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# **Client Experiences in Work Rehabilitation in Sweden: A One-year Follow-up Study**

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## **Abstract**

This study was carried out in a work rehabilitation unit in Sweden, investigated how clients experienced their work rehabilitation process at a one-year follow-up. A semi-structured interview was administered to 14 former clients and a content analysis was applied. Seven categories were derived from the results: 1. Expectations of the rehabilitation process. 2. Social relationships. 3. Client influences on the rehabilitation process. 4. Occupations engaged in during the rehabilitation programme. 5. Perceived outcome. 6. Current occupations and 7. Future aspirations. The dominating expectations were to find a job with an overall desire for change. The social relationships with the staff and other clients were of great importance. The positive outcome of the rehabilitation was described as feeling better or having new skills. The perceived negative outcome was that the rehabilitation programme had not turned out as the client expected. The clients reported varying daily occupations after the rehabilitation and a majority were contented and optimistic about their future.

The main conclusions of the study are that when planning a work rehabilitation programme, efforts have to be made to examine the clients' interests and skills and to develop a dialog between clients and staffs. However, further research is needed to evaluate the work rehabilitation experience from the clients' perspectives.

**Key words:** work rehabilitation, sick leave, client perspective.

## Introduction

The working population in Sweden consists of 77% of the adult population aged 16 to 64 years (SCB, 2005). In February 2005, 112, 118 persons in Sweden had been on sick leave for one year or more (The National Social Insurance Agency, 2005). The average age was 45 years and a majority (64%) were women (The Social Insurance Agency, 2005). Being on sick leave in Sweden implies that a physician certifies that the person is unable to work because of an illness and sickness benefits are guaranteed. The large amount of individuals on long-term sick leave constitutes a great socio-economic problem in Sweden with increased costs for society (Hogstedt et al., 2004). Since the early 1990s Swedish legislation requires that employers have the main responsibility to initiate work rehabilitation programmes for their employees on sick leave and that the regional Social Insurance Agency is responsible for the rehabilitation of those who are unemployed and on sick leave. For both the employed and the unemployed populations the regional social insurance offices are responsible for co-ordinating and supervising work rehabilitation programmes, in the public and the private sector. In close collaboration with the person on sick leave, the regional social insurance offices are expected to determine which steps to take in designing a meaningful rehabilitation programme (Soderberg et al., 2004).

Since work is an important part of an individual's everyday life, and contributes to a sense of security, independence, freedom and identification with a profession an occupation (Brown et al., 2001), it is imperative to assist those who are unemployed due to illness to find meaningful work (Provencher et al., 2002). Researchers have found that anxiety disorders and lack of social support can deter an individual's return to work (Allen and Carlson, 2003; Larsson Lund et al., 2005). Selander et al., (2002), found that being self-confident, happy with life and not depressed were positive predictors of return to work. In addition they found that the young, native and well educated were most likely to return to work after work rehabilitation. Ahlgren and Hammarström, (2000) and Kaiser et al., (2001) reported that psychosocial markers such as marital status were of greater importance to women than to men. Ahlgren et al., (2004) found that men were to a larger extent than women offered further investigation or education, while the women received more job training. Studies suggest that improvements in communication between the client and the staff could yield better rehabilitative outcomes (Pransky et al., 2004).

Despite a strong emphasis that the person on sick leave should participate in the rehabilitation planning (Millet and Sandberg, 2003; Wressle et al., 2002), there has been little

research on this topic. Söderberg et al., 2004 showed that the common work rehabilitation goals expressed by the clients were ignored and that the clients in the study perceived themselves as abandoned after the rehabilitation period.

The aim of this study was to determine how clients taking part in a work rehabilitation programme in Sweden perceived their experiences one year after its termination, with a specific focus on how they could positively influence the rehabilitation process.

## **Methods**

### ***The work rehabilitation unit***

The data collection was carried out at a public work rehabilitation unit in the south of Sweden in 2001, but the analysis was accomplished in 2005 due to a parallel project. The targeted unit specialised in the rehabilitation of persons on sick leave for a year or more. The rehabilitation staff were multi-professional, consisting of social workers, psychologists, nurses, occupational therapists, physiotherapists, and teachers. On entering the rehabilitation programme, each client had the same staff member as his or her contact person throughout the period of rehabilitation. The contact person, in collaboration with the client, was responsible for planning the steps in the rehabilitation process and taking into consideration the client's specific needs and desires. Together they drew up a treatment plan for about 20 weeks according to the needs of the individual. This plan consisted of different interventions such as educational visits to factories or worksites, preparatory work education, personal- and job counselling, conversational therapy, evaluation of work capacity, and trying out a suitable type of job.

### ***Selection procedure***

The participants in the study were all former clients from the targeted work rehabilitation unit. The retrospective approach was chosen in order to understand the clients' view of the work rehabilitation after they had returned to routine life and could from a distance evaluate the whole process, from the period of sick leave to the situation one year after the rehabilitation.

The rehabilitation unit kept a database that comprised information about the client's gender, age, and place of birth, education, former profession, impediments to work, and length of sick leave. The selection process was performed in four steps. The criterion for selection was that one year or more should have passed since the individual completed his or

her work rehabilitation period at the unit. In the database, 127 individuals fitted this criterion. A second criterion, important for being able to contact the clients, was that the former contact person should still be working at the unit; 56 individuals fitted both criteria.

The final sample consisted of 14 individuals who varied with respect to gender, civil status, and time on sick leave , but relatively homogeneous as regards to age, obstacles to work and ethnic origin. Characteristics of the participants are described in Table 1.

Table 1. *Sociodemographic data for the 14 interviewed clients.*

	Interviewed (N = 14)
Gender	
Woman	6
Men	8
Civil status	
Single	6
Cohabiting	8
Year of birth	
Born after 1970	-
" 1961-1970	-
" 1951-1960	8
" 1941-1950	6
Obstacle for work	
Rheumatism, chronic muscular pain	4
Slipped discs, backache	5
Other physical problems	4
Psychological	1
Ethnic origin	
Sweden	11
Remaining Nordic countries	1
Europe except the Nordic countries	1
The rest of the world	1
Educational background	
Elementary school	1
Not finished nine-year school	1
Nine-year school	2
Vocational training education	6
Upper secondary school	3
University studies	1
Time sick-listed	
1-2 years	6
2-3 “	4
4 years or more	4

## ***Procedure***

The contact persons at the work rehabilitation unit provided both written and verbal information about the study and obtained verbal consent from the participants. The 14 clients who participated in the study received written information and a request for their written consent. Six interviews performed at the work rehabilitation unit, three at the clients' current workplaces, one at a neutral place chosen by the client and four in the client's homes. The study was approved by the local research ethics committee.

## ***The interview***

The first and last authors developed an interview guide with semi-structured open-ended questions. An outside expert evaluated the content validity of the questionnaire.

The interview had four temporal foci. The first concerned the time before sick leave, what daily occupations the clients had at that time, and whether they were working full-time or less. The next temporal focus was the time just before entering the work rehabilitation programme, and the interviewer ascertained how and by whom the initiative was taken to enter the work rehabilitation, how the clients experienced this part of the process, and what expectations they had of the work rehabilitation. The third temporal focus was the actual period of the work rehabilitation. Questions pertaining to this part of the interview concerned experiences during the rehabilitation process. Examples of topics were the clients' experiences of influence on the rehabilitation process, what interventions and type of work training the clients had participated in during the rehabilitation process and the perceived outcome at the end of the rehabilitation period. The fourth temporal focus was on the clients' situation one year after the rehabilitation, and the interview focussed on their present daily occupations, i.e. maintenance, work, leisure, and play (Persson et al., 2001). The clients were asked about factors of importance in how they currently experienced life and about future aspirations. Finally, the interview was completed with additional questions about their former employment and any changes in their life situation.

## ***Data analysis***

The results of the interview were analysed by content analysis (Berg, 2004). A statement was regarded as a set of information, in turn constituting the unit for analysis. The answer to a single question typically consisted of several statements, meaning that the answer could

comprise several statements related to different topics. These statements constituted the basis for classification into higher order categories and they were also counted to indicate how frequently that type of statement was found in the data.

In all, the analysis of the interviews generated 151 statements. The statements were read through several times until themes could be identified. Seven themes emerged: 1. Expectations of the rehabilitation process, 2. Social relationships, 3. Client influences on the rehabilitation process, 4. Occupations engaged in during the rehabilitation programme, 5. Perceived outcome, 6. Current occupations and 7. Future aspirations. Subsequently, within each theme, sub-themes were discerned. In this stage the analysis went backward and forward to ensure that all statements were represented among the themes and sub-themes and that these did not overlap. An individual not involved in the study, checked the trustworthiness of the classification of 1/3<sup>rd</sup> of the statements into the seven themes. There was full agreement on 82% of the statements, which was considered acceptable.

## **Results and Discussion**

The statements organised in themes and sub-themes, reflecting the clients' expectations before the rehabilitation, experiences of their work rehabilitation, and description of their situation one year after the rehabilitation, are illustrated in Table 2 and further described below.

Table 2. The distribution of themes and sub-themes.

Themes	Sub-themes	Number of statements
1. Expectations of the rehabilitation process	Finding a job	6
	Just getting started with anything	5
	No or negative expectations	4
	Getting help in communication with other authorities	3
2. Social relationships	Positive and supportive relations to the rehabilitation staff	10
	New social relations	9
	Negative relations to the rehabilitation staff	3
	Negative relations to other authorities	4
3. Client influences on the rehabilitation process	Experiencing positive influence on the content of the rehabilitation	9
	Experiencing influence, but it took too long before things happened	2
	Experiencing having too much responsibility	3
	Having no influence	12
4. Occupations engaged in during the rehabilitation programme	The occupations available were adequate and sufficient	9
	The occupations available were inadequate and/or insufficient	8
	The occupations available were indifferent to the respondent	2
5. Perceived outcome	Feeling better	10
	New skills and/or work acquired	2
	Things did not turn out as expected	9
6. Current occupations	Eventful life with paid work	6
	Just work and no spare time	1
	Eventful life without paid work	4
	Having too little to do	2
7. Future aspirations	Improved physical ability	10
	Improved economic opportunities	15
	A paid job	3

### ***1. Expectations of the rehabilitation process***

Eighteen statements concerned expectations. The two dominant expectations of the rehabilitation were to find a job and an overall desire for change. A common expectation, also expressing a need for a change, was that anything that changed the monotonous everyday life and resulted in just something to do was welcomed, since the days as a person on sick leave, with a limited number of daily occupations, was tedious. Other statements expressing expectations concerned the contact person and were about help in finding work in general,

finding a specific kind of work or getting a former job back. Another expectation was expressed as a wish that the rehabilitation unit would provide opportunities for trying out job tasks in different workplaces, in order to find a suitable job. According to some statements there were clients who had had difficulties in coping with the different authorities involved in their individual cases. Those clients had expectations of getting support and guidance in future opportunities. This was expressed as a hope that the contact person, would help find a permanent job meaning that the client would be able to avoid consultation with the previously involved authorities.

Some of the statements reflected negative expectations. It could be that somebody else, such as the regional social insurance officer, wanted the client to attend a work rehabilitation programme, and therefore his or her participation was exclusively a necessity. Among the negative expectations were statements expressing a feeling that the contact person was just one more authority getting involved in the client's life, or a fear of being treated badly by authorities once again. A majority of the statements expressing negative expectations also reflected that when the clients had to consult the health care services, they felt deprived of the possibility of making their own decisions and felt that everything just circled around the disease.

The positive expectations concerned the possibility of finding a job or just to get started with anything, as the days spent on sick leave grew monotonous. Long-term life on sick leave means poorer finances, that the possibility and the motivation for leisure activities decreases, and mental health is negatively affected (Floderus et al., 2003). Fear of losing social security benefits can be one reason for reluctance to participate in a rehabilitation programme if the participants cannot foresee the outcome (McQuilken et al., 2003).

## **2. Social relationships**

The 26 statements that concerned social relationships that developed during the rehabilitation were generally positive. Implicit in the statements was that the contact person filled a need from both a social point of view and in relation to the clients' work rehabilitation process. A positive social relationship also meant that the clients' various needs for support and help were met. For example, the staff could convey a conviction that most problems were possible to deal with and that there were appropriate solutions for all clients. Another way of strengthening the social relations was when the staff helped expediting the work rehabilitation

process because other authorities were felt to be too slow. Other statements described the establishment of new social relations with other individuals participating in the work rehabilitation.

The statements reflecting negative experiences of social relationships revealed a fear of formerly encountered authorities, especially the regional social insurance office. For example, some clients described how they were deprived of the opportunity to make their own decisions. Likewise, the clients had felt maltreated by different authorities, by professionals in medical care, and in particular by their doctors. A few negative statements expressing social relationships concerned the contact persons and the perception that they expected the clients to take too much responsibility in the rehabilitation process. Another example of negative social experiences was when the client felt that the different authorities had made all the decisions before meeting with the client and that he/she was supposed to just accept these decisions.

It has been shown that individuals who have been on sick leave for a long time often feel a distance to rehabilitation workers and perceive them as indifferent to their situation (Svensson et al., 2003). The clients in the study mentioned scepticism and fear of authorities, which in some sense confirmed these previous findings. Based on earlier experiences, the clients stated that they needed support in the discussions with the authorities. Previous research has shown that the relationship between clients and staff seems to have an impact on the outcome of rehabilitation (Eklund, 1996) and that people are unable to work if deprived of social contacts with colleagues (Stridlund and Ekberg, 2004).

### ***3. Client Influence on the rehabilitation process***

Regarding the client's influence on the rehabilitation, a theme that comprised 26 statements, two main sub-themes were identified, one positive describing experiences of having influence on the rehabilitation and one negative declaring no influence. Circumstances that led to an experience of influence were above all when the clients' opinions and wishes were acknowledged by the contact persons, when they felt listened to and believed in. One example of this was when a suggested measure was perceived as inappropriate by the client and the contact person paid attention to this. However, in some cases the statements expressed that it took a while before they were listened to and something actually happened.

Some statements confirmed that the clients had experienced too much influence, resulting in a feeling of having to take on too much responsibility during the work rehabilitation process. These statements concerned a need for more guidance and specific assistance in finding different workplaces in which to try out one's work capacity. An additional reason for the experience of too much responsibility was when the contact persons had too high expectations of what the clients could perform.

The reasons for not experiencing any influence at all differed. Some statements indicated that the rehabilitation unit could not provide a particular kind of rehabilitation or some other preferred specific intervention. Other statements illustrated that everything seemed to be decided on beforehand and that the discussions were just a matter of form, or that there was too much discussion and too little action.

Influence on the rehabilitation has been described as central for successful work rehabilitation and is also an important part of client-centred practice (Law et al., 1998). Essentials in client-centred practice are respect for the client, a continuous dialogue and flexible and individualised solutions. In the present study the experience of influence was affected by the extent to which the clients felt they were believed and listened to. Crucial factors in order to make the clients feel involved in the rehabilitation are knowledge of the client's life goals and treatment goals (Sivaraman, 2003; Gard and Söderberg, 2004), individually adjusted rehabilitation programmes, and that the clients have power and are in control of their own rehabilitation process (Millet and Sandberg, 2003).

A few statements indicated that some clients had perceived too much responsibility for the rehabilitation and that the demands were too high. To accomplish a balance between a person's own capacity and the demands from the environment is essential in work rehabilitation (Gard, 1998) as well as in rehabilitation in general (Jonsson et al., 1999). This balance also applies when choosing occupations during the work rehabilitation. Concerning the occupations available during the work rehabilitation, some statements indicated that the selection of occupations available during the work rehabilitation was sufficient, and some pointed out that the options were too limited. Even if this result is somewhat inconsistent, it indicates that the occupations used were crucial for the experience of the rehabilitation.

#### ***4. Occupations engaged in during the rehabilitation programme***

The experiences of participating in the occupations that were available during the work rehabilitation differed. Some of the 19 statements pertaining to this theme revealed that the clients thought there were enough options in selecting occupations, while others indicated that there were too few or inadequate choices, or that the clients found them meaningless. The available occupations that were perceived as adequate were, e.g., educational visits to different workplaces and going through a test by means of a specifically devised computer program in order to evaluate one's work capacity. Among other satisfying occupations, a specific course was particularly singled out where the clients could learn how to think about their work in a more positive way.

Some of the occupations performed during the rehabilitation programme resulted in new skills such as being able to use a computer. One statement described this as a rather boring occupation, but still something useful in today's society.

The statements expressing that there were too few alternatives among the occupations at hand during the rehabilitation can be illustrated by the following quote: "the individuals were supposed to fit in with the occupations instead of the other way around".

#### ***5. Perceived outcome***

Perceived outcomes of the rehabilitation were expressed in 21 statements. The most commonly perceived positive outcome was that the clients felt better. Only a few statements concerned new skills and/or jobs as positive outcomes. Negative outcomes were also indicated in the statements, expressing that the rehabilitation programme had not turned out as expected.

The statements referring to feeling better were, e.g., enjoying people they met or the benefit of making new contacts with people in the same situation. To get together with other people seemed even more important than participating in the different occupations offered during the rehabilitation. Most of the statements mentioned better possibilities to enjoy life after the rehabilitation period than before, and in some cases the rehabilitation had contributed to new interests. Other positive outcomes concerned daily occupations, such as returning to work or studies, early retirement, or sickness pension, and meant an end to uncertainty regarding one's own future. The interviewees also expressed relief with current opportunities to take responsibility for their own lives without interference from different authorities.

Some statements describing a negative outcome, i.e., that the rehabilitation period did not turn out as expected, concerned interventions that were part of the work rehabilitation, such as trying a certain type of work. The work placement could be too limited in time, leaving the client in the same situation of uncertainty as before. Another example of a negative outcome was when the work training had been transformed into a regular job too soon, before the client felt ready.

A minority of the statements concerned a reluctance to attend work rehabilitation at all, due to a feeling of being forced to attend the rehabilitation. Furthermore, some negative statements regarding outcome concerned the different courses the clients had attended when being on sick leave, before entering the work rehabilitation, and these were perceived as totally meaningless. These courses were described as dealing with "... how to look for a job, how to dress, how to sit, and so on..."

The statements describing everyday life as it turned out after the rehabilitation varied between depicting an eventful life, with or without work, to experiences of having too much work or leading a tedious life. From an occupational therapy perspective this could be explained in terms of balance or imbalance among the daily occupations of work, play, rest and sleep (Backman, 2004). The optimal balance between these occupations differs between individuals, and from the statements of this study it seems possible to experience an eventful life both with and without paid work. This indicates that the clients who were satisfied without work had been able to structure their days as if they had a job, and they seemed to experience a satisfactory mixture of occupations. Both the person just working and not being able to do anything more and the persons describing the days as tedious seemed to have too few occupations and perceive an imbalance in the daily occupations (Wilcock et al., 1997), although for different reasons.

## **6. Current Everyday Occupations**

A majority of the 13 statements that concerned their everyday life reflected an overall satisfaction one year after the rehabilitation. The clients seemed to have no difficulties filling their time with meaningful occupations and social relations, and even if the reason for being on sick leave, such as pain, was still there, it was easier to cope with.

However, a few statements reflected experiences of boredom and isolation and in some case a feeling of being "...like something that society wants to get rid of". In these negative

statements, life was either perceived as too demanding, or the opposite, as very monotonous, “it’s TV, TV, and TV all day long”. There was one statement explaining that coping with work was so tiring that the rest of the day was spent resting in order to be able to manage the next working day.

## **7. Future Aspirations**

Regarding future aspirations, comprised of 28 statements, two sub-themes were discerned: better economic opportunities and improved physical ability. The statements regarding improved economic abilities involved wishes for better/different housing, or being able to travel more. Better physical abilities concerned being able to spend more time outdoors, taking long walks, being able to play golf, and going skiing or dancing. A few statements revealed a wish to have a job, and in most case a specific job. Other topics related to future expectations were a need for having more social contacts and a wish to experience some more joyful events. One person on the other hand seemed totally contented with life as it had turned out.

Among other things, work provides income and an opportunity for bettering one’s life There is a tendency in Swedish society for class distinctions to increase (Hetzler et al., 2005), and among the most vulnerable are individuals depending on unemployment or sickness benefits. This might to some extent explain the statements concerning wishes for better economic conditions.

With respect to wishes for the future, some statements indicated that the clients wanted to return to their former jobs even if these in some cases had contributed to making them ill. One explanation for this could be that the clients experienced a loss of the worker role, and this in turn meant that they had to find a new identity (Dale-Stone, 2003). In struggling with this, the individual cherishes a hope that life could turn out the way it was supposed to be i.e., the way life went on before the health problems (Gullacksen, 2000).

## **Conclusions**

The results showed that rehabilitation planning should be carried out in close collaboration between clients and staff. Adjustments to the clients’ needs are important for successful

outcome. There is a need for counselling the client to determine the clients' interests, capacities and what occupations are meaningful to the client. Moreover, the relationships between clients and staff were fundamental and indicated that the contextual factors were of importance and should be taken into consideration in rehabilitation planning.

When designing a work rehabilitation programme it is essential to consider the clients' desires and needs and to nourish the professional relationship. This study clearly pursued the client's perspective. However, it has methodological limitations and further studies exploring clients' interests and occupations during rehabilitation are urged. Such studies should be performed on a larger scale and be based on diverse groups of clients. We would further recommend, e.g., narrative and qualitative studies in order to grasp a deeper understanding of the client's experiences.

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