

“I used to panic quite a bit when I used to have a flare-up. I used to think, I can't stand the pain... it would be overwhelming. I think since being on the programme, they have explained that it is just a flare-up, and it is going to only last for five days, and then it will ease off... it's to remember that it's going to go and it's not going to be there forever, that's help me.

Whereas before, I would go to A&E quite a bit, maybe once every two months when I was in great pain.” [Participant 8].

“The thing that’s lingered longest for me is the morning exercise... I think mindfulness is the basis of it, but controlling pain through meditation and mindfulness rather than relying on drugs all the time.” [Participant 12].

In terms of outcomes, participants spoke about reduced healthcare and medication use, greater independence, increased physical activity, better mobility and enhanced ability to do their basic daily living activities.

“I wouldn’t even get out of bed before midday... Now at eight o’clock at least I’ll be out and about. I’ll go to the shower, get myself dressed slowly. It may take longer, but I don’t mind doing it because I’m doing it all myself, and I’m doing something, at least I’m doing something, before I was completely bedridden. From that, I’ve improved a lot.” [Participant 15].

Personal expectations

Expectations prior to attending the pain management programme were mixed. Some participants had been in pain for a long time and doubted that they could benefit from anything further. Low expectations were also influenced by previous negative experiences of healthcare. Others had high expectations, influenced by positive experiences in the host institution or having an acquaintance with a positive outcome from the programme.

“Well, it was just a pain all the time. I mean I have had it for so many years that you just have to learn to live with it and have a very high pain threshold. So, I must admit that I went to the programme I thought, well, I don’t see how this is going to help me, but it did.” [Participant 14].

“I didn’t have any expectations to be honest. It was one of those things because you think if you don’t have any expectations, then you can’t be disappointed.” [Participant 10].

Most participants understood the aims of the pain management programme to be learning to manage pain and improve quality of life. Some had had specific expectations from attending the programme, including help with psychological aspects of having persistent pain, functional improvements and generally learning to manage their symptoms.

“What I was really hoping they would do was to give me strategies to make me more mobile. I walk... with a stick and I had to wear a brace on my right leg.” [Participant 12].

“This is why I went on the programme, so they can teach me how to kind of control it.” [Participant 15].

Some participants acknowledged that the pain management programme met or exceeded their expectations. Where expectations had not been fully met, this was related to wanting more psychological input to help with periods of low mood. One participant was hoping for greater improvement in walking ability and was disappointed that this did not happen.

“There must be tools they can give you for this, the psychological side, when you get down in the dumps. Because when I get down, I get sometimes I get really down. I don’t answer the

phone, don't come out of the house, and sometimes it can take me days to get out of that. And I kind of sometimes wish... there might not be tools... nothing they could teach me to help me with that. But I suppose it would have been nice just to find out if there would have been."

[Participant 13].

Burdens of accessing treatment

Some participants had found travelling to attend the pain management programme difficult or costly. Attending had also interfered with other commitments in participants' lives, such as arranging childcare or stopping gainful employment to attend. Being away from home was an issue, and one participant described anxiety and distraction during the programme because their partner had found this so stressful. Another participant described difficulty focussing on the pain management programme because they had to call an unwell family member each evening.

Participants reported preparation for starting the pain management programme, having to self-motivate to learn from the programme and make changes mentally burdensome. Participants suggested that one way of reducing this burden was attending at a time that was right for them.

"It was a very stressful time when I did the programme, and we'd just moved, having had work done in the house. My wife was trying to sort the kids out, and I was worried about her because she's coping with that and everything else. Because we've had a lot of personal problems as well." [Participant 11].

Theme 2: Pain management programme and Real Life

Long-term application of self-management strategies

Participants had often been able to maintain pain self-management strategies after the pain management programme but reported that this was challenging and needed continuous effort. They surmised that this is the main reason for many people's self-management tapering off over time. It was easy to forget to use the strategies at the time of the activity. Some were aware that they needed to intermittently remind themselves of self-management principles and how these strategies can be applied to everyday life.

"It's harder as time goes by because you forget things, you let things slide, and then you forget about them. So, you have to try and find the paperwork again and see if there's something in here I've missed or something I've forgotten." [Participant 14].

Barriers to application of strategies

A number of participants recognised how their medical comorbidities could contribute to deconditioning and made adopting self-management strategies difficult in the long term. Poor mental health often dampened motivation, perseverance and enthusiasm for self-management. Some participants acknowledged that they were not able to do activity pacing or relaxation techniques even after completing a high-intensity programme. They identified the variable and unpredictable nature of persistent pain and high daily pain intensity, as the barriers to consistent physical activity and pacing. Competing demands on individuals' time and energy, such as personal daily activities and caring for dependents, deprioritise implementing self-management strategies. Financial difficulties prevent purchasing exercise

equipment. Exploring social opportunities such as community groups are hampered by anxiety.

"... you have bad days, you're under the weather, you don't feel like doing anything, you just don't feel like anything, and being at home there's no motivation, there's no one around you, you're alone in the four walls, and it's um it's very very difficult to do certain things."

[Participant 15]

Facilitators to using pain management strategies

Participants described how acquiring a strong knowledge base about pain management strategies and experiencing the benefits of using them were reinforcing factors, especially when adapted to personal circumstances and when there was support from family and friends.

"I still make sure I get up and I stretch in the morning. And I have to do that because otherwise, I just physically can't move about. ...so that I can up properly and do what I have to do."

[Participant 6].

"I know that if I hadn't got my husband and family and the close friends that I can call on, I know that I wouldn't have been able to put into practice some of the things that have made a difference to my life." [Participant 5].

Themes 3: Social support

Personal support from peers

Support from other patients was described as one of the most beneficial aspects of the programme. It was widely acknowledged that peer interactions during the programme were a source of mutual encouragement and emotional support that facilitated positive outcomes. Participants described relating well to a peer group for the first time and felt able to learn from each other. These supportive relationships developed despite cohorts having a range of ages and chronic pain conditions and often lasted after the pain management programme. Many patients said that their group had stayed in contact. However, some participants described negative peer interactions that “dragged them down” and said their group had lost contact.

“Being in a ward with people that are in the same predicament as you makes a big difference to you because you finally realise that you’re not the only person that’s trying to deal with the way you are. And we all said that talking between each other you pick up little things to try that may have helped somebody else.” [Participant 6].

Family and friends

Participants described relying on family and friends to different extents to help manage life stresses and daily living activities. Having to rely on others to go out of the home was frequently mentioned, particularly by participants who had a fear of falling. Despite friends and family being aware of their needs, participants often reported that the same people had a poor understanding of their needs. One patient admitted that they were often not honest about their pain levels and disability and, therefore, did not get the support they needed. Where support was given, it was generally appreciated, but participants broadly desired more independence and wanted to be less of a burden on others.

“There are some exercises that ... are very hard, like walking outside... without someone, I find it a bit hard because like what if I fall, stumble, who’s there to help me? And I’ve already had a very nasty fall once, and now all my metal work was loosened, and I had to go to surgery.”

[Participant 15].

Participants felt that family discussions about changes they planned to make after the pain management programme were helpful for them and their families. They believed that involving families more in the programme may be helpful, but acknowledged the difficulties of this, for example due to families being unwilling or unable to travel to the hospital.

“If you’re married with three kids, and you’re in agony, and you can’t cook dinner tonight, and they’re not prepared or able to do something to help you... you and the family go hungry, or you push through your pain, and you cook the dinner, which was what most people were doing. And so, they did address things by inviting family members in and explaining to the family what we on the programme were going through and what we were being taught, and all the rest of it. So, they did address it in that sense, but obviously, some people’s families either didn’t want to come in, couldn’t come in, whatever it was.” [Participant 5].

Support structures in local communities and wider society

Community exercise classes are a method participants commonly used to seek social interaction; however, they highlighted they can be unsure what to look for. They felt more able to utilise support services when using public transport, disability car parking badges and

carer support with domestic tasks. These helped with activity pacing and managing flare-ups but came at a financial cost.

“I have got someone in to do my housework, which I had to give up a bit on because the pain was so bad, so someone comes in and does all the housework for me, so that was one of the things I was really struggling with.” [Participant 1].

Theme 4: Healthcare interventions

The role of Healthcare Professionals

Participants described feeling isolated, disappointed and abandoned when discharged after the pain management programme. They felt that long-term support is necessary and would have many benefits, such as wider implementation and long-term maintenance of pain self-management strategies. This support could help overcome long-term habits, problem-solve complex issues, and find help during flare-ups. The dominant opinion among the participants was that it would be best coming from the pain management programme team and through easy access back into chronic pain services.

“[On finishing the programme I was] quite upset really, quite isolated. I think that for me I am not under a specialist anymore because there is no operation that I can have. I’m under the pain management psychologist, but on the physio side of it, I am okay what I am doing now, but in 6 months’ time, how do I know those exercises are still going to be appropriate? You know it is like there is nothing. It feels like there is nothing now. I understand they can’t keep people on forever, but I think your pain does not just go. People who have got chronic pain and chronic conditions, it’s something that I have got to get used to living with. I think it

would be useful even if we had a check-up maybe once every 6 months, just to see where we're at and maybe for some of the exercises to be tweaked. If there is particular areas that we still need a bit of help on or advice, I think that would be really, really useful." [Participant 8].

Healthcare interventions for people who self-manage chronic pain

Some participants had had medical support in general practice or secondary care after the pain management programme to optimise their medications. Many had accessed further treatments ranging from massage to injections, surgery and, in one case, another pain management programme. Investigations and treatment had been sought for new areas of pain or worsening pain intensity post-programme.

"I've not long found I got osteoarthritis in the hip and I got a problem with my spine..., that there is a problem with my lower back spine. I'm going to have some epidural injections done, so just trying to concentrate on that part." [Participant 4].

Discussion

In this qualitative study, patients' perspectives of pain management programmes were explored, with specific focus on unwanted effects of this intervention. Unwanted effects may be directly caused by the intervention itself (adverse reactions)¹¹ or the workload related to enacting the recommendations of the treatment (burdens).¹⁹

Study participants told us how the programme had resulted in improved day-to-day function and quality of life, and reduced medication use. These findings are consistent with

quantitative studies and other qualitative research.^{8,9} This consistency demonstrates that the pain management programme attended by the study participants is achieving its purpose.

A number of unwanted effects of pain management programmes are identified in this study. The most prominent of these is heightened anxiety, which occurred in relation to (1) being in a new environment, (2) worries about the ability to cope with the programme and benefit from it, (3) emotional stresses due to negative peer interactions during the programme and (4) social anxiety when attending pain management programme groups or seeking social opportunities after the programme to combat loneliness and low mood.

Other adverse reactions were strain on the patients' families due them being away from home and a sense of abandonment at the end of the programme. This sense of abandonment is understandable as people with chronic pain have often been counselled to view pain management programmes as a last resort, being referred to it by healthcare professionals when the medical model of care offers no treatment options. At the end of the pain management programme, patients may feel that they will have nowhere to turn for advice as future difficulties inevitably arise. In a recent review of psychological interventions for chronic pain, other adverse effects that did not come up in our study were an increase in pain intensity and falls during exercise.⁶

Our findings include other unwanted effects which do not fit the label of side effects but can best be described as burdens. These burdens are associated with accessing the treatments, following the recommendations of the therapists, or implementing self-management. Financial burdens include the costs of attending a programme, such as travel, childcare or loss of earnings and the costs of self-management, for example, buying exercise equipment or gym membership. Other burdens include the workload of finding suitable community and

social activities, the emotional burden of having to impose on family and friends for help during flare ups or getting out of the home, and the competing demands on patients' time and energy between self-management techniques and caring for dependents or gainful employment.

The results of this study indicate that unwanted effects of pain management programmes can affect patients' ability to focus during the programme and maintain self-management. In a proportion of programme participants, meaningful improvement in quality of life and function is not achieved or is only short-lived. We hypothesize that these unwanted effects have a role in pulling patients away from self-management towards the medical model of care in the long term.

Measuring the unwanted effects of all treatments is an ethical imperative, in both research and clinical practice, to minimise harm to patients. Discussion of unwanted effects of proposed treatments is integral to effective joint decision making. Our results provide evidence for the proposals made by Palermo et al. in their review of reporting adverse events in clinical trials of psychological treatments for chronic pain. They made specific recommendations for the measurement of unwanted effects including the stresses of adherence to skills training, feelings of hopelessness about treatment, and strains in family or work relations.²⁰ We would echo these recommendations for all pain management programmes. We would add that data on heightened anxiety or emotional stress, increased pain intensity, and exercise-related injuries should also be collected both during, and immediately after pain management programmes.

There is much room for research into the burdens of self-management for patients. Burden of treatment has been described as the workload of healthcare and its effect on patients'

wellbeing.¹⁹ Treatment burden reduces adherence, wastes resources and contributes to poor outcomes.^{21, 22} Themes on the need for ongoing support from healthcare professionals after completing a programme appear repeatedly in qualitative studies of pain management programmes,⁸⁻¹⁰ including in this study, and this is likely to have a relationship with the burdens of self-management. There are no general guidelines on when to assess treatment burden, nor is there a standardised method for assessing it.²³ Some measures of burden have been developed and broadly focus on medication use, attending medical appointments, administering tasks related to healthcare and difficulties in relationships with healthcare providers.²⁴ These components would be expected to ease in people who self-manage more effectively. However, there are other items, such as burdens of self-monitoring or recommendations to practice physical activity, which might be expected to rise in people who are encouraged to self-manage. In addition, our data shows that there are perceived trade-offs, for example, in terms of the time and energy spent on self-management at the expense of caring or work responsibilities. After attending a programme, the burdens of healthcare may be replaced by those of self-management, which will be inherently more hidden because they are neither measured nor acknowledged by health care professionals. These burdens may therefore be isolating experiences, manifesting in the sense of abandonment that many patients describe at the end of a pain management programme.

Improving our understanding of the unwanted effects of pain management programmes will help inform patients about what they might expect by participating. It would also generate hypotheses on how the interventions could be altered to reduce unwanted effects and consequently enhance the practice of self-management. Therapy teams could specifically tackle feelings of abandonment and anxiety during programmes to enhance long-term engagement with self-management strategies. Specifically acknowledging and tackling the

burdens of self-management in individual follow-up meetings after the programme may be an effective behaviour maintenance intervention.

This study has several limitations. The accidental loss of all data from one interview is important to consider. Our results indicate that code saturation was reached by the time 12 interviews were completed and the additional interviews, which were done because invited patients had returned their consent forms, confirmed this. Therefore, it is reasonable to conclude that the probability of finding new codes in the lost interview would have been low. Arguably, researching this topic in a different pain management programme setting or using different methodology would be far likelier to generate new and useful data than increasing the sample size of this study.

Participants in this study were recruited from a single centre, and, in the setting of a high-intensity residential programme, which is not typical of most pain management programmes. It is very likely that the frequency and intensity of unwanted effects change in different settings. In this study, the residential nature of the programme is a direct cause for the strain felt by some patients' families because they were away from home. It is possible that this also worsens anxiety with respect to programme participation. These factors undoubtedly have implications for the generalisability of our findings. Furthermore, we have used only one method to explore unwanted effects of a pain management programme. Studies using different methodology and/or in other programmes are needed to confirm and build on our findings.

As a preliminary investigation of unwanted effects of pain management programmes, this study was not designed to look into whether participant characteristics such as age, pain duration or pain severity could influence the findings. These factors are important

considerations for future studies and could be used to individualise behaviour maintenance interventions.

The methodology excludes people who did not finish the programme, did not want to have further contact regarding the programme or could not participate in the one-hour interview. Patients were recruited after having completed the programme some time previously, with a median of 74 weeks after PMP completion. Although ideal for exploring the real-life burdens of self-management, this time delay makes it likely that some memories of the immediate adverse reactions have faded. These limitations would have the effect of underestimating the adverse reactions and burdens of treatment. Finally, patients and members of the public were not involved in the design or reporting of the findings.

When semi-structured interviews are used, the interviewing researcher is inexorably embedded into the data collection process. A strength of this study is consideration of the impact of researcher reflexivity.²⁵ We considered that pain rehabilitation therapists may have strong beliefs about pain management programmes being effective and harm-free or may have developed their own ideas about possible harms. We designed the study so that the interviewing researchers were not pain rehabilitation therapists. This also meant that they were not involved in programme delivery or subsequent patient care, reducing any reservations that participants might have had in sharing negative views. We included a point of triangulation in the final data coding for thematic analysis when the researchers involved coded three interviews independently and met to compare their codes. At this point they had the opportunity to challenge each-others' perspectives and biases.

In summary, managing pain often involves changing and then maintaining multiple complex behaviours, whilst continuing to fulfil everyday life demands. Reasons for non-adherence to

self-management strategies have scarcely been viewed through the lens of adverse reactions or treatment burdens of pain management programmes. Gaining a better understanding of unwanted effects of pain management programmes has the potential to improve the short- and long-term outcomes of these programmes.

Clinical messages

- Standardised methods should be developed for collecting data on the unwanted effects of all pain management programmes.
- Discussing the unwanted effects of pain management programmes with patients is necessary to ensure effective shared decision making.
- Healthcare professionals involved in pain management programmes should intervene to reduce the unwanted effects of the programmes that they offer.
- The long-term burdens of self-management should be explored in pain management programme follow up sessions as targets for behaviour maintenance interventions.

Acknowledgements:

We greatly appreciate the generosity of the participants in this study who gave a considerable amount of their time. We also thank Oliver Lehmann for his valuable contribution to data generation.

Declaration of interest:

The authors report there are no competing interests to declare.

Funding:

Gregory Booth is funded by the NIHR Doctoral Fellowship Scheme (NIHR303240). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Ethics

Ethical approval was granted by East Midland-Leicester Central REC on June 6 2016 (IRAS ID: 202089)

References

1. Vos T, Lim SS, Abbafati C, et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet* 2020; 396: 1204-1222. DOI: [https://doi.org/10.1016/S0140-6736\(20\)30925-9](https://doi.org/10.1016/S0140-6736(20)30925-9).
2. Breivik H, Collett B, Ventafridda V, et al. Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain* 2006; 10: 287-333. DOI: <https://doi.org/10.1016/j.ejpain.2005.06.009>.
3. Cieza A, Causey K, Kamenov K, et al. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet* 2020; 396: 2006-2017. DOI: [https://doi.org/10.1016/S0140-6736\(20\)32340-0](https://doi.org/10.1016/S0140-6736(20)32340-0).
4. BPS. Guidelines for Pain Management Programmes for adults. An evidence-based review prepared on behalf of the British Pain Society., (2013).
5. Kamper SJ, Apeldoorn AT, Chiarotto A, et al. Multidisciplinary biopsychosocial rehabilitation for chronic low back pain: Cochrane systematic review and meta-analysis. *BMJ : British Medical Journal* 2015; 350: h444. DOI: 10.1136/bmj.h444.
6. Williams ACC, Fisher E, Hearn L and Eccleston C. Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database Syst Rev* 2020; 8: Cd007407. 2020/08/15. DOI: 10.1002/14651858.CD007407.pub4.
7. Buzasi E, Kurakata H, Gandhi A, et al. Effects of booster sessions on self-management interventions for chronic musculoskeletal pain: a systematic review and meta-analysis of randomised controlled trials. *PAIN* 2022; 163.

8. Franklin ZC, Smith NC and Fowler NE. A qualitative investigation of factors that matter to individuals in the pain management process. *Disability and Rehabilitation* 2016; 38: 1934-1942. DOI: 10.3109/09638288.2015.1107782.
9. Penney LS and Haro E. Qualitative evaluation of an interdisciplinary chronic pain intervention: outcomes and barriers and facilitators to ongoing pain management. *Journal of Pain Research* 2019; 12: 865-878. DOI: 10.2147/JPR.S185652.
10. Spink A, Wagner I and Orrock P. Common reported barriers and facilitators for self-management in adults with chronic musculoskeletal pain: A systematic review of qualitative studies. *Musculoskeletal Science and Practice* 2021; 56: 102433. DOI: <https://doi.org/10.1016/j.msksp.2021.102433>.
11. Aronson JK. When I use a word . . . Medical definitions: adverse events, effects, and reactions. *BMJ* 2023; 381: p917. DOI: 10.1136/bmj.p917.
12. Guest G, Bunce A and Johnson L. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods* 2006; 18: 59-82. DOI: 10.1177/1525822X05279903.
13. Malterud K, Siersma VD and Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research* 2016; 26: 1753-1760. DOI: 10.1177/1049732315617444.
14. Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health* 2010; 25: 1229-1245. DOI: 10.1080/08870440903194015.
15. Richie J, Lewis J, McNaughton Nicholls C and Ormston R. *Qualitative Research Practice. A Guide for Social Science Students and Researchers* SAGE 2013.
16. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3: 77-101. DOI: 10.1191/1478088706qp063oa.
17. Lumivero. NVivo (Version 12). 2017.
18. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007; 19: 349-357. DOI: 10.1093/intqhc/mzm042.
19. Dobler CC, Harb N, Maguire CA, et al. Treatment burden should be included in clinical practice guidelines. *BMJ* 2018; 363: k4065. DOI: 10.1136/bmj.k4065.
20. Palermo TM, Slack K, Loren D, et al. Measuring and reporting adverse events in clinical trials of psychological treatments for chronic pain. *PAIN* 2020; 161.
21. May C, Montori VM and Mair FS. We need minimally disruptive medicine. *BMJ* 2009; 339: b2803. DOI: 10.1136/bmj.b2803.
22. May CR, Eton DT, Boehmer K, et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Services Research* 2014; 14: 281. DOI: 10.1186/1472-6963-14-281.
23. Sheehan OC, Leff B, Ritchie CS, et al. A systematic literature review of the assessment of treatment burden experienced by patients and their caregivers. *BMC Geriatrics* 2019; 19: 262. DOI: 10.1186/s12877-019-1222-z.
24. Duncan P, Murphy M, Man M-S, et al. Development and validation of the Multimorbidity Treatment Burden Questionnaire (MTBQ). *BMJ Open* 2020; 8: e019413. DOI: 10.1136/bmjopen-2017-019413.
25. Jamieson MK, Govaert GH and Pownall M. Reflexivity in quantitative research: A rationale and beginner's guide. *Social and Personality Psychology Compass* 2023; 17: e12735. DOI: <https://doi.org/10.1111/spc3.12735>.

Tables – to be inserted into main text at publication

Table 1: Characteristics of study participants (n=15)

Participant	ICD 11 Chronic Pain Diagnosis	Time since initial programme completion (weeks)
1	Chronic post-surgical pain after knee surgery	74
2	Chronic MSK pain associated with structural changes (scoliosis)	65
3	Chronic MSK pain associated with spondylosis Chronic neuropathic pain (painful radiculopathy)	57
4	Widespread chronic primary pain	83
5	Chronic post-surgical pain after spinal surgery	84
6	Chronic neuropathic pain after peripheral nerve injury	78
7	Chronic post-surgical pain after spinal surgery	78
8	Localized chronic primary pain (Lumbar back pain)	52
9	Chronic post-surgical and post traumatic pain	87
10	Localized chronic primary pain (Shoulder Girdle)	74
11	Widespread chronic primary pain	82
12	Chronic MSK pain associated with structural osteoarthritic changes (knee pain) Chronic neuropathic pain after peripheral nerve injury	61
13	Localized chronic primary pain (Lumbar back pain)	65
14	Chronic MSK pain associated with structural osteoarthritic changes (multiple joints)	50
15	Chronic MSK pain associated with structural changes (scoliosis)	58

Table 2: Themes and subthemes

Theme	Subtheme
Theme 1: <i>Benefits and Burdens</i>	Perceived benefits Personal expectations Burdens of accessing treatment
Theme 2: <i>PMP and Real Life</i>	Long-term application of self-management strategies Barriers to application of self-management strategies Facilitators to using self-management strategies
Theme 3: <i>Social Support</i>	Personal support from peers Family and friends Support structures in local communities and wider society
Theme 4: <i>Healthcare Interventions</i>	The role of healthcare professionals Healthcare interventions for people who self-manage chronic pain