BEING IN AN EXCHANGE PROCESS: EXPERIENCES OF PATIENT PARTICIPATION IN MULTIMODAL PAIN REHABILITATION

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INTRODUCTION

Multimodal rehabilitation is a common recommendation for patients with persistent pain problems (1–5), defined as persistent or recurring pain of at least 3 months’ duration (2, 5). Persistent pain occurs in approximately 20% of the adult Swedish and European population, with a higher prevalence among women (2, 5, 6). Such pain may reduce health-related quality of life and increase societal costs (2, 7, 8). Persistent pain can be explained by the bio-psycho-social model as a complex and dynamic process whereby biological, emotional, cognitive and social factors interact (9–11). In multimodal pain rehabilitation, the patient and a team of health professionals co-ordinate the interventions from a bio-psycho-social perspective, such as physical exercise, functional training, education, and cognitive-behavioural interventions, towards a mutual goal (1, 3, 12, 13). Multimodal rehabilitation has been shown to improve self-rated health and work ability (14) as well as return to work (5).

In Sweden, multimodal pain rehabilitation is provided within primary healthcare as well as in specialized care. Patients with complex pain conditions in combination with moderate to severe psychological symptoms are treated at primary healthcare centres (13). The Swedish rehabilitation warranty was set up in 2008 to provide financial support for multimodal rehabilitation for patients with persistent pain. The warranty is available for individuals between 16 and 67 years, and specifies the minimum amount of rehabilitation as 2–3 times a week for 6–8 weeks, provided by a minimum of 3 health professionals of different occupations (12). The county council in northern Sweden develops multimodal rehabilitation within primary healthcare centres by certification of methods of working (15), financial support (15) and treatment settlements between primary and specialist care (16).

Participation in work and daily life is one of the main goals of multimodal pain rehabilitation (5, 12, 13). Patients’ integrity, autonomy and opportunities to reflect have to be acknowledged (5), as well as the opportunities to play an active role in rehabilitation planning (12, 13). Under Swedish legislation patient participation is acknowledged by focusing on the interaction between patients and health professionals, as well as the patient’s autonomy, integrity and equality in decision-making in clinical practice (17). The patient’s participation in multimodal pain rehabilitation is important in order to obtain positive rehabilitation effects (12). Effective interaction between patients and health professionals correlates with stronger treatment effects (18) and improved health outcomes (19).
The concept of patient participation can be understood in different ways as there is little agreement on how to conceptualize it (20). Participation can be defined as the action of taking part in something (21). The International Classification of Functioning, Disability and Health (ICF) defines participation as being involved in a life situation (22). Patient participation can be studied from several perspectives: for example, patient, healthcare organization, and societal perspectives (20). Within the patient perspective it is important to acknowledge the patient as an individual, and to improve collaboration through learning, understanding, confirmation and support for autonomy from the health professionals through dialogue (23). For high levels of patient participation it has been shown to be important for patients to acquire appropriate insights and knowledge, not only information, and to have the opportunity to interact with health professionals. This is in line with the ICF’s definition of participation (24). However, little is known about patients’ perspective on participation in multimodal pain rehabilitation.

The aim of this study was to explore primary health care patients’ experiences of patient participation in their multimodal pain rehabilitation.

METHODS

Subjects

Subjects were selected from patients at a primary healthcare centre, certified for multimodal pain rehabilitation, in northern Sweden. Among all patients who completed multimodal rehabilitation at the primary healthcare centre, a purposive sample was selected in accordance with the Swedish rehabilitation warranty (12). The following criteria were used: (i) age between 18 and 63 years; (ii) completed multimodal rehabilitation for persistent pain; (iii) rehabilitation 2–3 times a week for 6–8 weeks; and (iv) involvement of a minimum of 3 health professionals in different occupations. In total, 24 subjects fulfilled the criteria and were sent written information about the study. Seventeen persons gave informed consent to participate (14 women and 3 men, age range 23–59 years, mean age 46 years). They had all had persistent pain in the spine, shoulder or generalized musculoskeletal pain, for several years. All informants, except one who worked full-time, had been on sick-leave for at least one year at the time they entered multimodal rehabilitation. The interview was carried out between 4 months and 3 years after the end of rehabilitation. The study was approved by the Regional Ethics Committee of Umeå University, Sweden (Umeå University, Department of Epidemiology and the computer centre, UMDAC). The codes in each interview were then compared and compiled according to similarities and differences. Preliminary categories on a more abstract level were created. The analysis continued by comparing the preliminary categories in all interviews, in order to obtain further abstraction and to construct definite categories. Thereafter sub-categories at lower levels of abstraction were identified. A theme, which expressed a latent content of the text, emerged during the analysis. To ensure credibility, continuous comparison of the emerging codes and categories, against all data, was performed. All authors participated in the analysis process.

Data analysis

Data analysis was carried out by qualitative content analysis (28). Firstly, the transcript of each interview was read through several times and notes were made about the overall sense of the interview. The content in the text defined the concept “patient participation”, and conditions favouring patient participation as well as conditions restraining patient participation. The analysis proceeded with marking meaning units that answered to the aim of the study. The meaning units were condensed, and labelled with a code, which was kept close to the text. This was first made manually, then copied into the freeware computer programme Open Code (Umeå University). The codes in each interview were then compared and compiled according to similarities and differences. Preliminary categories on a more abstract level were created. The analysis continued by comparing the preliminary categories in all interviews, in order to obtain further abstraction and to construct definite categories. Thereafter sub-categories at lower levels of abstraction were identified. A theme, which expressed a latent content of the text, emerged during the analysis. To ensure credibility, continuous comparison of the emerging codes and categories, against all data, was performed. All authors participated in the analysis process.

RESULTS

Analysis of the content resulted in one theme Being in an exchange process, and 4 categories: Fruitful encounters, Inequality in co-operation, Confidence-inspiring alliance, and Competent health professionals. These categories represent the patients’ description of patient participation in their multiprofessional pain rehabilitation. Each category comprised 3 sub-categories. From the categories the comprehensive theme Being in an exchange process emerged. An overview

Table 1. The theme “Being in an exchange process”, with its categories and sub-categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Being in an exchange process</th>
</tr>
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<tbody>
<tr>
<td>Category</td>
<td>Fruitful encounters</td>
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<tr>
<td>Sub-category</td>
<td>Platforms to meet</td>
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<td></td>
<td>Health professionals invite to dialogue</td>
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<td></td>
<td>Health professionals’ personal qualities</td>
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<tr>
<td></td>
<td>Patients respond to dialogue</td>
</tr>
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of the results is shown in Table I. The theme, categories and sub-categories, illustrated with quotes from the patients, are described below.

**Being in an exchange process**

The 4 categories constituted a complex and individualized exchange process of emotions, thoughts and knowledge between the patient and the health professionals. The exchange process included both fruitful encounters with competent professionals in a confidence-inspiring dialogue, but also inequalities in cooperation. The quality of the exchange process was important for the patients to have opportunities to perceive the inequality in the co-operation as balanced. The health professionals played an active role in facilitating the exchange process.

_We (the patients) are all individuals, there is no model that fits all; you (as health professionals) have to be very flexible in the way you meet and communicate to be able to reach each person._ (Woman, interview 5)

**Fruitful encounters**

The category Fruitful encounters contained 3 sub-categories and described the patients’ opportunity to meet and communicate with the health professionals in the exchange process.

The sub-category “Platforms to meet” illustrated the patients’ experiences of opportunities to meet with the health professionals, as prerequisites to patient participation. Both team-conference meetings and individual meetings for treatment, planning and evaluation, were described as the basis for fruitful encounters. Experiencing that health professionals allowed enough time to meet the patient, scheduled recurrent visits and made it easy for the patients’ to contact them, were important for participation. Some patients experienced that there were few team-conference meetings, which limited the participation process.

_In the team-conference meetings, I feel that I am participating because I am present in the room; you (the health professionals) do not meet without me._ (Woman, interview 11)

In the sub-category “Health professionals invite to dialogue” together with the sub-category “Patients respond to dialogue”, the patients emphasized that the health professionals conducted the dialogue by asking questions about their symptoms and life situation, and proposed a variety of examinations and treatments for the patients to consider. The patients experienced that they participated in the dialogue by responding when asked for their opinion and when given the opportunity to reflect. Health professionals’ expectations that the patients would make their own suggestions about examinations and treatments were not experienced by the patients as patient participation.

_I don’t want to be expected to come up with suggestions on treatment options...if I had to, I think that this health professional is not competent._ (Woman, interview 12)

When they had different opinions from those of the health professionals, the patients experienced themselves as tuning out from dialogue rather than standing by their own opinions. Questions about the future were sometimes perceived by the patients as provocative and as a barrier to participation, while others found that the topic promoted participation. Experiences of leaving encounters with health professionals with unanswered questions or inadequate explanations were perceived as restraining patient participation.

The patients emphasized that patient participation meant being able to state their opinions and have a say in decisions. Patients expressed a wish to play a more active role in the dialogue with health professionals.

**Inequality in co-operation**

Inequality in co-operation, with 3 sub-categories, was the category describing the qualities of the co-operation. Co-operation was a common single-word description of patient participation in the content. Many patients referred to the completed multimodal pain rehabilitation as an example of co-operation where they perceived patient participation.

The sub-category “Working process” illustrated the means and ways by which the co-operation was experienced by the patients. The patients reported that working with several health professionals at the same time favoured participation, although patients also reported experiencing the imbalance between them and the number of health professionals as a disadvantage.

_I felt comfortable having health professionals from different occupations with whom I could discuss my situation._ (Man, interview 17)

The patients described themselves as recipients of help, support, guidance and feedback from the health professionals, as well as participants in planning, finding mutual solutions, evaluating results and making decisions. Patients emphasized a wish for taking a more active role in making decisions, but considered themselves not capable. This was partly accepted by the patients as a statement of reality, but also perceived as frustrating.

The “Need for increased knowledge”, representing a sub-category in the category Inequality in co-operation, illustrates some restrictions the patients experienced in co-operation with the health professionals.

_It is difficult (to participate) when you (the patients) don’t have enough knowledge (in medical issues) and you are not familiar with treatment options._ (Woman, interview 3)

Many patients experienced that the fact that they lacked knowledge in anatomy, symptomatology or adequate treatment, limited participation. There were descriptions of a need for increased knowledge through the provision of information, advice and education by the health professionals. Some patients experienced that patient participation was restrained by the authority given to the health professionals, and there were descriptions of having to accept the health professionals’ decision, even if they did not agree with the decision. However, some patients emphasized being comfortable with the health professionals making decisions for them.

The sub-category “Patients’ emotional and cognitive resources and restrictions” emerged from descriptions of emotions...
and thoughts experienced to influence patient participation. Resources that enhanced patient participation were: readiness for change in life, reassured self-efficacy, and willingness to try treatment. Having psychological symptoms, such as anxiety, lack of energy, being fragile, and/or sad, or feeling ashamed of being ill, were commonly experienced to restrain patient participation.

I felt exhausted and it was really hard to participate in the team-conference meeting...I just wanted to cry, and was not able to communicate the things I wanted to say. (Woman, interview 9)

Having pain was also emphasized as a restriction to patient participation, although some patients experienced it to favour participation, since it incited the patients to take measures.

Patients’ cognitive and emotional reactions on issues from outside the rehabilitation affected patient participation. For example, families’ and friends’ opinions on, and reactions to, the patients’ situation, were described to either favour or limit patient participation.

In addition, patients’ emotions and cognitions were influenced by positive, as well as negative perceptions of patient participation in an encounter with health professionals. Emotions of joy, inspiration, being confirmed, and a wish for recovery to health could emerge from sensing participating in the dialogue with the health professionals. These emotions were described to reduce pain, and to strengthen the patient as a person.

Leaving a team-conference meeting sensing having been respected, listened to and grasping that they (the health professionals) want to help me, gave me a boost to continue (the rehabilitation)...I felt happier, strengthened and felt less pain. (Woman, interview 15)

Experiences of planning meetings or treatment sessions that lacked patient participation brought out feelings of sadness, anger, stress, and increased the pain. As a consequence, the patients described a wish to change health professionals, end treatments, and choose a different healthcare centre.

Confidence-inspiring alliance

The category Confidence-inspiring alliance, with 3 sub-categories, was emphasized by the patients as a basis for patient participation in multiprofessional pain rehabilitation.

The patients experienced that it was satisfactory to perceive an alliance with one or two of the health professionals within the team. The allied health professionals supported the patient in disagreements with other health professionals, as well as with relatives and authorities, for example the Swedish Social Insurance Agency. In addition, the patients described that, in a confidence-inspiring alliance, it was easy to contact the health professionals, which in turn strengthened the patient’s sense of participation.

The sub-category “Mutual trust and respect” represents what the patients found to be crucial conditions in the category Confidence-inspiring alliance. The patients emphasized that being respected, trusted, and confirmed by the health professionals as a whole human being and not being identified by the illness, favoured patient participation.

Most important is to listen to and confirm the patient if you (the health professionals) want to reach the person and start a successful co-operation...the patient must experience being confirmed (by the health professionals). (Woman, interview 14)

In addition, the patients experienced that it was important to feel confident that the health professionals’ promises and agreements were kept. There were descriptions of once having trusted the health professionals, and then there were situations causing feelings of mistrust, which ruined the confidence-inspiring alliance permanently. Perceiving mistrust in the health care system in general, was also experienced to limit patient participation.

I now keep some distance from the health professional...I don’t believe in all the health professional tell me...I have lost my respect and trust in the health professional, since I was not confirmed. (Woman, interview 8)

“Patients’ choice and control” illustrated the patients’ experiences of their options to have control in the confidence-inspiring alliance. Patients reported that it was their own choice to be sincere and open in providing information to the health professionals. However, some patients described that it was easy, in the confidence-inspiring alliance, to be tricked into relating more than they had planned about their situation. The patients’ sincerity and openness were experienced to support patient participation as long as there were mutual trust and respect in the alliance. Patients emphasized that, in situations of mistrust with the health professionals, they felt that they could not always chose to end treatment, instead they found themselves to be psychologically not present in the situation. Patients’ fear of reprimands from authority was described as a cause for not arguing about participation.

I dreaded to decline participation in multimodal pain rehabilitation, thinking if I say no to this what will happen then ... I did not know if I wanted this (to participate in the rehabilitation)...but I chose to accept participation, having no other option. (Woman, interview 14)

However, some patients experienced having control to a large extent, for example choosing whether or not to listen to advice or follow ordinances.

“Personal relationship” was the sub-category that emerged from the patients’ experiences of having a personal relationship with the health professionals, which supported the confidence-inspiring alliance and patient participation. The patients emphasized that developing a relationship over time, in which they knew a little about the health professional as a person, and getting to understand their opinions on matters related to the patient’s situation, resulted in the patients feeling comfortable in the sessions. Some patients described this connection as “personal chemistry”. This promoted the patients to be trustworthy and to open up with the health professionals.
Without a personal relationship, there were descriptions of insecurity in not knowing what the health professional really thought. The patients experienced that the personal relationship with the health professional entailed that the patients did not feel comfortable with a change of health professionals. In addition, not perceiving a personal relationship was considered by some patients as a reason to change health professionals.

**Having a good relationship (with the health professional), makes you (the patient) be yourself and to feel relaxed when describing your symptoms to the health professional, even if you feel fragile...without the relationship I could never address those issues.** (Woman, interview 1)

**Competent health professionals**

The category *Competent health professionals* contained 3 sub-categories which described the patients' emphasis on a competent health professional to obtain patient participation.

**Once having met a health professional with broad competence, who listens to the patient, and makes me feel comfortable, you think you have won first price in the lottery...it is of significant importance.** (Woman, interview 5)

“Professional expertise” was the sub-category that illustrated the patients' descriptions of the health professionals' expertise; knowledge in medical issues and treatments, as well as work experiences, which were found to be essential conditions for patient participation. In addition, the health professionals' ability to confirm improvement in the patients' capacities, prior to the patients' awareness of it, was experienced to favour patient participation. Some patients experienced situations in the multiprofessional pain rehabilitation, when the health professionals did not have the qualifications that were expected, and this limited patients' participation. Professional confidentiality was important for patient participation, since it provided opportunity to be open with the health professionals. If professional confidentiality was not kept, this resulted in an emotional or practical distancing from the health professional.

“Empathic health professionals” and “Health professionals’ personal qualities” were the remaining sub-categories in the category *Competent health professionals*. The patients experienced empathic health professionals who listened to the patients, showed interest in their situation, and were sensitive, as favouring patient participation. In addition, the health professionals' body language; for example, eye contact, and their psychological presence, were important for patient participation. To be a competent health professional, which included having personal qualities such as presenting oneself as an ordinary human being when necessary, was also important in the participation process. This could mean being able to laugh, being pleasant, and taking criticism.

**The health professionals should be human and be able to laugh, not being so strict...simply be yourself and try to relax.** (Woman, interview 8)

Some patients emphasized that the health professionals’ empathic and personal qualities were of greater importance to patient participation than their professional expertise.

**DISCUSSION**

This qualitative study explored patients’ experiences of participation in multimodal pain rehabilitation, conducted in accordance with criteria from the Swedish rehabilitation warranty. The results show that having such a patient perspective had a multidimensional implication. All patients experienced satisfying patient participation and referred to the rehabilitation as an example of co-operation in which they perceived patient participation. Some patients reported situations during the rehabilitation in which they experienced restraints in the participation process. The comprehensive theme *Being in an exchange process*, indicated that emotions and cognitions were in focus in the patients’ perceptions of patient participation. For many patients, conditions such as trust, respect and relationships, which formed the category *Confidence-inspiring alliance*, were experienced as an important base for patient participation. Experiencing a confidence-inspiring alliance can be understood in relation to the fact that the patients had persistent pain and were on long-term sick-leave. Patients with chronic pain may experience being dismissed and mistrusted by healthcare professionals regarding their pain (29). Sickness absence leads to negative health effects (30), including feelings of helplessness and disempowerment (31). Such earlier experiences made it understandable that patients valued the importance of a confidence-inspiring alliance. Many of the patients emphasized that, in multimodal rehabilitation, for the first time their situation was confirmed and they could believe in recovery. The same positive result has been shown when exploring patients’ experiences of multimodal rehabilitation programmes for burnout (32).

In multimodal pain rehabilitation, the patients worked together with several health professionals. This was mostly experienced to favour patient participation. The patients reported that the confidence-inspiring alliance with the professionals also enabled patient participation in the team-conference meetings. The health professionals’ empathic capability and personal qualities, as well as the patients’ personal relationships with them, were emphasized as important. The patients’ experienced that a good relationship with the health professionals enabled an atmosphere in which the patients felt calm and relaxed during the meetings. This made it easy to communicate symptoms and concerns. The health professionals’ understanding of the patients’ illness and the social context in which the patients live is accumulated over many encounters with the patient (33). Empathy and sensitivity from the health professionals have been described positively by patients in several studies (18, 23). Developing an ongoing patient–health professional relationship is explicit in patient-centred medicine (33, 34). In this relationship the health professional as a person, as well as the patient as a person, both influence the interaction (34, 35).

The patients focused on the health professionals’ active role in dialogue and in co-operation, and relied on the health professionals to take action to facilitate patient participation. The patients experienced their role as a receiver and regulator in the co-operation, rather than playing an active role in the participation. Lack of knowledge was described as a factor.
limiting the opportunity to play an active role in planning and decision-making. Many patients asked for more knowledge, but found themselves reconciled in trusting the health professionals’ expertise. Some patients wanted the health professionals to make the decisions for them. A narrowing of the knowledge gap is described as an important attribute to increase the degree of patient participation (24, 36).

In situations of disagreement with, or lack of trust in, the health professionals, the patients chose not to confront this. The consequences of negative interactions were instead that patients decided to end treatment or the relationship with the health professionals. However, more common strategies were tuning out of dialogue or not being psychologically present in the meetings with the health professionals. This can be understood as acceptance that there could be no common ground for the interaction. Finding common ground is described as a process of mutual understanding whereby the patient and the health professional move towards consensus, in order to find a satisfactory solution. Mutual understanding in the interaction is the very essence of patient-centred medicine (33, 34).

Our study revealed rich descriptions of patients’ experiences of emotional and cognitive resources and restrictions influencing their participation. Little et al. (37) found that patients wanted a patient-centred approach, and health professionals who were sensitive to psychologically vulnerable patients. Patient-centred medicine has a bio-psycho-social perspective on illness that explores both the disease and the illness experienced by patients in their life context, as well as understanding the patient as a person (33–35). Health professionals must be sensitive to the best timing for each patient. In a trusting relationship they learn to recognize the patients’ main concerns and to understand the patients’ readiness for change (33). In our study, this can be illustrated by patients’ experiences of how questions about the future were perceived as provocative, as they considered that living with pain involved learning to cope, not planning for the future. Others were inspired by the fact that someone believed in a future for them, and were ready to proceed. The patients also reported that perceiving patient participation in multimodal pain rehabilitation implied positive effects. For example, participating in the dialogue with the health professionals was experienced to reduce pain and increase well-being, which in turn favoured patients’ participation. On the other hand, being unsatisfied with participation could increase their pain. Pain was described as an obstacle to patients’ participation. This demonstrates the importance of securing patients’ participation in multimodal pain rehabilitation by understanding each patient’s needs, in order to provide for optimum patient participation. This has also been confirmed by Eldh et al. (24).

**Methodological considerations**

To increase the credibility of these findings, data analysis was performed with care, and all researchers participated in the analysis. The meaning units and codes were kept close to the text, which may have reduced the risk of misleading interpretations. All researchers have a professional background in physiotherapy, and one is also a psychologist, which may have influenced the analysis. The fact that the interviewer had been involved as a caregiving physiotherapist or acted as a consultant in the rehabilitation, for some of the patients, may imply both a disadvantage and an advantage. The disadvantage is that there may be positive expectancy effects or bias, the advantage is an already established competence and authority. However, the interviewer perceived a genuine willingness from the patients, to participate in the interview, and to report both positive and negative experiences of the participation process. Despite the delay between the end of the rehabilitation and the interview, which may have reduced, to some extent, the patients’ recall of experiences, the narratives were rich. Negative criticism of patient participation was made to all professionals in the team, the interviewer included. One of the patients confined parts in the narrative during the interview, due to the interviewer’s working relationship with other co-workers in the healthcare centre. None of the patients was undergoing continuing physiotherapy treatment at the time of the interview. We consider the interviewer’s in-depth knowledge of the multimodal pain rehabilitation programme to be mainly an advantage in the interview situation, which made it possible to examine patient participation in more depth.

In this study, both men and women of various ages, contributed their experiences. The patients were selected from a single healthcare centre, which had implemented multimodal pain rehabilitation in 2006. The majority of patients had been on sick-leave for more than one year at the time they entered multimodal pain rehabilitation. Recent reports show that there are increased opportunities for return to work, as well as a reduced risk of sick leave for patients with persistent pain (14). It is likely that patients currently included in the Swedish rehabilitation warranty have a shorter sick-leave period compared with our informants.

Thus, we consider that the results of this study may be transferred to multimodal rehabilitation in primary healthcare centres treating patients with long-term pain conditions. Concerning future studies, we recommend additional qualitative studies to deepen the understanding of the concept of patient participation in multimodal pain rehabilitation. As there is an ongoing development concerning multimodal pain rehabilitation, content and treatment measures, this may further improve patient participation. Quantitative research to measure patient participation in multimodal rehabilitation is also a challenge; for example, to develop a questionnaire from the results of this study and test it for reliability and validity.

In conclusion, our findings on patient participation in multimodal pain rehabilitation have much in common with patient-centred medicine. A confidence-inspiring alliance may enable an ongoing trusting relationship between patients and health professionals. The patients emphasized that the health professionals needed to play an active role in building common ground in the exchange process of emotions, thoughts and knowledge. Patient participation in multimodal pain rehabilitation is complex and individualized. Increasing our understanding of each patient’s needs in the interaction may favour their opportunity to participate.
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REFERENCES


