

# FROM SHAME TO RESPECT: MUSCULOSKELETAL PAIN PATIENTS' EXPERIENCE OF A REHABILITATION PROGRAMME, A QUALITATIVE STUDY

Monika Gustafsson,<sup>1</sup> Jan Ekholm<sup>1</sup> and Ann Öhman<sup>2</sup>

From the <sup>1</sup>Department of Public Health Sciences, Division of Rehabilitation Medicine, Karolinska Institutet, Stockholm, <sup>2</sup>Department of Community Medicine and Rehabilitation/Epidemiology and Public Health Sciences, Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden

**Objective:** This study aimed to describe and analyse how participants with fibromyalgia or chronic, widespread, musculoskeletal pain, 1 year after completion, experienced a rehabilitation programme; and what knowledge and strategies they had gained.

**Design, methods and subjects:** Semi-structured interviews with 16 female patients were analysed using the grounded theory method of constant comparison.

**Results:** One core category, from shame to respect, and 4 categories, developing body awareness/knowledge, setting limits, changing self-image and negative counterbalancing factors, and hopelessness and frustration over one's employment situation emerged from the data. The core category represents a process where the informants changed emotionally. Three categories were identified as important for starting and maintaining the process, one category affected the process negatively.

**Conclusion:** The rehabilitation programme started the process of change, from shame to respect. The informants learned new strategies for handling their pain and other symptoms; they improved their self-image and communication in their social environment.

**Key words:** qualitative study, interviews, multidisciplinary rehabilitation programme, chronic pain, fibromyalgia syndrome, handling pain, physiotherapy.

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Correspondence address: Monika Gustafsson, Division of Public Health Sciences, Department of Rehabilitation Medicine, Karolinska Institutet, SE-17676 Stockholm, Sweden. E-mail: monika.gustafsson@ks.se

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## INTRODUCTION

Fibromyalgia syndrome (FMS) and chronic, widespread musculoskeletal pain are chronic pain disorders common among patients referred to rehabilitation clinics. Multiprofessional rehabilitation programmes aimed at teaching patients more effective ways of coping with pain are often recommended as treatment (1–3). Few studies investigate how patients experience these programmes and what they gain from them (4).

Current knowledge of FMS indicates that the symptoms may

originate from interacting disturbances, both in the neuroendocrinological system where stress is probably an important factor and in the muscles (5). This complex association makes it important that patients learn how to cope with pain and other symptoms. They need to reduce negative stress as much as possible, in order to have the best quality of life possible.

The generally-accepted treatment includes education with cognitive-behavioural techniques and physical conditioning (1–3), aimed at reducing symptoms and teaching the patients more effective ways of coping with pain. Physical training as a mode of treatment is often evaluated and has shown slightly positive effects in pain scores and aerobic fitness (6, 7). Exercise in a warm-water pool is an effective way of improving fitness, and is often favoured by patients (8).

“Body awareness” is a broad concept often used within physical therapy. It comprises body consciousness and different aspects of motor behaviour. Body awareness therapy (BAT) according to Roxendahl (9) is a treatment modality often used in the Scandinavian countries for treating patients with chronic pain conditions (10–13). In BAT (9), movements, breathing and awareness are used to restore balance and freedom in movement, emphasizing the resources of the body as a whole instead of concentrating on body parts where symptoms are present. Patients are taught to attend both to how the movements are performed and what they experience during performance. This stimulates mental presence and increases the awareness of the strengths and limitations of one's own body (9).

Studies evaluating multi-professional treatment programmes for patients with FMS have so far used mainly quantitative methods. Most show limited effects of pain, life interference, a sense of controlling pain and other symptoms, affective distress and depression (14). Properly used, a qualitative method is often more appropriate for capturing significant aspects of individual experience.

This paper focuses on a rehabilitation programme offered to women with diagnosed FMS or chronic, widespread pain (13), referred to vocational rehabilitation by the social insurance office. Statistical data presented in a previous study (13), show that the programme benefited the participants by improving quality of movement and reducing the experience of vegetative disturbances.

The aim of this study was to describe and analyse how participants experienced the rehabilitation programme one year

after completion; and what knowledge and strategies they had gained from it.

## METHOD

### *Study design and informants*

The study used a qualitative approach with semi-structured research interviews.

Eighteen women in a 1-year follow-up of a multi-professional rehabilitation programme for women with FMS, or with chronic, widespread pain, were asked to participate. Sixteen gave their informed consent and were assured of anonymity and confidentiality. The study was approved by the Ethics Committee of Umeå University, Sweden.

The 16 informants were aged from 23 to 59, mean 43 years. Six had diagnosed FMS according to the American College of Rheumatology criteria (15), 10 had diagnosed chronic, widespread pain (13). The women had experienced symptoms from 2 to 21 years (mean 11 years). The majority were married and had vocational/upper secondary school education. They lived in a rural area, centred on a town with about 60,000 inhabitants. Most of the informants lived in the countryside, within 20–150 km of the town.

Half of the informants worked to some extent and the rest were either unemployed or sick-listed and had employment they were unable to continue. The labour market situation was difficult. Most of them lived in country areas with few possibilities of changing a heavy job for a less heavy and stressful one.

### *Data collection*

Data were collected with semi-structured interviews, when the women came to the hospital for the 1-year follow-up.

The interviews lasted 15–35 minutes. They were audio-taped and transcribed verbatim. An interview guide was used, covering the following themes:

- What did they remember from the programme?
- What did they think was useful and what did they use?
- In what way did this help them?
- Had they changed anything at home or in other circumstances after the programme?
- How had attending the programme influenced their work situation?
- Had the programme in any way affected their experience of pain and fatigue?

The same guide was used throughout the study.

The first author of the present article, not involved in the group management, did all the interviews and was responsible for the administration of the quantitative data collection (13).

### *Data analysis*

The analyses were conducted in accordance with the ideas of grounded theory (16, 17) using the method of constant comparison. To increase credibility or truth value (18) the study design used triangulation in analysing data. Triangulation is a qualitative technique whereby the phenomenon is investigated from different angles or perspectives. The technique can be used in several steps in a study. Examples include using different data collection methods or data sources, using different theoretical perspectives and/or engaging several investigators. In this study, triangulation refers to the use of a research team with 3 researchers representing different professional background. Thus, the triangulation was made from the perspectives of physiotherapy, rehabilitation medicine and public health/medical sociology. Initially 2 of the investigators (MG, AÖ) performed a separate open coding procedure, which was followed by comparisons and a negotiated outcome. Central themes and categories emerged at the concrete level of analysis of the interview texts. As one of the investigators is a physiotherapist, trained to work with rehabilitation for women with FMS, we had an “insider perspective” that could be used as a source of knowledge. The other 2 investigators provided an outsider perspective. The combination of the different perspectives was fruitful in the analyses.

### *Rehabilitation*

The rehabilitation programme investigated in this study sought to provide the patients with adequate knowledge of FMS and chronic, widespread pain (13). During the programme the patients were firmly instructed to continue their exercises and to continue to apply the coping strategies they learned even after the programme.

The programme consisted of education, group discussion, physical training and individual guidance. Different focal discussion themes included pain, stress, coping, working situations, medication and how to improve sleep quality. The physical training provided by the physiotherapists consisted of BAT (9), relaxation training and fitness training in a warm-water pool. The BAT exercises used during the programme focused on a stable relation to the ground, posture, gait and a better co-ordinated breathing technique. The relaxation training was performed as modified autogenous muscle relaxation. The warm-water training was moderately intense and guided with music. All the women were given an individual programme for walking and stretching, continually evaluated and improved. The physiotherapists also introduced pain-relieving methods such as TNS, heat and acupuncture. Individual guidance by the social workers was aimed mainly at helping the patient to find new coping strategies.

The rehabilitation programme was financed by the social insurance office to enable the informants to get back to work and be less sick-listed.

## RESULTS

The analyses revealed 1 core category and 4 categories. The core category represents a process where the informants changed emotionally from initial feelings of “shame” to “respect”. Three categories were identified as important for starting and maintaining the process, whereas 1 category affected the process negatively. The process started with the rehabilitation programme, where “Developing body awareness/knowledge” represented the initial stage. This gradually led to action in the form of “Setting limits”. Developing body knowledge and setting limits both led to “Changing self-image”. This positive process was, however, influenced by a few “Negative counterbalancing factors”, “Hopelessness” and “Frustration over one’s employment situation”. These negative factors constitute the fourth category.

Fig. 1 describes the process in which the informants became involved from the onset of the programme. The process was still going on at the 1-year follow-up. In Table I and below, a more thorough description of each category is presented, together with quotations from the interviews.

### *From shame to respect*

The process of change in the informants’ emotions towards themselves, the sickness and their social environment was described during the interviews. When the informants started the rehabilitation they felt shame because of their sickness. They doubted their own experience of the pain and thought of themselves as hypochondriacs. They felt distrust from health-care personnel and misunderstanding from family and friends. As the rehabilitation started and they became members of a group, the emotions of shame started to change towards respect. Being believed and getting a diagnosis, raised self-esteem and gave security in relation to others. The 4 categories with their properties and dimensions, described below, represent the

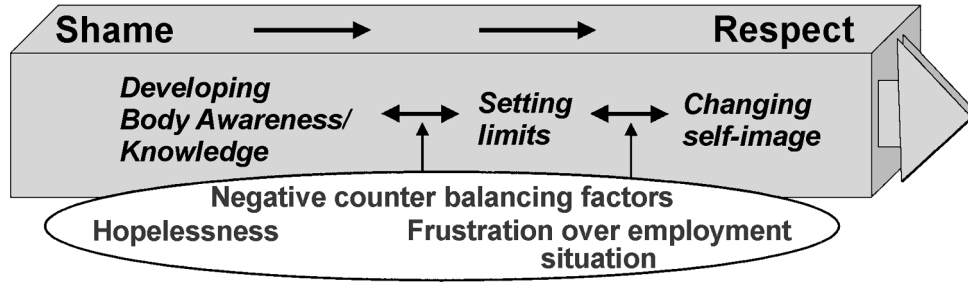


Fig. 1. The model describes the process in which the informants became involved from the onset of the programme. On top of the arrow the main category is shown. Under the main category, categories influencing the process positively are shown. The oval below shows the influence of negative factors.

substantial parts of the process. At the 1-year follow-up the informants described how they now were attentive to, and respected the signals from their bodies, that they knew that their pain was authentic and how they, when not feeling ashamed, could explain to people around them and how this gave them support.

*Developing body awareness/knowledge*

The category “Developing body awareness/knowledge” has 4 properties: relaxation, BAT, exercise, and theory. The category describes how theoretical knowledge of one’s body, together with the practical knowledge obtained through bodily exercise, became a starting point for the informants for a new approach to themselves and their pain. It also describes how the informants used their knowledge 1 year later.

*Relaxation.* Relaxation helped in everyday situations such as sitting in a car or standing in a queue. Before learning, relaxation was impossible to attain. Using relaxation strategies frequently improved body control, energy and concentration. Relaxation was also a way to attain pain relief, reduce stress and prevent deterioration.

The following is a quote from one informant. The number in square brackets identifies the informant.

“Almost all the time, I use it (relaxation) when I wash dishes, in

the bus queue, yes almost all the time, in front of the TV, when I go to sleep, I’ve had a lot of help from relaxation. [12].”

*Body awareness therapy.* With BAT the informants learned to be aware of how to best use their bodies, as a way to “check” the body, to find positions and balance, to avoid unnecessary muscle tension and to prevent deterioration. The BAT exercises were found helpful in relaxing and controlling pain.

“It has been very useful to me, just to drive the car, it used to be a horror to me. ... Like how to stand and walk, thinking about it all the time, letting your shoulders down... [21].”

*Exercise.* Exercise caused pain before the programme. Afterwards, it was emphasized as an important tool to feel good and comfortable. Walking was frequently used to improve fitness, although pool exercise was the preferred physical training.

*Theory.* Theory about pain mechanisms and body functions increased self-confidence and explained how experiences earlier doubted could be real. The informants were transformed from ignorance to being knowledgeable.

*Setting limits*

“Setting limits” was an action taken by the informants after learning body knowledge. It enabled them to say “no”. The

Table I. The table shows the four categories with their properties and dimensions.

Category	Property	Dimension
Developing body awareness/Body knowledge	Relaxation	impossible → means of pain relief
	Body Awareness Therapy (BAT)	unawareness → awareness for preventing deterioration
	Exercise	cause of pain → important for improvement
	Theory	ignorant → knowledgeable
Setting limits	Adjusting self-demands	high demands of self → reduce demands on self
	Adjust workload	chaotic → anticipate workload
	Telling others about symptoms	hard to explain → knowledge makes explanation plain
Changing self-image	Boundaries, because of sickness	feel a failure → own action meaningful
	Handling the pain	suppression, avoidance → self-examination
	Self-confidence	weak → tougher
	Housekeeper identity	satisfy others → restrict work hours
Negative counterbalancing factors	Hopelessness	no hope for recovery → optimism
	Frustration	dissatisfaction → satisfaction

category had 3 properties: adjusting self-demands; adjust workload; and telling others about symptoms.

*Adjusting self-demands.* “Adjusting self-demands” was emphasized as one of the most important things to accomplish to take care of oneself and control the symptoms. Former high demands on self were reduced. Much effort was put into learning how to “listen” to bodily reactions to find the limits, and to respect them.

“And then, mentally, to increase awareness and accept yourself as you are, just setting limits is something I worked with a lot. It’s not the boundaries of the world around that matter, it’s my body and the signals from it that have to give me advice. [5].”

*Adjust workload.* To “Adjust workload” the informants used strategies such as to change priorities, to ask others for help, to plan, to reduce demands on themselves and to have time for themselves. This changed the workload from being chaotic to being predictable.

“When there is a lot of ache and so on, then one wants to manage anyway, but now I don’t care a bit about it. If I have decided to do the cleaning the next day, and then don’t feel well, then I skip it. ... I think I demanded more of myself before. [19].”

*Telling others about symptoms.* “Telling others about symptoms” was a way of “setting limits” to demands from others. Before the rehabilitation programme it was hard to explain: with the new knowledge gained, it became possible to tell others about the diagnosis, to better explain what was wrong; and it became easier to talk about it.

“Before when people asked how I felt, how it was, then I said okay, but now I dare to say more, straight out. [22].”

#### *Changing self-image*

The category “Changing self-image” contained several changes where the improvement of the informants self-image was crucial: from boundary to possibility, from letting the pain rule one’s life to taking control over the pain, from focus on satisfying others to taking care of oneself. It comprises 4 properties: boundaries imposed by sickness, handling the pain, self-confidence and housekeeper identity.

*Boundaries imposed by sickness.* Life with chronic pain and fibromyalgia was presented as full of boundaries. This evoked feelings of being a failure and a hindrance to the family, rigid and insufficient. In addition the informants were easily stressed and tired all the time. The informants’ ability to affect these boundaries themselves grew successively. Their own action became meaningful. Self-reflection and thinking differently were considered important for the ability to live a better life with chronic pain and fibromyalgia.

*Handling the pain.* The way of handling pain changed through the programme. Before the programme, there was a shameful doubt of one’s own experience of pain: sometimes the pain was thought of as imagined. Common ways of coping with it then

were: trying to ignore it, pushing oneself to do things and telling oneself that “if others can, I can too”. From handling the pain by suppression and avoidance, the informants described how self-reflection was important for handling the pain. Rest was not possible or permitted before the programme; afterwards it became possible and frequent.

“Now I always think beforehand: I think, if I’m doing this now, how will I feel tonight and tomorrow? And I check – will it hurt? Stop! I never used to think like that before, I just continued. [3].”

*Self-confidence.* The informants presented a self-confidence that had been negative before the programme but changed positively during and after the programme. They felt tougher, and described how it became easier to have an opinion.

“I do know now, anyway, that I’ve got pain, it’s written down, I can tell them I’ve got pain. I couldn’t do that before, then it was that I imagined it, yes mentally. [23].”

“Somehow I dare say openly that I’m alright, although I’m ill. [22].”

*Housekeeper identity.* The “Housekeeper identity” was important to the informants. Much effort was put into keeping the home tidy and neat, and satisfy others’ needs. One year after the rehabilitation programme, new house-keeping strategies were being used, such as reducing one’s own demands, using different planning, restricting the amount of housework, demanding help from others and using body awareness at the sink.

“I can leave the dust and do something for fun instead, well maybe not always, but sometimes. [19].”

#### *Negative counterbalancing factors*

The positive process described above was, however, influenced by the fourth category, “Negative counterbalancing factors”. This category represents the struggle with never-ending illness and the impossibility of attaining a satisfactory employment situation, a struggle that influenced the informants throughout the process. The category has 2 properties: “Hopelessness” and “Frustration over one’s employment situation”. The boundaries of not being able to do the work one was used to caused anger and frustration. Things done for pleasure, such as sewing and holding grandchildren in one’s lap, were difficult or impossible to continue. The informants could feel hopeless, downhearted; they described how they tried everything but just got worse, as if there was no hope for help any more. Some, though, felt that life had become better and that it was possible to affect the future.

The employment situation was mainly frustrating. The work situation was experienced as stressful, demanding and difficult by those who continued to work; while unemployment meant isolation, and sick-listing was boring. Neither alternative seemed positive or satisfying.

The significance of the rehabilitation was shown in different areas. Being believed by the experts made it possible to stop neglecting one’s own experience, made families and health-care

staff believe in the limits one was trying to set, and gave the respondents the courage to express their personal limitations at work. Those who could stay at work stressed that they would have worked less, or not at all, had they not attended the rehabilitation programme.

## DISCUSSION

The rehabilitation programme started the process of change from shame to respect described by the informants in this study. The work with their bodies in the group initiated several positive changes. The informants began to acknowledge their needs and boundaries. When this action proved successful, the process of “changing self-image” towards recognition and upward valuation of self continued. The improved self-image turned out to be important in the informants’ social relations and in continuing to “set limits”. Acting more self-confidently resulted in respect and increased understanding from family, friends and the health-care staff. Tendencies to feel ashamed and “no better” were now replaced with demonstrations of support.

We had no specific theoretical perspective in the analyses of the data, but 3 perspectives proved important. One concerns how different paradigms affect our perceptions of our bodies (19). The experience of the body changed during the rehabilitation programme. Before, it was something that could be ignored or compelled to act, something separate from the self, not recognized. The “old” body employed to manage every demand was the one connected to the ideal self. The pain was something from outside, a hindrance not recognized as belonging to one’s own body. The body was thought of as a machine supposed to manage all hard work without rest or care. This view accords with the dualistic theory, which describes the body as a physical/mechanical phenomenon. The body is categorized as not intentional and not meaningful (19). When health-care staff showed distrust of and disregard for the pain and other symptoms experienced by our patients, this attitude strengthened the experience that the signals from the body were unimportant and maybe even false. Ideas such as “you just have to do some exercise” or “it’s all a matter of positive thinking” were common. When the condition, the suffering and the expression of the body are not acknowledged, the body’s solution is to dissociate from itself or communicate itself through sickness or symptoms (19).

The rehabilitation team taught a different attitude: the signals from the body are important, one has to respect one’s own limits. Body and mind are not separate entities, but two sides of the same entity. This more holistic view was taught with body awareness therapy and relaxation, during the education and the group discussions, and made the symptoms more understandable. When experience was confirmed and respected, self-image improved and new coping strategies could develop (19).

Secondly, the fact that the informants in this study were all women makes the gender perspective and how gender relates to health and work (20) an important part of the analyses. The

Swedish labour market has a gender structure: the majority of women work in health care, administration and service (21). The predominantly women’s occupations in health-care and service often entail heavy work, with a risk of work-related disorders (21). The severe economic decline of the 1990s brought about organizational changes in workplaces, increasing work tempo and time pressure. These changes have particularly affected women in the health care sector. The labour market in the study area is limited, the public-sector cutbacks during the 1990s leading to a decrease in employment in traditionally female sectors. In 1999 the employment rate in this county was the second lowest in Sweden, with few possibilities for our informants to find jobs that are appropriate considering their pain condition.

Ninety percent of FMS patients are women, i.e. about 3.4% of the female population (22). Stress is mentioned as a probably important factor in developing and aggravating the symptoms of FMS. Stress-reducing strategies are recommended as a part of rehabilitation programmes (2, 3). Keeping house was important to the informants. Previous studies have shown that most women, regardless of their employment status, retain primary household and child-care responsibilities (23). Time-studies show that women in Sweden work on average 53 hours per week: 28 hours in the home and 25 hours in paid work (24). Men work on average 50 hours per week, 12 hours in the home and 38 hours in paid work. For a rehabilitation programme aiming at reducing stress and strain, the home situation is as important a target as the workplace. Women today are exposed to contradictory messages: they are expected to take part in – and profit from – the labour market (25). Social expectations of “womanliness” relate to cleaning, caring and accessibility for others’ needs – the traditional housewife, with the life goal of creating and maintaining a home, seeing that the family grow and thrive (26). The present informants had difficulty in putting their own interests and needs first, they concentrated on family and the needs of others. These findings are confirmed by the results of interviews with primary-care patients with musculoskeletal pain in the north of Sweden (27). The informants spoke of “setting limits for themselves” as one of the most important things to accomplish to control their symptoms. This expression contains increased self-awareness, an intention to change behaviour and not always to try to live up to others’ expectations.

Thirdly, theories of shame and stigmatisation are important for the understanding of the informants’ initially low self-images. A stigma may be seen as an aspect of status, an object of shame (28). Shame is a large family of emotions that includes embarrassment, humiliation and related feelings such as shyness and reactions to rejection or feelings of failure or inadequacy. All these cognates unite in the feeling of a threat to the social bond. These variants have in common that the subject sees herself negatively in others’ eyes (29).

People with FMS often report having the reality of their symptoms questioned (30). In a study of women’s experience

of stigma in relation to fibromyalgia (30), the informants reported that their moral attitude came into question in interaction with others. They also experienced distress from being “psychologized” by others, doctors in particular. This tallies with our findings, where the informants experience distrust and misunderstanding from their social surroundings as well as from their doctors. After the rehabilitation programme the informants reported increased respect, that their families had started to believe in their symptoms and their doctors to understand that their symptoms were not imaginary. This is closely connected with their own raised self-esteem and increased knowledge of their own problems. In an examination of factors influencing the decision to remain in a work role, limitations in work capacity, but also possibilities to adjust work environment and work tasks were found important (31). Those of our informants who remained at work, emphasized that increased understanding from the environment, a change of old ways to perform working tasks, and their own demands on the workplace and working situation were important.

One way of defining the rehabilitation process is to look upon it as empowerment, a concept used when patients take control of and responsibility for their own health care (32). The possibility to continue working is connected with the new strategies and the improved self-esteem gained during the rehabilitation programme; our informants took more control of their own living situation and more responsibility for their own health.

#### *Methodological considerations*

The fact that our informants referred mainly to the physiotherapeutic methods could be because the interviewer (MG) is a physiotherapist. Had the interviewer been a social worker, the respondents might have answered differently. However, had the informants considered the social worker’s counselling as a very important part of the programme, they would probably have talked about it during the interview. Every interview started with the question “I’d like you to tell me about what you remember from the programme”.

Due to the design of the rehabilitation programme, all the interviews were conducted 1 year after the programme. We might have got richer information if the interviews had been analysed using an emergent research design (18), in which the questioning would have further explored interesting themes that emerged from previous interviews. However, we judged that the information given by the informants was valid and appropriate for the present aim.

Qualitative research explores structures, mechanisms and phenomena in society that affect human beings. The abstract knowledge obtained by this type of research might also be generalized to other social contexts sharing similar structures (33). Our aim in this study was not to test any existing hypothesis, but rather to construct a conceptual model for the understanding of the rehabilitation process. The model is not generalizable from a statistical point of view, but theoretically,

drawn from the concrete level of interview data to the abstract, theoretical level.

## CONCLUSION

The rehabilitation programme started the process of change, from shame to respect, described by the informants. The women learned new strategies for handling their pain and other symptoms; they improved their self-image and communication in their social environment.

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