

# Paper I

# **Barriers against returning to work - as perceived by disability pensioners with back pain: A focus group based qualitative study**

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## **Abstract**

**Purpose.** The aim of this study was to explore the issue of perceived barriers for returning to work, based on the experiences and beliefs in a group of disability pensioners with back pain.

**Method.** Focus groups were used to interview 12 women and 5 men, aged 38-56, who participated in a larger project aiming to help disability pensioners back to work.

**Results.** The barriers appearing were related to earlier negative experiences, poor self-judgement of work ability and low self-esteem, lack of support from social security authorities and unsuitable economic arrangements. The pensioners also suggested alternative solutions for making a possible return to work.

**Conclusions.** Our study provides insight into the perceived barriers of returning to work and might be useful in future efforts aiming to help disability pensioners back to work.

**Keywords:** Barriers, return to work, disability pensioners, low back pain, focus groups

## **Introduction**

Early retirement due to health problems is one of the greatest problems facing social security systems in the western world [1, 2]. In Norway, 10.6 % of the labour force is receiving disability pension, and nearly 15% of them are disabled due to diseases of the lumbar spine [3]. Disability pension represents a large economic burden for society, in Norway reaching more than €5.2 billion in 2004. Therefore, efforts have been made by the government to increase participation in working life and reduce dependence of allowances [4]. These efforts are not only explained on the basis of high public costs, but also for the sake of the individual. Employment means possibility to utilize peoples' abilities and skills in a meaningful way. Work occupies a major place in our lives, it provides financial support and it defines who we are. Besides, work is an important arena for network building and integration in a social fellowship [5].

It has been shown that the chance of ever returning to work after a period of absence due to back pain is reduced over time [6, 7]. Waddell [1] has reported that after 2 years of absence a person is unlikely ever to return to work. For disability pensioners the situation is even worse. Their vocational skills may be outdated, they may have difficulties in finding suitable work, and there may be prejudice from employers against persons with disabilities. Loss of benefit entitlements and concerns over personal economy may also play a prominent part [8]. Lack of access to vocational rehabilitation [9] and too demanding working conditions are also considered to be obstacles to a return to work [10].

Movement from disability benefits into work is very low [3, 9, 11]. To increase the success rate of bringing disability pensioners with back pain back to work, it is crucial to have knowledge both of the characteristic of this group, and also to gain insight into the possible

barriers for a successful return, as perceived by the pensioners themselves. There is some knowledge about factors predicting a return to work in sick-listed patients with back pain. [12-15]. However, Watson and co-workers [9] found that these factors do not apply to disability pensioners with chronic back pain who had been out of work for years. They suggest that perceptions and concerns about health and work conditions, and how these influence one's work ability, are important obstacles against returning to work [15]. To our knowledge, these perceptions have not been extensively explored in earlier research.

In this study, we wanted to explore perceived barriers for returning to work, based on the experiences and beliefs in a group of disability pensioners with back pain. We considered knowledge of these barriers to be of interest, as they might be possible to influence in future efforts to encourage pensioners to return to working life.

### *Methodology*

The study is anchored in hermetic epistemology, which implicates that meaning is created, present it self and can only be understood in context [16,17]. In our study, experiences and beliefs highlighted are seen as co-created by the participants (including the researchers), dependant on questions asked, atmosphere created as well as interaction in the group more generally. Negotiated meanings and choice of perspectives are interwoven throughout the research process, demanding continuous reflection on the part of the researchers.

### *Participants*

Seventeen disability pensioners with low back pain participated in 3 focus groups examining perceived barriers against returning to work. This study was part of a larger project aiming to evaluate the effect of a vocational related intervention, seeking to bring disability pensioners

with chronic back pain back to work (n=89, 58 women, mean age 49, range 36-56). All the participants had given written consent to participate in an interview. Of these, 23 individuals were invited and agreed to participate (15 women and 8 men, age 38-56). Six persons, 3 women and 3 men with-drew before the interview. The participants were selected for strategic reasons, as we wished to sample participants of different characteristics like age, gender and number of years receiving benefits, which we thought might influence their experience of the issues in question. The informants were divided into three focus groups containing 4, 5 and 8 persons respectively. We decided to have only women in two of the groups and men in the third, to facilitate more free-flowing conversations within groups, and to examine possible gender differences in perspective [18].

### *Procedure*

A detailed interview guide was composed, containing the topics of interest. In this article, the main focus was perceived barriers against returning to work. The interview guide was developed through several steps. First, we reviewed the literature to get an overview of the field, and relevant items were selected. Secondly, a group of disability pensioners was invited to discuss the relevance of the items. Based on a discussion between the authors, the interview guide was then composed. Finally, the interview guide was tried out as a pilot. A qualitative approach by means of interviews was used to explore these issues, as we expected to gain a more detailed and richer material than would be possible by means of a questionnaire or other quantitative methods. Focus groups, as described by Kvale [16], were used for the interviews, as they are well suited for gathering broad information about perspectives of the participants, based on the interaction in the group [19].

### *Transcription and analysis*

The focus groups took place at the work-place of the researchers. The interviews were audio-recorded, and the interviewer (LM) was supported by a co-moderator (MR) observing, taking notes and supplementing with additional questions to expand on or validate the issues which were explored. The interviews were fully transcribed by the interviewer. In addition, field notes based upon observation during the interviews, were completed by the co-moderator. Further analysis consisted of several steps: The transcribed interviews and field notes were first read to get a general overview of the interview material as a whole. Then, text was closely studied to seek out the different themes and sub themes contained in the material, and identifying the text elements related to each of the appearing themes. The researchers made separate analysis of the text, and agreement was reached through discussion where differences in analysis appeared.

## **Results**

### ***Experience of barriers for returning to work***

Several conceived barriers for returning to work appeared:

- earlier negative experiences
- poor self - judgement of work ability and low self-esteem
- lack of support and understanding from social security authorities and unsuitable economic arrangements
- possible solution suggested by the pensioners

### ***Earlier negative experiences***

Many of the participants pointed to conditions at their former work places that they believed contributed to the disability process, and which would make it difficult to return to work. One of the factors mentioned was a high demand for efficacy and productivity. One female gas

station attendant told that she fell out of work because she could not carry out her duties at night when working alone, and her boss could not afford to employ two persons for the night shift. Another issue mentioned was lack of flexibility and tailor-made jobs when disability occurred. A male factory worker experienced great support from his company after an injury, and managed to keep on working. After another accident some years later, the working conditions had changed and become tougher, and the management was not willing to assign him a less demanding work task. He reported that he fell out of work because he could not any longer keep up with the production goals. Another former factory worker put it this way:

*“The politicians have to do something about the job situations, it is far too demanding. It seems like the management wants to make greatest possible profit with no concern for employers. We (the disabled) are not welcomed as employees anymore.”*

Another point made by some was negative or hostile attitudes towards employees with health problems. A man being retrained for a more suitable job experienced criticisms and harsh comments from colleagues when he was assigned easier tasks, and felt they pushed him back to duties he was not able to keep up with. A female high school teacher experienced lack of understanding from her superiors:

*“I got a schedule which was impossible to fulfil. Eight classes in a row, not even time for lunch. When I complained to the principal, he promised he would look into it, but nothing happened. Then I told him, there has to be a change, this is making me ill. He laughed at me and asked if I thought it was that easy to improve the schedule. Towards the end of the term I was totally exhausted. My work load was never changed, however, and eventually I was not able to work anymore.”*



Attending strainful and monotonous work tasks was also underscored as a contributing factor to the development or maintenance of back problem by some, and they expressed fear of having to return to such work conditions. A woman, who had worked as shop assistant, explained:

*“I often had to serve the customers while being alone in the shop. I had to lift heavy boxes filled with vegetables, potatoes and so on, over and over again. I said I cannot do this alone, but it seemed impossible to get any help. After going through surgery for my back problems, I was not able to return to this kind of work. “*

#### *Poor self-judgement of work ability and low self-esteem*

Poor self-judgement of work ability due to chronic low back pain was considered by many to be a main barrier for returning to work. Even though some of the informants underscored that they really missed working life, they felt that the pain and general disability made this impossible to achieve. A woman expressed it like this:

*“It is the pain, always the pain. I don't want to work with all this pain ever again. I did that for such a long time, and hoped that the pain would ease off. To start working again with pain means having a bad time both at work and during the rest of the day.”*

Another woman said:

*“You have to drop the idea of ever returning to work. For me, it took years to accept it. I would gladly go back if I got well. However, one day you have to realise that this is not a realistic goal. You should not put more energy into it.”*

Some informants also expressed a general lack of self-esteem and a pessimistic view of the future. A woman expressed fear that she would not be able to handle the emotional pressure of another try-out for work, and experience a new defeat. Another woman mentioned that her low self esteem prevented her from speaking out for her needs and rights at the working place, and that this would deem re-entering work an impossibility. A third woman put it this way:

*“To be out of working life for such a long time does something to your self confidence. You ask yourself, will I ever be able to cope with a job again? It really takes some courage to try.”*

Some also expressed lack of hope of ever finding a job that would suit their specific needs.

A woman told that she needed to change work position every few minutes, and questioned if there were anybody who would employ a person with such limitations. Another woman, a 50 year old former nurse, spoke of her need to lie down once in a while due to back pain, and this, in her age, would make re-employment impossible. A man, formerly employed as store clerk, expressed it like this:

*“I have to consider my work ability from day to day. I have experimented with different small jobs at home. Most often, I can manage a few hours. But suddenly you are totally incapacitated and then you are not worth anything. I don't think that the right job exists for me.”*

Some of the pensioners also expressed that a part time job was the only possible option if they should ever succeed in returning to work. A male carpenter said:

*“I could have managed a 50% job. But suddenly my back snaps and I become completely unable to go on working. Therefore, I cannot manage a job with a fixed time schedule.”*

#### *Lack of support from social security authorities*

Some of the pensioners complained about lack of help from the social security office or job centre. They described the system as inflexible and not tending to individual needs. The job centre was accused of focusing solely on full time jobs, and not being willing to discuss combinations of work and pension. One woman felt that the job centre paid no attention to her specific needs as a back patient when trying to force her through a re-education programme. Others felt they were assigned jobs at random with no consideration of specific preferences and abilities. A man said:

*“I have visited these offices a lot, but it does not work out for me. Their information is too general with no specific concern for my situation. They (at the social security office) are just following strict rules and are not willing to show any flexibility.”*

De-motivating economic arrangements for pensioners were also mentioned as a barrier. Some pointed to the fact that income under re-education was so low that the effort was not worthwhile. In addition, several had experienced that taking a small part time job when receiving pension would reduce the benefit so that nothing **was** gained economically. Finally, trying out for new jobs arranged by the job centre put them in an economical uncertain

position and made them afraid of losing their disability benefit all together. More appropriate transitional arrangements were asked for. One of the men said:

*“I was offered re-education, and worked in a factory. The wages was lowered compared to ordinary employment by 40 %, and the company found that this was profitable for them. But I found it was not worth the effort, I could just as well have stayed at home and gotten exactly the same income.”*

Another man put it this way:

*“It must be possible to find transition solutions when trying to get back to work, solutions that make us feel economically secure. Otherwise, who would dare to try?”*

Another man expressed it like this:

*“No matter what, the most important thing is to feel secure. Being disabled means being granted this security. In fact, we get our salary and can sit back and relax as we like.”*

*Possible solutions suggested by the pensioners*

Several of the pensioners talked about the need for tailor-made, flexible and part time jobs where they could put their limited work ability into use. One mentioned the need to regard each person as a unique individual with specific needs, and this would call for greater flexibility from the social security authorities. One issue raised by many was the need for economic incentives, staying in work must yield a higher income compared to the disability benefit. A 40 year old male suggested:

*“Five of us could have shared one job if the wages were acceptable. Each of us worked one fixed day. If one got ill, he could have asked the next one on the list to take over his duty that day.”*

Another man added:

*“We have to feel economically secure. With a job like that (flexible and not risking to loose benefit) every one of us could possibly have returned to part time work.”*

## **Discussion**

This study aimed to explore what disability pensioners perceive as barriers in the process of returning to work. The barriers appearing were related to earlier negative experiences, and the impact that chronic pain and disability had on their self-esteem and belief in own ability.

Also, financial and organizational issues of the disability process were underlined, especially the effect of economic support and the efforts by government agencies.

A main issue appearing in our study was the tough demands regarding productivity and efficacy that employees felt they met in their workplace, and how this became important factors why they found it impossible to go back to work. It has been suggested that modern working life, characterized by constant change, downsizing and readjustment, is putting increasing demands upon the employees' flexibility and productivity [20, 21]. It is claimed that this demand for efficacy makes room only for healthy individuals with a full production capacity. A generation ago when working life was more inclusive, society morals implied that workers not as fit and productive as others were a natural part of the labour force [10]. Today

there is less regard for this obligation by employers. Also, to participate in work means making oneself feel useful and being an integral part of society, and is emphasised as most important[5]. Post- modern, profit driven economies seem oblivious of this perspective, and it might be difficult to turn around this development.

Some of the pensioners also experienced a hostile attitude and lack of understanding from the co-workers during the disability process, and believed they could have stayed longer in work, given a more supportive attitude from colleagues and superiors. Social support at the working place is shown to be an important factor for job satisfaction, and the opposite might discourage motivation staying in or returning to work [15, 22, 23]. Suggestions have been made that the process of becoming long- term sick-listed involves both a change in the employer's attitude to the employee, as well as a change in the employee's attitudes to his own work [5].

Many of the informants in this study experienced an increasing intensity of pain over the years, leading to further deterioration of working ability. Thus, retirement from work did not tend to improve their painful condition. None of the pensioners in our study felt they were able to do more than part time work; others describing their work capacity as non-existing. Low self confidence in own skills and general working abilities were also expressed. They had been out of work for so long that they had lost confidence in their vocational skills, and feared a new defeat should they try out for work again. Other studies have also shown that unemployment aggravates pain and may lead to poorer physical and mental health [24, 25]. It may also lead to loss of work- related attitudes and habits [5].

Some of our informants described the disability process as a vicious circle. Other authors have also described the complexity in the disability process [24, 26]. In this process, the deteriorating health is followed by increasing disability, lower tolerance for emotional stress, and eventually development of hopelessness and restricted participation in social life in general. These observations are in concordance with the theory of CATS (cognitive activation theory of stress) which describes a situation where an individual develops an expectancy that all responses or actions will bring a negative result, leading to a sense of hopelessness, and eventually, to depression [27]. Negative expectations according to a return to work were expressed by several of our informants. This lack of hope and self regard indicates that close support and encouragement are key factors in schemes that intend to help disability pensioners back to work.

The great need for support and the failure of society to provide it was verbalized by several of the informants. Some pointed to the lack of flexibility and low regard for individual needs by the social security and work offices. Others expressed being pushed in the wrong direction, the authorities not taking into consideration what kind of work they actually were interested in. Supporting individuals in a vulnerable position is a demanding task, and requires a skilled and dedicated staff at the work office. A re-organization of the different agencies supporting people not able to support themselves is planned in Norway, one goal being to improve the support given to individuals trying to return to work. In this process, focus on individual communication skills and attitudes of the officers should be emphasized.

The security of a predictable pension benefit was underscored by some as important, and fear of losing this benefit by trying to return to work would discourage the process. This point has also been reported by other pensioners who have been in the process of returning to work

[8, 28]. Our informants also criticized the lack of economic incentives. To receive only a small increase in income when trying out for work was described as de-motivating. Incentives already introduced by the Norwegian government includes a opportunity to be employed for 3 years, and then go back to disability benefit if the person can not manage to stay at work. To encourage employment of disability pensioners, the employer's contribution to sickness benefit is covered by the government. These arrangements seem generous, but are probably insufficient to support a return to working life. On the other hand, one might question whether the pensions in Norway are in fact too generous to encourage a return to work.

Lack of part time jobs with flexible time schedules were also mentioned as an important barrier and our study indicates that the authorities should consider providing flexible alternatives to full time work for groups that have been out of working life for years. On the other side, this claim for optimal flexibility might be partly due to low self esteem that can be diminished after having made a successful return.

Our informants pointed to a number of conditions that they felt needed to be fulfilled in order to be able to return to work, and most of these changes were beyond their own reach or control. Some of the informants tended to blame politicians or employers for lack of support, and seemed to accept little responsibility themselves to reach the aim of staying in work. Theories concerning "health locus of control" might explain this way of perceiving one's situation [29]. Findings which support this interpretation have been reported elsewhere. Individuals responding positively to treatment programs reported more trust in their own influence of their health (internal control), while persons on long-term sick-leave for back pain reported lower levels of belief in personal control of their pain, thus, might be less likely



to return to work. Non-returners expressed that their health status was under control of chance or powerful others (external control) rather than feeling in control themselves [12].

Another aspect concerns disability status and economical security. Several of our participants described the disability process as a hard fight against being pushed out of work. However, when they eventually passed the barrier of not considering themselves being able to stay on in working life, the fight seemed to be directed the opposite way. Now, the struggle was to obtain official acceptance of their disability status, a difficult task in many instances. It might take years to reach this safe haven: an official identity as a disability pensioner securing financial support for life. Trying to return to work at a later stage meant abandoning this safety net, voiced by one informant as “*who would dare to try?*”

The arrangements mentioned as prerequisites for returning to work are for the most part expensive and require considerable changes, both in structure and in attitudes. One might ask if society is ready to increase their expenses to return pensioners to work, as these barriers seem high and insurmountable. The most obvious way to decrease the number of disability pensioners in the future may be to prevent them becoming disabled in the first place, because reversing the disability process seem so difficult. In Norway, the development might be going in the opposite direction. A recent revision of the disability laws has granted some of the disabled a time-limited disability period for 1-4 years, intending to revise their working ability after this period. Although well- intentioned, this study might indicate that this arrangement is unwise, because an eventual return to working life seemed unrealistic for most.

### *Strengths and limitations*

Group interviews are ideal for exploring common experiences, but may also induce conformity [16,18]. In our study, similar views seemed mostly due to genuine agreement, as there appeared to be a good atmosphere and willingness to share views in the groups. Accordingly, nuances were also expressed on several items, disagreement in a few. Several participants expressed explicitly that taking part had been a positive experience, supporting the interpretation of a good atmosphere. In one of the groups the moderators had to encourage some of the participants to express their experiences, since domination on the part of one participant did appear in the first part of the interview. In the other groups, discussions and sharing among informants came into being spontaneously. In sum, meanings were co-created, dependant on questions asked and the interaction in the groups. Individual interviews could have disclosed other and more sensitive issues, but could on the other side have missed more common experiences. It is also claimed that group interviews are less suspect to reproduce socially constructed images of vulnerable groups compared to individual interviews as participants probably feel more comfortable and empowered [30].

The participants in the focus groups were initially recruited for a study where disability pensioners with back pain were given a program of physical examination, coaching to obtain increased physical fitness, specific job information and other support to help them to return to work. Selecting informants from a group of pensioners, at least some of them willing to consider a return to work, would probably represent a bias towards a more positive view of barriers than in the general disabled population. Of the 89 participants in the main study, twenty-three (24 %) were asked to participate in the focus groups. Six persons did not show up for the focus group, not giving any reason for this, reducing the number of participants to 17 (18%). One might speculate that the most incapacitated or least interested would be among the drop-outs, also resulting in a bias towards a less negative view. On the other hand, one

might surmise that pensioners with high working ability, but low motivation for work would be afraid of demonstrating a possible work capacity, and not volunteer for a study like this. The informants were selected for pragmatic reasons, excluding those living in remote areas, in order to minimize time spent for the focus group. This might represent another bias if one suspects that urban versus rural dwelling would have an influence on their views. Men and women were interviewed in separate groups, but we found no apparent gender difference in perceived barriers. A single group of men, where 3 out of 8 withdrew, gives a rather weak foundation for generalizations of their views. LM, who carried out the interviews, was already known to the participants, as she previously had been in charge of their physical testing. She had, however, no other relation to the participants, and it is no reason to suspect that their voiced opinions would be influenced by their previous brief contact. On the whole, there is some indication that, even if perceived barriers against returning to work appearing in this study seemed many and high, there probably are some selection biases towards a too positive view and that the experienced barriers toward returning to work might be more negative than expressed by our informants. A small sample size was included in the present study; similar research in a more heterogenous group as well as individual interviews would probably capture broader and more representative information in the area. Further research to explore these issues is needed.

## **Conclusion**

This study shed light on the barriers that disabled individuals with chronic back pain perceive as obstacles for a return to work. These included earlier negative experiences in their work life, low self evaluation of working ability, low self-esteem, organizational and economical conditions of the disability process. Some possible solutions to these barriers seem to appear. These include flexible job possibilities, secure and incentive economic arrangements, and an

understanding and supporting attitude from all parts involved in the process. Reformation of these arrangements will, however, require great organizational and economical resources, especially from the government. This study might support the view that for many, the process of disability is a one- way street, where the main effort would be to prevent more individuals from going down this street.

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