

ORIGINAL REPORT

PERSONAL CHARACTERISTICS INFLUENCING PATIENTS' ADHERENCE TO HOME EXERCISE DURING CHRONIC PAIN: A QUALITATIVE STUDY

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Objective: To identify the beliefs and perceptions of patients with chronic neck and low back pain that influence adherence to home exercise during exacerbation and/or remission of pain.

Design: Qualitative study using a focus group technique.

Subjects: Thirty-four patients (23 women, age range 26–70 years) with chronic neck or low back pain who had participated in a home exercise programme.

Methods: Seven focus groups were formed. Participants were sampled purposefully from all patients with chronic neck or low back pain who attended for physiotherapy at 4 primary healthcare centres. Patients were interviewed about how they perceived their adherence to a home exercise programme during chronic pain. Data were analysed using a phenomenographic method.

Results: Several themes about patients' beliefs and perceptions were identified as factors related to adherence. These factors change when pain or disabilities appear, decrease or disappear for an extended period. Beliefs about illness and treatment are more likely when pain is present and when pain disappears for an extended period. However, patients consider perceptions about barriers, social support and physical environment when pain decreases.

Conclusion: These findings may represent an important potential for improving the adherence of patients with chronic pain to home exercise programmes.

Key words: chronic pain, adherence, physical therapy, exercise, qualitative research.

J Rehabil Med 2009; 41: 347–352

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Submitted February 15, 2008; accepted November 20, 2008

INTRODUCTION

Exercise has been documented as an effective intervention for treatment of back and neck pain (1–4). Usually, exercises are taught and prescribed for home (5). However, research suggests that inadequate adherence to home exercise during the intervention period might attenuate the effectiveness of

intervention (6, 7). It has also been suggested that recurrent cases of low back pain might be avoided if patients adhered to home exercise programmes after intervention (8, 9).

Several studies report that a lack of adherence to exercise is often a serious problem for patients with chronic pain. Estimates of what proportion of patients does not perform their exercises according to prescription vary depending on differences in the definition of adherence and measurement, but it is approximately $\geq 50\%$ (6, 7, 10–12).

Research suggests that patients' personal characteristics influence adherence to home exercise programmes (13). Empirical studies have related patient's beliefs about seriousness, prognosis of illness and treatment efficacy with adherence (10, 14). Perceiving barriers to carrying out home exercise programmes has also been related to adherence (10, 12, 15). However, there are contradictory results from various studies concerning the association between adherence and perceptions such as pain or disability (10, 12, 16, 17).

It has been suggested that the relevance of pain in influencing adherence depends on the interaction between pain and patient's beliefs or other perceptions (17). Furthermore, several authors have suggested that patients might use different beliefs and perceptions to guide their adherence during periods of exacerbation or remission (10, 13, 17). However, this last issue has not been demonstrated for patients with neck or low back pain. Qualitative studies have not focused on this point of view in patients with neck or low back pain (15, 18) and quantitative studies that have investigated patients' perceptions, beliefs and adherence have not focused on its relative significance in exacerbations and remission of pain during the course of chronic pain. Therefore, although previous studies recognize the importance of patient's beliefs and perceptions on adherence to a home exercise programme, further work is needed to understand its importance during exacerbation and remission of pain.

The aim of this study was to explore patients' perceptions with the purpose of identifying those beliefs and perceptions that patients perceive to influence their adherence to a home exercise programme during exacerbation and remission of pain in the course of chronic pain. Physical therapists would benefit from a better understanding of such perceptions and their potential influence on adherence to their interventions as they attempt to maximize patient adherence.

METHODS

Qualitative methods provide a set of strategies for conducting a rigorous research study with the above aim (19). In order to describe completely the experience of adherence during exacerbation and remission of pain, a phenomenological study was undertaken. Phenomenology as a research approach aims to describe the experience of the everyday world as it appears, varied and complex (20). A focus group technique was used to obtain detailed data from patients' with experience of participating in home exercise programmes.

Participants

Four typical public primary healthcare centres in the region of Murcia, Spain, were selected. Murcia has a population of over 1 million and has a well-developed healthcare system that is mainly publicly operated. We selected these centres because patients with mechanical neck or low back pain referred to physical therapy intervention participate in both clinic visits and a home exercise programme during the period of intervention and afterwards.

Inclusion criteria for the study were: all patients with mechanical and chronic neck or low back pain who received and finished physical therapy treatment in the last 3 months. Exclusion criteria were: patients with mechanical neck and low back pain due to trauma, or patients with a physical or mental disability that precluded participation in focus groups (i.e. those who were deaf, blind, or had learning disability). Following research ethics committee approval, we identified patients from clinic records. A total of 94 patients were eligible for the study and a mixed purposive sampling strategy was used to select participants (21). Sampling was therefore dependent on the saturation of information.

Procedures

Recruitment. Stratification according to homogeneous and heterogeneous criteria was used to set up groups: homogeneous groups by centre (common experiences) and gender (to avoid diffidence in discussing health issues in the presence of the opposite gender), and heterogeneous groups by age and clinical condition (neck/back pain) to add variability of experiences to stimulate discussions. An invitation to join the study was sent by post to eligible patients and followed up with a telephone call. As patients declined to participate, we invited new patients to obtain a minimum group size of 4.

Data collection. Two people, a moderator and an assistant, conducted all discussions in the public and neutral location of the city hall (i.e. not in the health centre). They used a topic guide initially derived from a literature review and later agreed upon by the research team. The topic guide was then reorganized after a preliminary analysis following the first focus group (Table I). During the interview dialogue the researcher posed questions such as: "What do you mean?", "Can you explain it more?", "How do you feel?", "What did you think?", "Please give an example". Audiotape was used for data collection during discussions. Videotape and field notes were used to record non-verbal language and incomplete or sarcastic expressions. Patients gave permission and were assured of confidentiality before the start of each session, prior to using these means of recording.

Table I. Focus group interviewing guide

Why did you go to the physical therapist?
How did you feel about having neck or low back pain before physiotherapy treatment?
What have you been told about chronic pain and its treatment?
Did you find easy your adherence to physiotherapist's instructions at the beginning of treatment? After your treatment, was it easier?
What kind of problems do you encounter for adherence when pain is not present?
Is there anything else you would like to say about your home programme or your pain?

Analysis

Interview transcripts were analysed in 5 steps: (i) overall impression of categories; (ii) independent generation of an initial code to label phrases; (iii) revision of categories and coding scheme as we accumulated data; (iv) elaboration and application of a final code scheme to the final data-set; and (v) exploration of the categories' relationships (22).

In the first step, transcript and observational notes were read to gain a sense of entirety, to identify significant phrases and to obtain tentative ideas about categories and relationships. It was agreed to define 2 kinds of categories to code information (23): (i) substantive categories, which help understand the experiences of patients; and (ii) themes or organizational categories, which gather substantive categories in logical areas according to study objectives. The agreement was reached using concepts that participants used or theoretical terms employed in the literature for substantive categories. The differences in the initial coding schemes generated independently by each of 4 researchers were resolved by discussion. This step was iterative, allowing emerging categories as the groups progressed. When saturation was being reached, it was implied when no new major themes arose by the end of the seventh focus group. The defined categories were presented to the physical therapists who treated the participants, as an external audit of the initial results before applying codes to the final data-set of phrases. Subsequently, a final coding scheme was elaborated by 2 researchers (PER and FMM) and confirmed for consistency through blind review of 2 transcripts. Disagreements between the 2 researchers were resolved by discussion. Codes were then applied to the final data-set, and category relationships within and among patients were explored.

Describing. Using a phenomenological method, a synthesis of the transformed meaning units was described, thus explaining the inner core of the phenomenon. Finally, taking into account all results, the essence of the investigated phenomenon was described (24).

RESULTS

There were 34 participants in this study (22 of these had chronic neck pain, and 23 were women). Their mean age was 48 years and age range 25–70 years. All participants were included in home exercise programmes by physiotherapists. Since their inclusion they had experienced periods of exacerbation and remission of pain. Most patients expressed beliefs and perceptions in some form to report problems with adherence to home exercise programmes.

The patients' experience was expressed in 5 themes: beliefs about illness and adherence, and perceptions in relation to barriers, support social and physical environment. Patients balanced these beliefs and perceptions to decide adherence to their home exercise programme. We classified them according to the emergent taxonomy shown in Table II, which identified variation in categories of beliefs and perceptions that concern patients under our 3 pre-established conditions: perception of presence, decrease or absence of pain or disabilities. From these themes and classification, an essential structure emerged. Identifier, for example Interviewed Person (IP), and demographic characteristics are given for the quotes below.

When pain or disabilities appear

When patients perceive pain or disabilities associated with pain, they report deciding whether they should adhere to home exercise programme recommendations. At the moment of

Table II. Beliefs and perceptions associated with adherence to home exercise

<i>When pain or disabilities appear</i>
Beliefs about illness
Prognosis expectations
Beliefs about adherence
Outcome expectations with exercises
<i>When pain or disabilities decrease</i>
Perceived barriers
Lack of time for exercises
Tiredness
Forgetting
Adverse effects of exercises
Comorbidities
Perceptions of support social
Incentives from family
Interactions with people exercising
Perceptions of physical environment
Entertainment
Recreational centres
Beliefs about adherence
Self-efficacy
<i>When pain disappears for long time</i>
Beliefs about illness
Vulnerability to relapse
Beliefs about adherence
Distance between adherence and its benefits or costs

perception, patients report doing exercise regardless of other considerations.

IP 3: *"When the pain bothers me or my usual activities, I remember the exercises, and leave what I am doing, and do the exercises that the therapist gave me"* [Male, 53 years].

Some patients report that their beliefs can interfere in the decision that occurs between perception of pain and adherence to exercise recommendations. Patients report that these beliefs are related to illness and treatment.

1. Beliefs about illness. Prognosis expectations are the beliefs that patients regard in this phase. Those patients who believe their problem is chronic and immutable tend to have a resigned attitude toward their pain, and consequently decide not to adhere to exercise recommendations. However, patients with optimistic *prognosis expectations* do not associate this optimism to adherence.

IP 16: *"I have my problem since so many years and nobody could help me. Because that often I don't do advice of the brochure that physical therapist gave me"* [Female, 63 years].

2. Beliefs about adherence. Patients also assess the credibility of the treatment offered. If patients doubt the effectiveness of the recommended advice, or if its rationale is not clear, they are less likely to adhere. Conversely, when patients believe that treatment is effective they report having high *outcome expectations* and consequently adhere to recommendations.

IP 10: *"Exercising was for the pain, I saw myself with disabilities and I hoped to get better with this treatment"* [Male, 55 years].

When pain or disabilities decrease

When the pain or disabilities associated with pain decrease, patients report perceiving that the home exercise programme requires some degree of alteration to their lifestyle. They report deciding about whether to adhere to recommendations once again. Patients initially prioritize to complete daily routine activities and discontinue exercises. Additionally, it is a positive reinforcement for the patients that symptoms take time to reappear after this decision.

IP 20: *"When I feel better, I forget the exercises and do other things; besides that, I don't have pain again"* [Male, 35 years].

In spite of the initial prioritization, patients try to maintain some degree of exercise. However, patients report that several perceptions – related to barriers, social support and physical environment – and beliefs about ability to adhere, interfere with their intention and then they do not give priority to their home exercise programme.

1. Perception of barriers. Perceived barriers are associated with low or no adherence. Common barriers usually include lack of time to fit exercises into a daily routine, tiredness, forgetting to exercise, adverse effects of exercises and symptoms associated with comorbidities.

IP 5: *"After work I arrive home at 9:00 o'clock at night, have dinner, sit down and put my feet up to watch TV"* [Male, 45 years].

IP 22: *"I had to stop using the bicycle because my knee was swelling. She also recommended that I walk, but I cannot do that either"* [Male, 65 years].

IP 32: *"I have another problem. Then, the days I feel good I can do exercises and the day I don't feel good I can't"* [Female, 46 years].

Patients report that a lack of time to fit exercises into their daily routine leads to barriers such as forgetting to exercise or tiredness.

IP 13: *"Being in the house I usually forget to do exercises because I am doing other things I am very busy and when I finish I want to sit or lay down because I am tired"* [Female, 44 years].

2. Perceptions of social support. Patients perceive that social support from family by means of incentives and reminders is helpful to adherence at times. Nevertheless, they recognize that this kind of support has less influence on adherence than social support from interactions with people exercising.

IP 8: *"In the clinic I had to comply, after, in my house, nobody was watching me or telling me what to do, sometimes my wife told me to do exercises and then I did them, but generally I did not"* [Male, 61 years].

IP 32: *"Exercise is different in the clinic than in my house, because in the clinic I was in front of other people and at home I am alone"* [Female, 46 years].

3. Perceptions of physical environment. Patients report having effective resources from the physical environment to overcome perceived barriers. These resources include using entertainment, such as television at home, and attendance at recreational cen-

tres. Some patients even feel that attending recreational centres is fundamental for adherence in post-treatment periods.

IP 28: *"I exercised every day when I woke up in the morning. I turned on the TV and I did the exercises while I watched"* [Female, 52 years].

IP 14: *"If I don't go to a gym or a recreation centre then I don't exercise, and if I do it's boring, unless I turn on the TV, a record or have a partner"* [Female, 45 years].

4. Beliefs about adherence. Patients' self-efficacy to overcome the common barriers to do exercises is a belief that has a strong influence on adherence. Low self-efficacy is associated with low adherence, and high self-efficacy is associated with high adherence.

IP 14: *"I can't do the exercises. I know it depends on my will-power to have a routine, but when I wake up I go directly to do the things I have to do, and I don't stop to exercise... A woman who tells herself to take care of herself or that she needs to exercise, she finds the time"* [Female, 45 years].

When pain disappears for long time

When pain or disabilities are absent, patients tend to make decisions regarding adherence, and this usually results in low or no adherence. Patient's beliefs about illness and benefits/costs of adherence influence their decision.

IP 11: *"I exercised in my house because I could move my arm better. I did them for a long time until I saw my arm didn't have pain and my hand was no longer asleep. Since then I have not done the exercises"* [Male, 49 years].

1. Beliefs about illness. Patient's beliefs about vulnerability to relapse influence this decision in relation to adherence. Nevertheless, patients report feeling no vulnerability to relapses as a consequence of not undertaking the prescribed home exercise programme. Only a few believe they might have a relapse.

IP 3: *"I exercise because I am afraid that I will have the pain again"* [Male, 53 years].

2. Beliefs about adherence. Even when beliefs about vulnerability to relapse are present, they are not strong enough to promote adherence. Thus, when patients believe that continuing exercises might prevent relapses, they face a conflict between knowing that they should perform (i.e. adherence to exercises and other advice) and at the same time feeling it is difficult to adhere. Most patients attenuate or stop exercising because relapse might be a long time away and they prefer exercising only if pain reappears. Only a few prefer initially to continue exercising. This decision is highly influenced by fear of relapse.

IP 30: *"After a time being good I stopped exercises. I am not doing well but when I feel pain again I will probably restart the exercises"* [Female, 37 years].

The essential structure

The essential meaning of patients' experiences was desire to live without pain and without exercise programmes that alter their lifestyle. If either of these factors disturbs their lifestyle patients decide about adherence to exercise programmes.

Conditions for adherence were different in subjects under conditions of exacerbation and remission of pain. During exacerbation of pain, conditions for adherence were to have high expectations about the prognosis of illness and outcomes of exercises. When pain decreased, essential conditions were related self-efficacy to overcome perceived barriers and to having social and environment support.

Lack of these conditions gave way to feelings of worse pain management and difficulty in accepting adherence to home programme. It also led, especially when pain had disappeared for a long time, to feelings of guilt about subsequent relapses. However, patients who had these feelings were not discouraged and trusted themselves or their capacity to carry out exercise programmes.

DISCUSSION

We examined the beliefs and perceptions of patients that influence their adherence to home exercise programmes during periods of exacerbation and remission of pain during chronic pain. The study provides evidence on several issues. First, patients relate adherence to perceptions of pain itself or disabilities associated with pain. Secondly, these perceptions interact with other patients' perceptions or beliefs to decide adherence to a home exercise programme. Thirdly, these perceptions and beliefs change over periods of pain and disability exacerbation and remission, and between patients.

Regarding the first issue, our participants associated positively perceptions of pain or disabilities and adherence, but for a limited time. Previous studies have reported contradictory relevance of perception of pain itself or disabilities associated with pain (10, 12, 16, 17). Our finding may explain apparent discrepancies between studies with back pain patients, resulting from variance created by the measurement of adherence at different points of time across the spectrum of chronic pain or disability. For example, studies that measured both disability and adherence at the same time found significant relationships (10), while studies that measured initial disability and follow-up adherence found no relationships (12).

Perceptions of pain or disability could be relevant because they can contribute to a patient's belief of a more severe condition (14) or vulnerability to further problems as a consequence of not undertaking the home exercise programme (17). Both beliefs, severity and vulnerability, are related to adherence to physical therapy activities in empirical studies with a variety of musculoskeletal conditions (10, 25, 26). However, these beliefs were not explicitly identified as in our taxonomy, during the period of pain.

Our taxonomy included patients' beliefs and perceptions that interact with perception of or not of pain in different periods of chronic pain. The taxonomy's distinction in periods of pain exacerbation, remission and disappearance suggests that there is a dynamic influence between pain perceptions and other perceptions or beliefs. The dynamic influence of determinants of adherence according to another determinant, such as pain, is a central component of social cognitive theory (27).

This study suggests that only beliefs about illness prognosis or outcome expectations are able to interact negatively with

such perceptions when pain or disability appears. Thus, when patients believed their complaints would continue or their exercises would not help them, lower adherence was reported. These findings regarding illness prognosis support empirical studies in physiotherapy and medical research (10, 28). On the other hand, the relevance of outcome expectations is mirrored in another study that also found that sport's injury patients with lower outcome expectations were less adherent (25). This is reinforced by another study that related high levels of adherence to beliefs about the effectiveness of rehabilitation (26).

Perceived barriers to exercise, such as comorbidity, adverse effects, or lack of time to fit recommendations into a daily routine, have been strongly associated with adherence (10, 29, 30). Lack of time is a very consistent barrier identified between studies (13, 15). For some subjects, reporting lack of time may be a more socially acceptable excuse (10, 15) and may reflect a lack of interest in their commitment to compliance or could be the reflection of poor behaviour skills, such as time management (31). Thus, lack of time may not be a true determinant of adherence, but a perceived determinant. Furthermore, our participants also reported that, at times, the perception of a lack of time appears to be related to other barriers such as tiredness and forgetting. Traditionally, forgetting has been considered a determinant of non-intentional adherence (17). However, our finding suggests that sometimes this non-intentional adherence could be due to a previous and implicit prioritization between the exercises and other activities that leads to a lack of evocation of the reminder for exercising.

While perceived barriers are negatively associated with adherence when pain decreases, perceptions of social support and physical environment and belief of self-efficacy are positively associated. Self-efficacy has been related to adherence to home exercise programmes (17). Social support from family and from social interactions has been related to adherence to clinic programmes of physiotherapy (32), but not to home programmes. In addition, the type of social support might be more relevant for home exercise programme adherence and has not been studied. Patients in this study perceived that social interactions impact on adherence to a greater extent than does social support from their family.

Prevention of relapse is not something our patients wish to avoid when pain disappears for an extended time. Besides, prevention as the desired outcome is not strong enough to promote adherence because the relapse may be a long time away. According to social cognitive theory (27), it is likely that a patient's balance between distal desired outcomes and proximal costs influences adherence behaviour. Balance between costs and benefits of treatment has been identified in qualitative studies of other conditions (33, 34) and in psychological models such as the theory of planned behaviour (35).

Recommendations for practice and research

Most factors identified in this study have clear implications for patient management in physical therapy as well as other instances in healthcare providing self-management therapies. The predominant emergent view is that large improvements could be made in designing therapeutic encounters in order to

maximize adherence. First, it is a problem that patients often do not communicate their beliefs about treatment, particularly regarding adherence to home exercise programmes when pain or disabilities decrease or disappear. Patients probably lack basic background knowledge about why it is important to follow the exercises even without pain. Thus, it is not odd that patients use their symptoms and disabilities to decide whether they should adhere to the home exercise programme. This knowledge and belief can be addressed by the therapists in the ordinary clinical situation in order to improve adherence. In this respect, this study provides potential support for enhancing the impact of educational interventions by targeting them to address factors that emerge in each period of chronic pain. Therapists should first establish patient's prognostic expectations and their perceived credibility of treatment, and only later reinforce positive factors and offer balance between perceived barriers or other problems with knowledge and beliefs of benefits.

The results of this study also have potential implications for patterns of delivery of physiotherapy. Patients usually stop adhering to home exercise programmes at the end or after a period of treatment, when pain decreases or disappears. For these patients, improving adherence might be an unrealistic aim if there is no physiotherapy follow-up intervention, such as programme adjustment or reinforcement of schedules.

This study focused on home exercise programmes and did not address other common home interventions, such as activities for self-management of pain (e.g. heat, rest) and self-care of back or neck (e.g. rest position, posture) (36, 37). Perhaps patients perceive that different beliefs and perceptions influence their adherence. Because this study was limited to home exercise, future research should explore other home activities.

Focus group studies have some potential disadvantages. They involve relatively small numbers of people; therefore, findings may not be representative of the general population in terms of opinions voiced. However, this qualitative study was designed to highlight the phenomenon being studied, and not to measure variables. Future research should provide more comprehensive and sensitive measurement of factors related to non-adherence during different periods of chronic pain.

In conclusion, this study has provided a deeper understanding of patients' beliefs and perceptions and their relationship with adherence to home exercise programmes during periods of exacerbation and remission of chronic pain. Knowledge of patients' priorities regarding the most important beliefs and perceptions that have high potential for adherence to home exercise may be helpful in improving the quality of care of patients with neck or low back pain. Adherence is usually a reasoned response in relation to a person's beliefs and perceptions. Managing adherence successfully can be a difficult task that cannot be accomplished simply by informing or instructing patients about home exercise. Overcoming negative perceptions and beliefs will require comprehension that the significance of each specific determinant of adherence must be considered in other determinants and techniques of continuing education, such as programme adjustment or reinforcement schedules.

ACKNOWLEDGEMENT

This study was supported by a research grant from the Ministry of Health and Consumer Affairs (PI030317) Spain.

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