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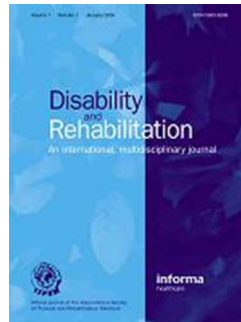
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**A Qualitative Investigation of Factors That Matter to
Individuals in the Pain Management Process.**

Journal:	<i>Disability and Rehabilitation</i>
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Keywords:	Chronic Pain, Pain Management, Patient Satisfaction, Patient Perspectives

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Implications for Rehabilitation

- This study highlights the importance to patients of being given information to help them understand their pain condition and to learn strategies for self-management to cope better.
- Where information was not provided and inadequate time allowed for questioning and discussion, patients tended to desire more frequent access to the care services. More effective communication may result in reduced demand and more efficient management.
- Patients suggested that ongoing peer support may offer an alternative to clinician led services.

For Peer Review

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Abstract

Objective: Chronic musculoskeletal pain is a complex condition to manage with widespread consequences including physical disability, psychosocial effects and increased use of healthcare. Previous research has found patients' experiences within health care can be influenced by factors such as expectations, therapist characteristics and treatment process. This study used patient interviews to identify the key factors that influence individuals' experiences in the management of chronic pain.

Design: Qualitative study using semi-structured interviews in either a home or hospital setting.

Methods: Semi-structured interviews were conducted on eight participants attending hospital-based pain management. Participants were asked about their experiences of pain management and living with a chronic pain condition. Interviews were transcribed and analysed thematically.

Results: Three main themes were identified; impact of their condition on daily life, clinical interactions and the pain management process. Understanding the condition was a key factor for the patients, in particular, explanation by the clinician. The temporality of their pain meant timing of appointments was critical. Patients reported factors such as family days and follow up sessions would improve their treatment experience.

Conclusions: This study highlighted important factors for healthcare professionals and patients in the management of chronic pain. Participants indicated a desire to understand their condition and learn strategies for self-management to allow them to cope better. As patients found benefit from being involved in the management process, discussions around the options for treatment may enhance management and rehabilitation. It is important we

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1 continue to research factors important to individuals with musculoskeletal pain to find an
2 effective, evidence-based framework for understanding and managing this condition.

3 Key words: Chronic Pain, Patient Satisfaction, Patient Perspectives, Pain Management

4 **Introduction**

5 Chronic musculoskeletal pain is a complex condition and one of the most significant causes
6 of suffering in the United Kingdom. The number of people being treated for/experiencing
7 chronic musculoskeletal pain is approximately 10 million and it is the second most common
8 cause for days off work (1). Due to its complexity, chronic pain is a challenging condition to
9 manage, with widespread consequences such as physical disability (2), psychosocial effects
10 (3) and regular or repeated use of healthcare services (4). There is a growing body of research
11 investigating the importance of how patients perceive their pain. Patients can find it difficult
12 to come to terms with their pain and its consequent impact on their daily life (4). This extends
13 not only to their ability to work, but also to complete normal activities of daily living (e.g.,
14 cooking, dusting, vacuuming etc.) and to interact socially with family and friends.

15 When an acute injury is experienced, pain provides a stimulus to rest and protect the
16 affected area until it heals. However, this can become maladaptive when coping with chronic
17 pain. Patients may believe that activity and movement could aggravate the injury, therefore
18 they become fearful of movement, avoid physical activity, and can become isolated, thereby
19 experiencing heightened pain and maintained disability (5, 6). Patient behaviour is an
20 important determinant of the maintenance and development of chronic pain and the resultant
21 disability. Patients are often referred to specialist Pain Management Programmes (PMPs) if
22 they persist in representing their case to care providers and self-report high levels of
23 disability. These programmes aim to change the way patients perceive their pain, to reduce
24 threat, promote self-management and reduce the use of health care services (2). Although
25 PMPs are designed to provide the individual with the skills to manage their pain without

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3 1 clinician intervention, Campbell and Guy (3) found that their patient population re-engaged
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5 2 with health care services (suggesting the PMP failed). This may be because treatment did not
6
7 3 meet patient expectations, or because they had developed an over-reliance upon healthcare
8
9 4 services to provide them with a validation of the pain experience, which may be lacking in
10
11 5 other areas of their life. Verbeek et al.(12) found that patients are normally dissatisfied with
12
13 6 treatment if it does not meet their expectations. They prefer to have a specific diagnosis,
14
15 7 instructions and information and a comprehensive plan of their treatment process. This
16
17 8 presents a significant challenge for health care providers because, for many chronic
18
19 9 conditions, no direct relationship has been established between physical pathology and pain
20
21 10 intensity. The intensity of pain, time-course, impact on daily life and personal meaning are all
22
23 11 individual experiences. Previous research has shown that patients perceive the knowledge and
24
25 12 understanding of health care providers to vary, particularly on the social and emotional
26
27 13 impact of pain (13). In addition, it has been suggested that, although clinicians adhere to the
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29 14 current pain management guidelines, they do not always consider the patient's preferred
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31 15 management strategies (14). If patient expectations are not met, this can promote the
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33 16 increased use of health care services as patients seek more effective ways to cope with their
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35 17 pain.
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41 The majority of studies investigating PMPs have focussed on quantitative techniques
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43 19 to assess treatment effectiveness (4-6). However, it is important to understand how patients
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45 20 perceive the treatment experience and what factors contribute to their expectations and
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47 21 satisfaction with treatment. Previous studies have identified that relationships with health
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49 22 professionals, therapist characteristics, clinical outcome and treatment process (7-9) affect
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51 23 patient reports of satisfaction with treatment. Patients tend to judge these factors based on
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53 24 pre-conceived expectations of treatment and if the services they receive match such
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55 25 expectations. There are few studies that utilise qualitative methods to provide insight into
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1 patient experiences and expectations of pain management, and the impact on their daily life
2 (10). Addressing the patient perspective is an essential step to enhance the relationship
3 between patient and clinicians leading to improved treatment outcomes and satisfaction (11).

4 Over the past decade, there has been an increase in research investigating patient's
5 satisfaction with treatment within the chronic pain population (15-20). Satisfaction with
6 treatment, however, is a very broad term and is not always a particularly specific measure of
7 how patients perceived their treatment process as they frequently focus solely on treatment
8 outcome. Questionnaires designed to assess satisfaction with treatment often lack specificity,
9 for example, items such as 'Are you satisfied with treatment?' are not uncommon and fail to
10 determine which aspects of the treatment (e.g. outcome, process, therapist, coping with pain
11 etc.) are the referents for patient response. Research using more qualitative methods has
12 identified key areas which patients use to evaluate their degree of satisfaction with the care
13 they have received. The findings show that relationships with health professionals, therapist
14 characteristics, clinical outcome and treatment process (9-11) are key influences on
15 satisfaction. Patients tend to judge these factors based on pre-conceived expectations of
16 treatment and if the services they receive, match such expectations. Studies have reported that
17 the therapist's ability to communicate effectively is an important factor when rating
18 satisfaction. This is particularly the case when providing a more detailed explanation for the
19 condition and providing management strategies (19, 20). Cooper, Smith and Hancock(21)
20 investigated physiotherapy care in chronic low back pain patients. They identified the
21 communication skills of the therapist as a key factor that also influenced other emergent
22 themes (e.g. individual care, decision-making, information, the physiotherapist and
23 organisation of care). Cooper et al.(21) highlighted the need for adapting communication
24 styles to accommodate individual needs. Participants reported feeling more involved in their

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1 treatment when there was good communication compared to those who perceived
2 communication to be poor.

3 Chronic pain is a biopsychosocial problem, with each element having a distinct
4 influence upon the other. Through the use of patient interviews, the aim of this study is to
5 identify key factors which have influenced individuals' experiences in the management of
6 their chronic pain.

7 8 **Method**

9 *Participants*

10 Both the university ethics committee and the NHS Health Research Authority gave ethical
11 approval for this study. Participants were recruited from two hospitals and included in the
12 study if they were 18 years of age or over, had been suffering from chronic musculoskeletal
13 pain for more than three months, and had been referred to the hospital for a pain management
14 programme. Participants were invited by letter to participate in an interview. Those who
15 replied were then contacted by phone to arrange the interview. Over a three-month period, 15
16 letters were sent out and eight participants volunteered to enter the study and were
17 interviewed. It was made clear to participants at the start of the interview that their
18 involvement would have no impact on the care they received from their treating hospital and
19 they had the right to withdraw at any time. Demographic patient characteristics are presented
20 in Table 1. Of the eight participants, six were female and two male, with a mean age of 53.8
21 years. All participants had some form of chronic musculoskeletal pain, with a mean pain
22 duration of 17.3 years. All participants were either retired or unemployed due to health
23 reasons.

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Insert Table 1 here.

For Peer Review

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1 *Data collection*

2 Semi-structured interviews were conducted either face-to-face (n= 2) or over the telephone
3 (n= 6) depending on patient preference. An interview guide (appendix 1) was developed from
4 a literature review and the aims of the study to ensure that the same general questions were
5 covered in each interview. The interviewer, aided by the interview guide asked open-ended
6 questions to explore the key factors which had influenced each individual's experiences in
7 the management of their chronic pain. Further probe questions were asked of the participant
8 and the conversation was flexible and responsive to allow the interviewees to elaborate on
9 their responses and to gain richer information of each individual's experience (12).

10 The interviews lasted approximately 45 minutes and were audio recorded with a
11 Dictaphone and transcribed verbatim. Face-to-face interviews were conducted at the clinic
12 where the patient normally attended for treatment. Phone interviews were conducted in the
13 participant's home. Interviewing continued until saturation was reached and there was
14 repetition of the same issues.

15 *Data analysis*

16 The steps for qualitative content analysis and interpretation were guided by the thematic
17 analysis described by Braun and Clarke (13, 14). Coding and data management were
18 facilitated using qualitative data software NVivo (version 10). The first step in the analysis
19 involved initial familiarisation with the information by reading the transcript as a whole, then
20 re-reading to identify the repeated pattern of thematic content. Secondly, the presence of
21 these themes was checked across each transcript. At this point the transcripts were read
22 several times to confirm the meaning of the texts. Words and passages were highlighted and
23 assigned a code. For example, passages in which a participant described how their family
24 influences their condition were assigned the code "family support." The third step involved

1 identification of themes defined as a recurring set of codes or connection made between
2 codes. This method was chosen for systematically identifying and describing features of the
3 data which recur across participants (15). The data were returned to on several occasions to
4 define and refine the evolving themes.

5 Strategies to enhance analytic rigour included constant comparison of categories and
6 themes between the interviews and discussion of the emerging themes by the research team to
7 ensure they were comprehensive and inclusive. To eliminate bias, two of the researchers met
8 regularly to verify the data and reach a consensus. There were no differences in the themes to
9 emerge from the interviews conducted face-to-face in the clinical environment and those
10 from the home-based telephone interviews.

11
12 **Findings**

13 Analysis of the interviews provided three primary themes for the participants' perspective of
14 the chronic pain management process:

15 Theme 1: Impact on daily life; this broad theme relates to how chronic pain affects
16 their lives on a day to day basis, subthemes include the emotional and mental
17 impact as well as physical effects.

18 Theme 2: Clinical interactions; this theme related to factors about the patient's
19 experience with the clinicians throughout the process, subthemes included
20 communication, explanation and understanding.

21 Theme 3: Management process; this theme relates to positive and negative factors,
22 which influenced their management process, subthemes included involvement,
23 understanding, outcome and follow-up.

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3 1 *Impact on daily life*
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6 2 Participants reported a wide range of emotional and physical factors which influenced daily
7
8 3 life as a result of their chronic pain. Generally, participants found that chronic pain changed
9
10 4 their daily life significantly, more specifically, there were tasks and activities that they were
11
12 5 no longer able to complete. Participants described how the physical impact of pain affected
13
14 6 their daily lives, particularly, poor mobility, lack of sleep, fatigue, and difficulty standing or
15
16 7 sitting. All of these factors made participants feel as though they had lost their independence,
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18 8 as others had to perform basic tasks for them.
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21
22 9 “... I used to be active all the time... I know it sounds stupid, but I can’t just
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24 10 get on and do things, like house cleaning, so my Mrs. has to do it all for me,
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26 11 and I really hate that because ya know if I see dust up on the top of the door
27
28 12 frame, I would normally just sort it out.” [participant 3]
29

30 13 “my parents have to miss work to take me to an appointment.” [participant 5]
31
32 14

33 15 The temporality of the pain experience is also important to the participants.
34
35 16 Participants reported that mornings were the most difficult period of the day because of the
36
37 17 amount of time it took each participant to get ready in the morning varied, and was often
38
39 18 dependent on the amount of sleep the night before. Depending on how they felt in the
40
41 19 morning and how long it took to get ready, would then have an effect on the rest of the day.
42
43

44 20 “... something that does really annoy me is that they don’t listen to what I
45
46 21 say about what time of day I want my appointments because the tablets
47
48 22 really knock me out and it makes it difficult in the mornings for me to get
49
50 23 up in time ... they make an appointment for half eight in the morning which
51
52 24 just doesn’t help.” [participant 6]
53

54 25
55 26 The temporality of the pain experience is further highlighted through participants
56
57 27 reporting that they had to carefully plan the day and ensure that they paced themselves in
58
59 28 order to reduce the amount of pain experienced. Participants also reported that if their pain
60

1 was not managed they could end up in a vicious cycle of high pain, tension and doing too
2 much. Using the coping strategies they learnt at the treatment sessions helped them avoid
3 relapses and gave more consistency to daily life.

4 “... you have some good days and then you try and get everything done that
5 you’re trying to catch up on and then you wonder why you’re in bed for a
6 week afterwards because you can’t move.” *[participant 4]*

7 “... they’ve sort of said, right well on a good day, stand, say ...for 10
8 minutes but on a bad day you can stand for 3, on a good day stand for 3
9 minutes and then sit back down again and then you don’t have such a lull in
10 the ups and downs, and you have quicker, hopefully quicker recovery times.”
11 *[participant 7]*

12
13 In addition to physical effects, participants reported a significant impact on emotional
14 and mental aspects, such as feelings of depression, lack of self-confidence and negative
15 mood. Participants commented on how these physical and mental aspects all contributed to
16 the extent that pain affected their life if they were unable to control it or implement effective
17 coping strategies.

18 “You can cope with it [the pain] a lot better if it’s managed. You will never
19 get rid of it but if it’s managed you can have a reasonably normal life. But if
20 it’s not, it basically puts a full stop on it” *[participant 8]*

21 “I mean it is depressing, because it affects the quality of your life always.”
22 *[participant 2]*

23
24 Some participants commented on feeling a sense of isolation and that they were
25 under-valued due to their pain and inability to do certain tasks. A particular source of conflict
26 was when patients thought that there was a lack of understanding by family and friends. They
27 reported feeling that others thought they were ‘making it up’ and it was ‘all in their head’,
28 invalidating the pain experience.

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1 “because you feel very, very alone, very alone, especially when you’ve got
2 people in your family who don’t understand and don’t care and just make life
3 really, really difficult.” [participant 4]
4

5 Although the amount of family support varied between participants, they all
6 commented that this was an important factor for them and it significantly affected their lives,
7 either positively or negatively. The participants reported that their mood was often affected
8 by how much pain they were in and, as a result, this tended to impact their social interactions
9 with family and friends.

10 *Clinical interactions*

11 The participants reported on a number of characteristics in relation to their experiences with
12 clinicians and their consultation preferences. The issues reflected whether their consultants
13 were caring/friendly, the level of communication, whether participants felt they were taken
14 seriously about their condition and the clinician’s understanding of the impact of the pain.
15 Generally, participants liked their clinician to have a caring and friendly attitude, which gave
16 them more confidence in the clinician’s suggestions.

17 “I liked it because they were all so friendly and so nice and so caring and you
18 know it was lovely.” [participant 1]
19

20 Participants were more trusting and more likely to adhere to the self-management
21 suggestions of clinicians they felt were interested in them and listened to what they had to
22 say. Some participants, however, felt like they had to pester the clinician for an appointment
23 or more information and that their condition was not being taken seriously. They felt at some
24 stages of the treatment process they were passed around to different practitioners, which led
25 to miscommunication as patients felt their treatment was not progressing. The participants
26 understood the time restrictions that clinicians were under, however, they often felt like the

1 treatment sessions were too short and they had to push them for answers and be assertive in
2 order to make clinicians listen to them. An important factor to the participants was to have
3 more communication and contact with the clinician in order to help them better understand
4 their condition and to address issues that arose.

5 “I still feel like I’m getting passed off from one to another and no one is
6 really making a decision... they’ve not really said what’s going to happen, it
7 just seems like we are going round in circles and I keep going back for more
8 sessions.” [participant 8]

9
10 Participants differed in their views of how well clinicians explained their condition
11 and the course of treatment that needed to be undertaken. Some participants reported that
12 when they were first diagnosed they were told the clinical name of their condition but not
13 what the name actually meant or the consequences for rehabilitation or management. It was
14 not until they did their own research and attended either a pain management or living with
15 pain course that they truly understood the process of their pain and the consequences of their
16 condition. There were three key areas that participants wanted more information about; (i) the
17 problem itself, (ii) the treatment process, (iii) the long-term implications of the condition. The
18 explanation of their condition also helped improve patient satisfaction with treatment. The
19 level of explanation that participants received varied, the provision of some anatomical
20 information was found to be useful, particularly when used in conjunction with pictures and
21 drawings. In addition, this approach reassured participants that their pain was recognized as
22 real and being taken seriously.

23 “it hadn’t really been explained, I didn’t understand my condition, I had no
24 idea how to tackle it or any insight into if it’s going to get worse, if it’s going
25 to get bad, or what I can do and the course has completely changed that. I
26 understand what my body’s doing now, which I didn’t before, so I understand
27 like how it’s going to behave if I do like certain things... and that was just Oh
28 my god, so that is what’s going on.” [participant 7]

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3 1 *Management process*
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6 2 Participants liked to be given an outline of what was going to happen in the management
7
8 3 process, why that particular intervention was used and how it was going to influence them.
9
10 4 Some participants became pessimistic about the treatments effectiveness.
11

12
13 5 “personally, I don’t think it’s going to do anything... because the last time I
14 6 was at physio it didn’t work.” [participant 3]
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19 8 Some participants found the management process very frustrating if they could not
20
21 9 find answers for their questions, or felt as though they were just being passed from one
22
23 10 clinician to another. They also reported difficulty with travelling to appointments,
24
25 11 particularly if they have to rely on family and friends to take them. They understood that they
26
27 12 had to go to the hospital to see the clinician, however, they reported frustration if, when they
28
29 13 arrived, appointments were delayed or brief. They preferred to have more time at each
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31 14 session in order to allow them to find out more information and gain a better understanding of
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33 15 their course of treatment. In addition, they reported that there were very few follow-up
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35 16 sessions to assess how the condition and the treatment were progressing and if there had been
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37 17 any changes.
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41
42 18 “I would like to see someone like every 3 or 4 months or something, umm
43 19 just so that they can get an update, umm because I’ve got a load of
44 20 questions that I want to ask the specialist.” [participant 5]
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48
49 22 The majority of participants understood that they had a long-term condition and that
50
51 23 they should be active in managing their pain, however, they reported that the treatment
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53 24 process was often more prescriptive rather than a consultation. Participants wanted to have
54
55 25 more involvement in planning their treatment so that it addressed their individual needs and,
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57 26 as a result, they felt they would be more likely to adhere to the advice. Benefits from the
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1 PMPs were widely reported as they gave patients the opportunity to talk to people who were
2 in a similar situation to themselves. By talking with others, they were able to identify
3 different strategies to manage their pain that others had found effective. In turn, this gave
4 them more self-confidence and an empowerment to cope with their pain rather than letting it
5 control their lives. All participants reported that the coping strategies had been a key part of
6 their treatment process and would have liked to know about these strategies at an earlier stage
7 of treatment.

8 Participants reported that their perception of outcome changed over the course of the
9 management process. When they first sought treatment, often their main aim was to find a
10 cure, however, the longer the condition went on and the less effective they found the
11 treatment, their main concern was to be better able to cope and reduce the pain.

12 “So I’ve gone from like cure/fix me to maybe, like you know, just calm it
13 down a bit/reduce it.” [participant 2]
14

15 It was important for participants to understand their condition as it changed their
16 expectations of treatment outcome. Although the majority of participants reported that the
17 intensity of their pain had not significantly improved, they felt better able to cope so that they
18 had more mobility and as a result an improved quality of life. Improved daily life was
19 important to all participants, and they reported that the coping strategies they had learnt from
20 treatment were key to helping improve their level of activity. Participants understood they
21 had a long-term condition that could not be cured, however, they were still willing to try
22 anything in the hope that the treatment would fix them and they could go back to their normal
23 life:

24 “You know you just have to hope that you’re the lucky one and it works,
25 but what do you do? Do you not try it because it’s got a high chance it’s
26 not going to work or do you try it, on the off chance that there’s a slim
27 chance that it can like block some of the pain signals going down your

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1 legs and get you out of some of the pain, maybe off some of your
2 medication, you've got to give it ago haven't you." [participant 1]

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Even though prescribed medication was intended to provide relief or limit to the pain,
all participants reported their dislike of them, and how important it was that they reduced
their use of medication. Some participants reported that the medications worked for a while
but then stopped, or were ineffective on days of greater pain. Several reported that they
became allergic, and were afraid of the suggested side effects.

Discussion

This study provides insight into the complex nature of the impact of chronic pain on
participants' lives and the factors they consider to be important in the management of their
condition. This complements previous literature by providing greater richness and detail of
these factors and their impact on the management process. The main themes which emerged
were the impact on daily life, interactions with clinicians and the management process.

Although chronic musculoskeletal pain itself is not life threatening, it does
significantly affect the individual's quality of life. In particular, the absence of a diagnosis
and effective coping strategies can lead to life changing emotional and social consequences
(16). The complex nature of chronic pain and the difficulty clinicians face in providing a
clear diagnosis, present significant challenges as understanding their condition is a critical
step for patients to help them engage with the treatment process. Zanini et al. (11) highlighted
that enhancing the communication between patients and clinicians, by addressing factors
from the patient's perspectives, helps to build a more critical discussion about the treatment
options, giving the patient a greater feeling of control and higher patient satisfaction.
Previous research has found that having a diagnosis for their pain is important for individuals

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1 as it gives them a feeling of legitimacy for their pain. Validation of their condition, through
2 diagnosis can help improve their social situations and patients feel less of a burden on family
3 and friends (17). Participants reported being more satisfied if their condition had been
4 effectively described to them. Particularly if diagrammes were used as this gave them a
5 greater understanding of the pain process. Without a valid explanation for their pain, patients
6 belief in the linear diagnosis-treatment-cure model was disturbed, which initially caused
7 feelings of worry, depression and anxiety about the future (3). This will in turn undermine
8 their self-efficacy with daily tasks, thus, resulting in higher disability.

9 The participants in this study also reported that their expectations changed over time
10 as they learnt more about the condition. In particular, as treatment progressed and the pain
11 remained, they became more interested in learning coping strategies, and identified that they
12 may have accepted the chronicity of their condition earlier if they had known more about
13 these strategies. This is particularly important for healthcare professionals to consider
14 incorporating some initial short-term coping strategies for daily tasks into the first
15 assessment. Satisfaction with treatment and expectations of outcome are key areas for
16 clinicians to consider (18). Studies have shown that patients who have remained in the care
17 system expect more information, and make higher demands on the interpersonal relationship
18 with their health care provider (18). Campbell and Guy (3) suggested that the reason some
19 patients re-present is that they are unwilling to accept the prospect of living with pain without
20 some form of input from clinicians. It could be suggested that patients who re-present for
21 treatment become attached to the support from the clinician. In relation to attachment theory,
22 Ainsworth and Bowlby (19) suggested that threats to the availability and responsiveness of
23 an attachment figure can produce dysfunctional emotional reactions. This could lead to an
24 increased attention to threatening information, which in turn reduces their self-efficacy with
25 particular tasks. These emotional reactions cause individuals to report higher levels of

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1 disability and fear of movement (20), therefore, they are more likely to enter back into the
2 care system. In addition, clinicians have commented that some patients may not have a
3 willingness to self-manage and that the concept of accepting their condition is long term and
4 a 'readiness to change' is necessary before their behaviors will change (21).

5 Participants reported how beneficial it was for them to talk to other patients about
6 their pain and to discuss coping strategies with individuals in a similar situation. This gave
7 participants the opportunity to have social interactions with people who would take them
8 seriously and listen to their concerns about their condition as well as learning new strategies.
9 Such inter-patient sharing of experience and social interaction may offer an effective means
10 to engage with groups of patients and facilitate more self / group help based approaches. In so
11 doing, it may be possible to facilitate greater opportunity for patients to discuss and learn
12 about their condition without increasing the clinical resource demands of treatment.

13 Support from family and friends was important to how the patients coped with
14 exacerbations in their pain. Those who felt their family and friends understood the condition
15 and how it impacted upon their ability to complete tasks found it easier to be more active and
16 felt less isolated. On the other hand, those who had little or no family support reported feeling
17 very lonely and as though they were not needed for anything anymore. This feeling of
18 loneliness was more likely to be associated with participants becoming less active and social,
19 a loss of self-confidence and increased levels of depression. Previous research has found that
20 cognitive behavioural treatments which include an education element for family are more
21 effective at reducing pain severity and increasing activity (22). Within this study, when
22 family members had a better understanding of the patient's condition, and the variability in
23 function and experienced pain, patients felt more supported and better able to manage their
24 condition. However, participants also reported a loss of independence with daily activities,
25 which was evidenced through reliance on family members to complete daily tasks, and a role

1 reversal with their children. In line with the findings in this study, previous research has
2 identified a significant impact on the social and family roles for patients. Patients experience
3 significant reductions in parenting, participation in family and social leisure activities, and
4 role reversal (e.g. children taking their parents food shopping) (23). These factors have also
5 been associated with anxiety and worry about how the individual's pain affects their family
6 (24). It is suggested that limitations in fulfilling normal family roles intensifies negative
7 affect, and frustration of role limitations was evidenced in this study. This highlights the
8 necessity for PMPs to include an educational element for family members, as they may be
9 unaware of the impact they have on the pain-affected individual. The provision of clear
10 information about the pain process, not only to the patient but also to their immediate support
11 networks, was vital to ensuring successful management.

12 PMPs are designed to educate patients about their pain and to help them set goals
13 which will improve the areas of their lives where pain has a significant negative impact.
14 There is good evidence for the efficacy of PMPs (4-6), however, limited research has looked
15 at the impact for patients after treatment. Whilst patients reported enjoying the social
16 interactions associated with attendance on a PMP, they also indicated that at the end of the
17 management programme they went back to a feeling of isolation. Attendance at a PMP gave
18 participants something to look forward to each week, not only to have social interactions with
19 people but also to feel involved in their pain management in an active way. This finding
20 highlights the need to support follow-up sessions, which encourage individuals to be more
21 socially active and rely less on support from the clinician. This suggestion is contrary to the
22 aims of most programmes or guidelines which is to promote more self-management,
23 however, it may lead to individuals utilising less clinical appointments and lead to more
24 independence.

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1 Failure to understand their condition and how best to self-manage their pain led many
2 participants to report, in the early stages of their management, that they were often 'over-
3 doing it' because they were trying to catch-up on tasks on their 'better days'. This increased
4 the likelihood of a relapse, and participants found they would then feel worse for the next
5 couple of days, both physically and mentally. In some cases, participants reported that this
6 negative reaction to activity left them worried and fearful of future activity, causing them to
7 avoid tasks due to lower self-efficacy, thereby leading to higher disability. This is typical of
8 the fear-avoidance model described elsewhere in the literature (25).

9 This study highlights some important implications for treatment. Firstly, the patient
10 interviews suggested that the treatment process and clinician interactions would influence the
11 individual's ability to develop effective coping strategies and their satisfaction with
12 treatment. Improving factors surrounding the treatment environment, may lead to an
13 improved patient experience. Secondly, in relation to the treatment process and clinical
14 interactions, the participants suggested that more information relating to their condition and
15 coping strategies at an earlier stage of treatment may be more beneficial. Therefore, changing
16 clinical practice guidelines to give short-term coping strategies may improve levels of
17 satisfaction. Finally, the patients within this study suggested the inclusion of a family support
18 day within PMPs would give the patients' relatives a better understanding of the effect pain
19 can have on the patient. Some hospital PMPs already include a support day, however it would
20 be beneficial to include this as an essential element. Giving relatives an active involvement in
21 the treatment programme may provide more support by relatives as they are made to feel
22 included and a sense of justification in their input.

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Table 1. Participant characteristics (N= 8)

	Participant							
	1	2	3	4	5	6	7	8
Age	69	81	51	49	19	44	76	42
Sex	Female	Female	Male	Female	Female	Male	Female	Female
Pain duration (years)	40	20	3	4	4	10	37	21
Type of pain	Back pain and arthritis	Back pain and arthritis	Low back pain	Back pain and Fibromyalgia	Chronic Fatigue Syndrome	Back pain	Back pain	Back pain
Employment status	Retired due to health reasons	Retired not due to health reasons	Unemployed-due to health reasons	Unemployed-due to health reasons	Unemployed-due to health reasons	Unemployed-due to health reasons	Retired not due to health reasons	Unemployed-due to health reasons