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Thoughts and experiences from returning to work after stroke

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Abstract

Both prognosis and outcome for stroke survivors in working age are usually good. The possibility to return-to-work, however, seems to be hap hazardous. The aim of this study was to increase the understanding of stroke survivors' thoughts and experiences from returning to work after stroke. Semi-structured interviews were carried out with twelve persons, based on a thematic interview guide. A qualitative content analysis were performed. The main theme; was *Striving for optimal function at work creates mixed feelings of appreciation and frustration*, contained three categories: 1) Multiple arrangements and strategies are necessary for returning to work, 2) Work as an activity holds multiple subjective meanings that are important for the motivation to return to work, and 3) The return-to-work process generates many and mixed feelings. The complexity of the process involving many different actors constitutes great challenges for the affected person in addition to general and medical problems. The stroke survivor should be encouraged to be an active participant during the return-to-work process. Our findings can be used for the development of a programme, including a personal mentor, to support the person striving for returning to work. For detailed planning of such a programme further research is needed.

Keywords: societal arrangements, adaptations, coping, meaning of work, lack of control, confidence, future work situation, return to work process.

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INTRODUCTION

Work is one of the most important elements of adult life and occupies about one third of our time. Proportionally more time is spent on productive activities such as work than on activities for self maintenance or leisure. Work might be regarded as anything from an unpleasant necessity to a meaningful and enriching activity. Historically, attitudes towards work have changed from being regarded unworthy of a free man to being regarded as something enjoyable and enriching. Work is, however, viewed as an important part of somebody's identity [7, 20]. The question "What do you do?" illustrates the close connection between working and identity [7]. Kielhofner [20] stated that the more the working role defines a person's identity, the more essential work is to that person.

If persons in working age experience an injury or illness it is usually expected by the society that they should return to work (RTW), if possible. Studies about regaining work ability after a serious illness often focus on diagnose, impairments, treatments, and objective personal factors such as sex and age [32, 34]. Some authors emphasize more subjective aspects and the perceived meaning of work as important for the RTW process [1, 6, 32]. In a review of qualitative studies concerning RTW, MacEachen and co-workers [23] identified good will and trust as overarching factors for successful RTW. The complicated interaction between many players was pointed out as a challenge important to overcome. In a Swedish project the strategic cooperation among the primary health care, the social insurance office, the employment service, the employers and the social services, proved to be successful [39]. There was an increase in people actually going back to work, and a decrease in the number of days on sick leave. Such rehabilitation was calculated to give nine times return for every Swedish crown spent.

Rehabilitation of stroke survivors is frequent in Sweden and the need for RTW is urgent

since many people today are in their working age. According to Swedish official statistics annually 35,000 – 40,000 persons experience a stroke, and the proportion of younger persons in this category, i.e. < 65 years, has increased in later years. From 1998 to 2007 there was an increase in persons < 65 years from 17.4 % to 20.3 %. The reason for this was two-fold; while the number of younger persons experiencing stroke *increased* (1998/2007); 6,836 persons/7,138 persons, there was a *decrease* in the total number of stroke victims; 39397 persons/35195persons. Both prognosis and outcome for stroke survivors in working age are usually good [27], and they are usually well motivated for RTW. The actual RTW, however, seems to be hap hazardous and has become less frequent over the years. According to Swedish stroke studies from the 1970's [11, 12, 16] a relatively high proportion (64 %) of stroke survivors returned to work, but according to recent public statistics in Sweden and Vestling et al [37] 15 to 20 years later only about half of the persons who were working before their stroke did. Since the 70's the labour market situation has in our experience made it more difficult for stroke survivors to RTW, while at the same time this younger group has increased. Better efforts for rehabilitating younger stroke survivors back to work is in our opinion needed, but little is known from the patient's point of view about how this could be done.

Stroke in younger adult survivors is generally considered to have a substantial and lasting negative impact on quality of life, well-being and life satisfaction [26, 35, 37]. Young stroke survivors have reported strong feelings of frustrations during and after the rehabilitation, due to the lack of focus on their special life situation and especially their working situation [25, 29]. They express an urge to RTW [25, 40] and being able to do so seems to have a positive effect on their quality of life, well-being and life satisfaction [19, 37, 38]. When stroke patients take active part in their own rehabilitation they also express pride in their own capacity [26].

While reviews of studies concerning indicators for RTW after stroke show varying results [34, 40], there is congruence in that being younger, having a higher education level and a white collar employment have a positive influence on the opportunity to do so [37]. Still, among persons with similar impairment some RTW and others do not [31], and the knowledge on this diversity is insufficient.

Whereas a lack of motivation in relation to work is viewed as a problem for RTW [6, 4, 13, 21, 17], younger stroke survivors are often motivated for RTW [25, 29, 40]. In a previous study [37] based on a postal questionnaire survey, the most frequent motivation factors for work after stroke were financial and inherent aspects of work, thus regarded as the most important among the response alternatives given. Still, little is known about how the person, although motivated, perceives the experiences of RTW after a stroke in a more free and subjective way.

Rehabilitation during the RTW process typically involves many different actors. Vocational rehabilitation programs facilitate early RTW for persons with temporary or permanent disabilities [3]. It is usually recommended that vocational training should be gradual, starting with part-time work and then successively increasing to longer working hours. Persons with injuries or illness who are offered modified work programs RTW twice as often as those who are not. The importance of active participation by the stroke survivor in all aspects of the management of the RTW process as well as a stroke educator/workplace advocate has also been stressed [40]. Since the RTW process is extremely individual and case-specific [30], the success is dependent on the individual as well as on the work environment [2, 9]. In order to increase the knowledge about RTW, and to nurture the development of programmes to support the process, the aim of this study was to elucidate stroke survivors' thoughts and experiences from returning to work after stroke, in order to

further facilitate the RTW process. This study will hopefully reveal a better and deeper understanding of the RTW process for persons post stroke and hence facilitate the process.

MATERIALS AND METHODS

For this study, work was defined as continuing occupation in the production of supplies and services for payment [8]. The concept, RTW process, covers all actions with a specific aim for the person to be able to return to work and includes both getting back to any degree of employment and preparatory vocational training, as well as testing such employment. The process sometimes started already during the phase of medical rehabilitation, while the person who had experienced stroke was still at hospital. In some cases the process did not start until the person had been discharged.

Study Design

The research was carried out by semi-structured interviews in order to capture self-experienced descriptions of the RTW process after a stroke. A study-specific interview guide was used; the first author (MV) performed all the interviews. A qualitative content analysis approach [3, 15] was chosen in order to analyse the interviews about thoughts and experiences concerning the RTW process. The analysis highlights everyday activities and allows both description and interpretation of the content, offering possibilities to generalizations of the findings because most likely little human behaviours are unique [3, 28].

Sample

The informants were younger stroke victims (<65 years), recruited from the Department of Rehabilitation at one of the major University hospitals in the south of Sweden. Statistical data vary slightly year by year at this hospital, but the rehabilitation period is about four to five

weeks. The inclusion criteria were: i) having had a first stroke, ii) living in the county of Scania, and iii) returning to work. In order to get varied data a sample was strategically chosen [3, 28], aiming for mirroring the variation found in the most important indicators for RTW, based on a previous study [38]: walking ability, profession, and cognitive ability. The variation of walking ability ranged from a need of a mobility aid to being able to walk without any aid. As for professions, blue-collar workers, white-collar workers, and self-employed were of interest. The variation of cognitive ability ranged from having a cognitive impairment to having preserved cognitive function.

The sampling was made in collaboration with occupational therapists and social workers of the stroke team. Thirteen persons (four women, nine men) corresponding to the inclusion criteria were asked to participate. One man declined without giving any reason, leaving us with a sample of twelve persons. The Ethics Committee, Lund University, Sweden, approved the study.

Table I

In ten informants, stroke was caused by an infarction and in two by a haemorrhage. The median age at the time of the interviews was 52.5 years (range 43 - 61 years). Detailed background factors are shown in Table I. The interviews were carried out in median 3 months (range 3 weeks - 8 months) after the person had returned to work, i.e. either for vocational training or paid work. Three informants started to work without any initial vocational training at the workplace. At the time of the interview none of the informants had returned to the former level for working hours, irrespective of whether this had been part or full time. The interviewer (first author, MV) had met all the informants during their medical rehabilitation periods, although not as their treating occupational therapist.

Interviews

The interview guide was created in collaboration with experienced rehabilitation staff. It focused on central themes such as functions and disabilities due to the stroke, perceived meaning of work, and supports and barriers in the RTW process based on theories about work and previous research results. In order to get the informants to talk about their experiences, as recommended by Taylor and Bogdan [34] the interviews started by asking the informants to talk about something important to them. According to clinical experience, many persons who have survived a stroke choose to talk about the falling ill. Therefore, the interview guide contained a first theme about “the stroke onset” and thereafter the RTW process was brought into focus.

Procedure and data collection

The selected persons received an information letter together with a prepaid reply envelope. When a positive answer had returned, the informant was contacted and a suitable time and place for the interview was decided.

All informants approved of having their interviews tape-recorded; the interviews lasted 45-90 minutes. The interviews were based on the idea of a dialogue [34], i.e. even though the interviews did not always follow the order of the interview guide, all themes were covered. Before finishing the interviews the informants were asked if there was anything else about the subject that they wanted to bring about.

The interviews were transcribed directly verbatim by the first author (MV), including silences and laughter, although dialectal expressions were transformed into the corresponding non-dialectal word.

Data analyses

According to Graneheim & Lundman [15], information from interviews can generally be both descriptive and interpreted, and contain several ways in that the material can be understood. This type of analysis originates from communication theory and can be used when a text needs to be systematically described (manifest analysis). Over time, the analysis has developed to include interpretation (latent analysis) [15].

After the transcription of the interviews, the analysis was accomplished in several steps applying the qualitative approach as recommended by Graneheim and Lundman [15] and Berg [3]. It started with naive readings by the first author (MV) while making notes in the marginal, with the intention to understand and acquire a comprehensive view. The next step was to exclude all data not to be included in the analysis, such as the information about falling ill. The remaining text was searched for its manifest content, i.e. actual and descriptive statements. Statements such as phrases, sentences, or paragraphs were marked in the text and statements that appeared to share the same sense were placed in meaningful units. These units were descriptively coded, close to the wording in the text. Three other persons (one occupational therapist, one industrial designer, and one physiotherapist (second author, ER) with different pre-understanding, took part in this step. They coded two interviews each. Sometimes these codes differed slightly due to a different pre-understanding or the use of different wording for the same implication. After thorough discussions consensus was reached. In the next step the text was re-read line by line by the first author (MV), critically analysed and questioned several times. A matrix as recommended by Graneheim and Lundman [15] was used. Questions asked during this step of the analysis were for example: What is this? What does this mean? What is it similar to? What is it different from? That is, comparisons of similarities and differences were made. Eventually, the understanding from the meaningful units resulted in a set of sub-categories, subsequently put into three

distinctively different categories (Fig II). Successively, a final, interpretive theme that contained the essence of the three categories and all the interviews emerged. The theme interpretation was extensively discussed with the second (ER) and the last author (SI).

FINDINGS

The overarching theme which was in different ways present in all interviews was labelled *Striving for optimal function at work creates mixed feelings of appreciation and frustration*. It involved descriptions of feelings that mirrored difficulties and insecurity but yet a strong capacity and willpower to overcome problems in the RTW process. The theme contained three categories with sub-categories (Table II). The categories were labelled: 1) Multiple arrangements and strategies are necessary for returning to work, 2) Work as an activity holds multiple subjective meanings that are important for the motivation for returning to work, and 3) The RTW process generates many and mixed feelings. These categories were distinctly separated from each other. The first category contained thoughts and experiences related to personal and societal support. The second category involved perceptions of different aspects of work important for motivation. The third category concerned different emotions about the RTW process and the future.

Table II

Multiple arrangements and strategies are necessary for returning to work

Returning to work was often an explicitly formulated goal by the informants, but the interventions differed and individual arrangements and strategies concerning how to RTW were used. For some informants, the vocational rehabilitation started during the medical rehabilitation period including workplace visits and plans for vocational training at the

workplace, in collaboration with the person himself/herself, the rehabilitation staff, representatives of the workplace, and/or representatives of the Social Insurance Office. For some the RTW process started after discharge from the medical rehabilitation which meant that the rehabilitation staff was not involved in the RTW process. The self-employed persons, however, did not take part in such interventions. Different arrangements were perceived differently by the informants. Two sub-categories were identified 1) "Getting personal and societal help and support", and 2) "Using personal willpower and efforts is important". The sub-categories were distinguished by the degree of the informants' own activity regarding interventions.

Getting personal and societal help and support. Some informants were critical about the support provided and commented on being exposed to other peoples' interventions and sometimes bad treatment. They expressed feelings of humiliation or frustration, by using wordings such as: "it disturbed me", "nobody is concerned", and "I felt as if I was being punished". In general, the informants expressed how much they appreciated personal support from e. g. medical staff, family, friends, fellow workers, their employer, and/or from representatives from the Social Insurance Office by describing the support as "helpful", "understanding", and "competent".

"...the support came from everyone, from cleaners to doctors. They were always encouraging...They have done that a lot, both my daughters and my husband. A lot of people have been supportive, I must say. And then I have had support from friends and neighbours, not support as such, but they have showed it."

The support from professionals and the societal support, involving interventions such as technical aids and adaptations of the physical environment at the workplace, were

appreciated. Regarding this kind of practical interventions, some informants expressed worries that had there been a need for a wheelchair, this would have been a barrier both regarding accessibility at work and the ability to socialize with workmates. Heavy manual work assignments would also have been hard to perform independently. It was, however above all, cognitive impairments that were considered to be a problem for the working ability. It was also pointed out that a full time personal assistant at work would not have been appreciated but instead thought of as a barrier.

“...but I would have somebody with me always to help me all the time. That doesn’t work, you know.”

None of the informants had an especially appointed person at the work place for support and help, but everybody except the self-employed had by themselves found a person they usually turned to, if or when they experienced any problems. For the self-employed a supportive spouse was highly regarded and considered “necessary”. Other informants’ comments revealed that if a support person had been appointed in advance it would have been a great help.

“It would have been nice to have somebody who sort of came along on his own accord to ask if he could take over: can I help you, can I get you anything?”

For all informants the working hours had increased gradually since they returned to work. Even though this was not always appreciated initially, it was after some time.

”We began with two hours per day. I remember that the welfare officer said: Let’s begin with two hours. I thought that two hours were hardly worth the trouble. I hardly got there before it was over. But it really was very sensible.”

The informants explained how work assignments usually were adapted in some way initially by excluding the more complex tasks. Some informants did not experience any pressure to perform and felt this as a relief. There were, however, comments that some expectations or demands would have been appreciated, even if not at the same level as before the stroke.

“They don’t expect anything from me. It just couldn’t be better. They know too, that this is going to take a long time. They could have had some sort of demand on me. But at the same time it is a relief for me. To be allowed to do it in my own time.”

Using one’s own willpower and efforts are essential. Having a strong willpower and being persistent was believed to be important personal characteristics for a successful RTW process.

“But basically, if I hadn’t wanted to get into anything, I would not have been sitting here today. I thought to myself, I am going to make it.”

Statements such as: “I will make it”, “I wanted to ...”, and “being stubborn” were frequent during the interviews. Without personal willpower the RTW process would fail. Several informants expressed that they were carrying on with their lives as usual. It was, not unusual for them to describe an active change of their lifestyle as a choice compared to before

the stroke. The change could be dramatic or less so, e.g. doing physical exercises or changing eating habits. It was considered important to live a busy life with different activities, sometimes considered more important than work, or at least full time work.

“.....but that would mean that I would have to use my free time for the exercise that I need. And if I felt tired some day I might say no, I'll wait until tomorrow - and then you're out of your schedule just like that. I have a lot of training left to do, you know.”

Individual creativity was also important for developing active techniques for adaptation and problem-solving. The techniques were often preventive such as trying to find out in advance when and which problems might appear, and then find a solution. Problems could be avoided by for example actively seeking help from family, friends and workmates. Concentrating on one issue at a time in order to stay calm and avoid making mistakes was another way to keep away from problems described. The use of checklists and memory notes was also common, as well as the use of audio-signals such as alarm-clocks, to be reminded of the time, or as a means to start getting ready.

“I have a sort of alarm bell and when it sounds I must stop reading the paper or whatever I am doing, because it will be time to get dressed and maybe go to the toilet before leaving.”

Work as an activity holds multiple subjective meanings that are important for the motivation for returning to work

The informants expressed that work was an important activity with multiple meanings in their lives; even if one sometimes was tired of it, work was mostly thought of as enjoyable and meaningful. Comments like “I have a god job” and “to do what is expected of one” and “I must work” were frequently made. Work was spontaneously thought of and appreciated as something to do and an opportunity to meet people. Statements about what motivated the individual to strive to RTW were part of this category but distinguished as three different aspects (hence three sub-categories) of motivating factors in the interviews. 1) “Emphasizing social aspects”, 2) “Emphasizing intrinsic aspects”, and 3) “Emphasizing financial aspects”.

Emphasizing social aspects. Work offered a welcomed change in everyday life, and even if domestic work was appreciated, it was mostly not recognized to be sufficient as a daily occupation. Comments like “just sitting there” and “it’s boring,” were frequently used as a way of expressing the urge to have something to do outside the home. Often, the informants had felt isolated during the sick leave and had longed to get back to work.

“It was more boring than I could imagine hanging around at home, so even if I don’t do that much at work sometimes, it is still more fun thanks to the variation in everyday life.....”

Employers, executive managers and work-mates played an important role for a good psycho-social environment at work. The work-mates were sometimes thought of as family and friends, with whom one socialized also during one’s spare time.

“ We are five or six girls who go to Denmark sometimes, and sometimes we meet in somebody’s home.”

Emphazising intrinsic aspects. The informants often expressed that work was important on a personal level, but it was sometimes difficult for them to describe exactly what was important. It was evident in several of the interviews that work seemed to stimulate internal personal aspects such as self-fulfilment, often expressed with comments like “being someone”, “being needed”, and “getting response”. The informants stressed that in their work they were often allowed the freedom to decide what to do and when to do it, as long as the work was done. This personal freedom was regarded as very important for being motivated to work.

“I have my little corner where I sit and then I know that they’ll put those papers there for me. And then they know that “she’ll take care of it”. And then they don’t have to do it. I feel that they trust me: “We’ll put it there and then she’ll take care of it.”

Other motivating factors were that work tasks were felt to be demanding and challenging and also included personal flexibility and creativity. Work was thought of as a means for personal development and feelings of pride of one’s own performance.

“.... and having forever new challenges and every day is full of surprises. There is always something going on. Both taking care of problem presentations and specific problems that have annoyed customers and that needs to be corrected, and to re-establish the contacts to the level where you want them.”

Emphasizing financial aspects. Financial aspects were only occasionally mentioned as the main reason for work, e.g. that the sickness benefit was not high enough, but were instead considered in terms of getting a little “extra” in daily life. The informants showed an ambivalent attitude; the money was thought of as handy and necessary for affording for example maintenance and leisure activities, but at the same time also thought of as being of less importance. Work was regarded as a way of earning one’s living and a way to do what one was expected to do financially.

“.....you are there to make money to be able to get by. It’s not exactly a calling.”

The return-to-work process generates many and mixed feelings

The informants all shared the experience of adapting to a new life situation and whether it would include work or not. The interviews revealed their feelings of insecurity, frustration and at the same time confidence in getting back to a life which included work. Statements concerning their experiences from the RTW process and all the mixed feelings it had caused formed the third category, which in turn included two separate sub-categories: 1) “Struggling with feelings of lack of control versus feelings of confidence” and 2) “Having trust and fear for the future work situation”.

Struggling with feelings of lack of control versus feelings of confidence. The informants reported that they frequently were worrying about problems due to circumstances out of their control. Several persons expressed feelings of being down or even depressed. In general, the informants now and then had had negative thoughts concerning the RTW process and their new life situation, represented by statements like “I don’t recognize myself”, “I was unsure of

myself”, and “I’m brooding”. These feelings were especially frequent at the initial stage of the RTW process, but faded with time and when their efforts had been successful. Still, informants revealed that feelings of uncertainty were present or easily awakened when something troublesome happened. Contrary to the worry, the informants also experienced feelings of satisfaction and happiness regarding life in general as well as the RTW process, demonstrated by comments like “It’s going well” and “I’m so happy”. It was, however, not uncommon that the feelings and thoughts fluctuated between insecurity and confidence.

“I was both happy in a way and grateful that I had come back, but incredibly afraid too, and insecure. You could say that one does not go through this unaffected.”

Fatigue was a main source of frustration. Feelings of fatigue, although of varying degree, seemed to be a constant companion and with tiredness to an extent that the informants had never felt before. Such a fatigue created feelings of lack of control because it could appear at any time. Regardless of the amount of sleep, the feeling of fatigue was always there and affected life in a negative way, and the word “tired” was frequently used. A mutual experience was that there were occasions when even small events were irritating.

“..... I was so tired that I sometimes hesitated; I just did not have the strength to get up and so... ”

Having trust and fear for the future work situation. Irrespective of all mixed feelings, the informants mostly expressed confidence in the future. Even if a full time job turned out to be impossible, one would be satisfied with part time; at least 50% but preferably 75%. A few of

the informants had thought of job alternatives offered by for example friends and acquaintances or organizations, jobs such as giving lectures about having had a stroke and its consequences for daily life. Work played an important role in their lives, but an imagined replacement of work with other activities was often commented with “it’s no problem”.

“Sure, there is work. if you can’t work full time you can start planting flowers again.”

There were mixed feelings concerning early retirement. Some were planning for early retirement and had taken measures to finance this. Some of the statements showed feelings of fear and frustration about having to accept the possibility of being a burden to other people, especially for the family but also for society in general.

“I don’t want to become, what’s it called, retired you know. Uhu, I am dead scared of that. It makes me, yuk. Just imagine getting those cards cheap for football games. The pension card. No, no, no, no.And that’s final.”

DISCUSSION

Discussion of findings

The focus of this study is on the individual’s experiences while trying to RTW after stroke, and the common theme “*Striving for optimal function at work creates mixed feelings of appreciation and frustrations*” depicts that the informants shared experiences from struggling in the process of RTW, emphasizing the importance of multiple arrangements and strategies. There seems to be a need for adjusted assignments, shorter working hours and increased assistance in some work situations regardless of work and employment situation, and the

informants were sometimes appreciative of this and sometimes frustrated because of it. The findings elucidate that every individual has his/her own personal way in adapting to work, similar to a learning process [9] and the motivation was triggered by different subjective meanings of work. The individual's motivation is often the key for success [30] which is why this needs to be greatly emphasized in all rehabilitation. For stroke patients in working age the mere hope of returning to work is a great motivation [29] which was found also in our material. The outcome also depends on others, such as employers, who may need to find their own motivation for the process in order for it to be successful [13]. Some of the informants in the present study stressed that a supportive and understanding employer was of utmost importance. One person especially stated in the interview that he would not approve of an appointed professional personal assistant but other informants were often glad that they had someone, beside the employer, to discuss with and/or ask for help. This person was not specially appointed but rather someone who took a personal interest in the matter. Obviously, the RTW rehabilitation involves so many different actors that we believe that a mentor should always be appointed to help dealing with all the contacts and problems that might occur. Such a mentor can be anybody that the patient trusts and who is somewhat familiar with rehabilitation, although there is no absolute need for a professional healthcare person.

All informants of this study took an active part in the RTW process, which has been greatly stressed by legislation and suggested in reviews [2]. It is noteworthy that for most of the time, the informants experienced no special demands either from employer, manager or workmates concerning the work assignments. For those being self-employed, the RTW process seems to be lonely, with lack of societal support after discharge from the medical rehabilitation. In order to provide support, Ekberg [9] suggested that the case responsible worker from the Social Insurance Office could serve as a support person. However, since the Social Insurance Office is a public authority and as such associated with supervision, such an

arrangement might give double messages. The rehabilitation team is often an integrated part of the RTW process and a professional from the rehabilitation team could be such a case manager.

According to the findings, the informants tried to actively cope with their disabilities in different ways, which demanded strong willpower, effort and creativity. These findings are in contrast to the experience that stroke survivors look at themselves as being less capable and having difficulties in adjusting to the effects of the stroke [10, 26]. This study shows that the informants actively changed their lifestyle and tried to live as actively as possible compared to before the stroke, which is in line with a more recent study reporting positive consequences after stroke [14], i.e. that stroke survivors are able to reframe their experiences in a positive light after surviving a stroke. Furthermore, in order to cope with difficulties, individual creativity was used. Theorell and co-writers [36] argue that effective coping involves an agreement between emotion and reason, either through dealing with the situation or as an emotional reassessment. Due to different circumstances, an individual's coping pattern changes through life. People who have experienced stroke have earlier been seen to use coping strategies [26] such as accommodative coping (acceptance of limitations) and assimilation. Our informants mostly used assimilation, since they in order to RTW strived for a set of goals and did not accept limitations; they focused on improving their functional ability. Since work is an important part of an individual's identity [7, 20] and returning to work seems to be an important factor for life satisfaction [38], the fact that all our informants were striving hard to reach their goal to be back in work it would probably be beneficial for their life satisfaction.

According to the findings, work has multiple subjective meanings. When asked what work meant to them, the informants spontaneously answered mostly in terms of social aspects like meeting people and having something to do. This is somewhat in contrast to a previous

quantitative study [38] where the respondents were asked to choose among different given aspects and a majority instead rated economic factors as the most important. The fact that earning one's living might be taken for granted [18] could explain why this is not much discussed in an interview but easier ticked off in a questionnaire. In congruence with Brown et al. [6] our informants emphasized internal and social aspects. Financial aspects were also mentioned, but often commented on as less important.

The findings of this study reveal that experiences of the RTW process after stroke is a source of many feelings, such as lack of control versus confidence, and both trust and fear for the future work situation. It is not unusual to become depressed or to have depressive thoughts after a stroke [5, 22, 26], and just the thought of perhaps losing one's job can be a reason for depressive feelings. Our informants mentioned that they often suffered from fatigue, which has been recognized as an especially disabling and frustrating feeling [5]. He describes fatigue as a pseudo depressive syndrome after stroke. It typically involves stroke survivors with total or near total neurological recovery like several of the informants in this study. However, according to the findings the informants also, due to positive working outcome, experienced growing confidence in their work ability during the return-to-work process. Individually directed societal interventions probably would increase and strengthen positive experiences during the process and again, a mentor could be an effective solution.

According to the findings the future was mostly looked upon with trust and with a fulfilling of the personal goal to RTW. Whether or not this was done on a full time basis or with decreased working hours seemed not to be a problem. In the case of individuals not being able to RTW, Swedish Public Health Insurance guarantees about 60% of the income, which might be an explanation? In Sweden, added private insurance is also common. All in all, these arrangements make it easier to plan for an active full time or part time retirement.

Overall, being able to cope effectively with the new life situation after the stroke strengthens the possibility of a good life [6, 26].

The group of informants was chosen because they had all been able to RTW to some degree or were in the phase of vocational training at the work site (Fig 1), and they were therefore expected to have opinions about the subject under study. They all had their previous employers' support for returning to work, and consequently, the involvement of the Employment Service as mentioned by others [9] was not needed. When return to the previous work situation is not possible, such involvement is of course necessary and adds yet another actor in the process.

Methodological discussion

More than one person was involved in the analysis procedure as recommended by Berg [3]. The descriptive statements were sorted into sub categories and later into categories and even if statements can seem rather obvious, a certain amount of understanding is needed in order to both choose and sort text from the large material. According to the content analysis method [15] the interpretation of the material, when for example naming a theme, was reached by discussion and consensus with co authors. During the analysis it became obvious that one of the categories dealt with motivation for RTW. As motivation had been focused in a previous study this pre-understanding by the authors might have affected the current analysis of the material. But, it seems obvious that motivation is important for RTW, which also have been pointed out in other studies [e.g. 25, 29, 40].

The informants were chosen because they all had been able to RTW to some extent and therefore were expected to have opinions about the subject. The variation concerning the RTW process in the sample was considered an advantage as a means of attaining width as well as depth in the findings. A weakness regarding the credibility might be that the

interviewer had met the informants before, during the medical rehabilitation period, although not in the role as the responsible occupational therapist. This previous relation might have influenced the interview situation positively, making the informants feel relaxed. A potential weakness might be the actual interaction between the interviewer and the informants. The informants did perhaps not go deep enough into their reflections because they were not used to reflect upon the meaning of work and the RTW process. However, the informants were used to communicating with rehabilitation staff and other people in general, and there is no apparent reason why they should have withheld their reflections. The interviewer encouraged the informants to tell about their experiences, applying techniques such as posing open questions, pausing, and repeating small parts of their stories, as recommended by Taylor and Bogdan [34]. In order to increase the trustworthiness and to assure that the aim of the study was in focus, a semi-structured interview-guide was used. The guide also was helpful in structuring the interviews in a similar way.

The findings have implications for occupational interventions, e.g. supporting the patients' coping adaptation strategies during long term follow up and could be relevant for the planning of such interventions. Even if the results from a qualitative study are difficult to generalize to other groups a content analysis can make this possible [3, 28]. A client centered approach and a deeper understanding of a real life situation in RTW process can be important support for directing occupational interventions for similar groups. However, individual motivation, issues, and adaptation must be considered in every case.

Conclusion

In stroke rehabilitation, we recommend that the RTW process is highlighted and that coping and adaptation strategies are strengthened. It is also important to intervene against feelings of depression and fatigue. Furthermore, personal willpower seems to be important and we

strongly suggest that the stroke survivor is encouraged and supported to be an active participant during the individual RTW process, in collaboration with the employer and/or public authorities. Our findings can be used for the development of a RTW programme, including a personal mentor to support the person striving for returning to work. We suggest rehabilitation teamwork, including occupational therapy, as an integrated part in the RTW process. For detailed planning of such a programme, the role of a personal mentor and to develop a personal evidence based practice further research is needed.

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REFERENCES

- [1] Alaszewski A, Alaszewski H, Potter J, Penhale B. Working after stroke: survivors' experiences and perceptions of barriers to facilitators of the return to paid employment. *Disabil Rehabil.* 2007; 29 (24): 1858 – 1869.
- [2] Andersson A, Ekberg K, Enthoven P, Kjellman G, Ockander M, E Skargren, et al. Vad är en god arbetslivsinriktad rehabilitering? Slutsatser baserade på en litteratursammanställning. (What is a good vocational rehabilitation? Conclusions based on a literature review). Linköping, HIS rapport 2003:1, The University of Linköping, Linköpings universitet.
- [3] Berg BL. Qualitative research methods for the social sciences. 5th ed. Boston: Allyn and Bacon; 2004. pp. 34 - 37, 259 - 260, 265 - 271.
- [4] Berglind H, Gerner U. Motivation and return to work among the long-term sick listed: an action theory perspective. *Disabil Rehabil.* 2002; 24 (14): 719 - 726.
- [5] Bogousslavsky J. Emotions, mood, and behavior after stroke. *Stroke.* 2003; 34 (4): 1046 – 1050.
- [6] Brown A, Kitchell M, O'Neill T, Locklear J, Vosler A, Kubek D, et al. Identifying meaning and perceived level of satisfaction within the context of work. *Work.* 2000; 16 (3): 219 - 226.
- [7] Christiansen CH. Defining lives: occupation as identity: an essay on competence, coherence, and the creation of meaning. *Am J Occup Ther.* 1999; 53 (6): 547 - 558.
- [8] Dubin R. The world of work. Engelwoods Cliff: Prentice-Hall; 1985. p. 4.

- [9] Ekberg K, Rehabilitation to work. In: RÅ Gustavsson, Lundberg I, editors. *Work life and Health in Sweden 2004*. Stockholm: National Institute for Working Life; 2005. pp. 389 - 406.
- [10] Ellis-Hill CS, Horn S. Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clin Rehabil*. 2000; 14 (3): 279 - 287.
- [11] Espmark S. Stroke before 50: a follow up study of vocational and psychological adjustment. *Scand J Rehabil Med Supp*. 1973; 5: 1-107.
- [12] Fugl-Meyer L, Jääskö, L Norlin V. The post-stroke hemiplegic patient. *Scand J Rehabil Med*. 1975; 7 (2): 73 - 83.
- [13] Gard G, Larsson A. Focus on motivation in the work rehabilitation planning process: A qualitative study from the employer's perspective. *J Occup Rehabil*. 2003; 13 (3): 159 - 167.
- [14] Gillen G. Positive consequences of surviving a stroke. *Am J Occup Ther*. 2005; 59 (3), 346 - 350.
- [15] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2003; 24 (2): 105-112.
- [16] Hindfelt B, Nilsson O. The prognosis of ischemic stroke in young adults. *Acta Neurol Scand*. 1977; 55 (2): 123 - 130.
- [17] Isaksson Mettävainio B, Ahlgren C. Facilitating factors for work return in unemployed with disabilities: A qualitative study. *Scand J Occup Ther*. 2004; 11 (1): 17 - 25.
- [18] Jahoda M. Work, employment, and unemployment. Values, theories, and approaches in social research. *Am Psychol*. 1981; 36 (2): 184 -191.
- [19] Johansson U, Bernspång B. Life satisfaction related to work re-entry after brain injury: a longitudinal study. *Brain Inj*. 2003; 17 (11): 991 -1002.
- [20] Kielhofner G, Braveman B, Baron K, Fisher G, Hammel J, Littleton M. The model of human occupation: understanding the worker who is injured or disabled. *Work*. 1999; 12 (1): 3-11.
- [21] Liedberg G, Henriksson C. Factors of importance for work disability in women with fibromyalgia: an interview study. *Arthritis Rheum*. 2002; 27 (5): 266 - 277.
- [22] Martin C, Dellatolas G, Viquir D, Willadino-Braga L, Deloche G. Subjective experience after stroke. *Appl Neuropsychol*. 2002; 9 (3): 148 - 158.
- [23] MacEachen E, Clarke J, Franche R-L, Irvin E. Systematic review of the qualitative literature on return to work after injury. *Scand J Work Environ Health*. 2006; 32 (4), 257-269.
- [24] McMahon R Slowinski Crown D. Return to work factors following a stroke. *Top in Stroke Rehabil*. 1998; 5 (2): 54 - 60.
- [25] Medin J, Barajas J, Ekberg K. Stroke patients' experiences of return to work. *Disabil and Rehabil*. 2006; 28 (17): 1051-1060.
- [26] Murray C, Harrison B. The meaning and experience of being a stroke survivor: an interpretive phenomenological analysis. *Disabil Rehabil*. 2004; 26 (13): 808 - 816.
- [27] Musolino R, La Spina P, Granata A, Gallitto G, Leggiadro N, Careri S, et al. Ischaemic stroke in young people: a prospective and long-term follow-up study. *Cerebrovasc Dis*. 2003;15 (1-2): 121-128.
- [28] Patton MQ. *Qualitative research and evaluation methods*. 2nd ed. Newbury Park: Sage Publication; 2002. pp. 205-208, 227.
- [29]. Röding J, Lindström B, Malm J, Ohman A. Frustrated and invisible - younger stroke patients' experience of the rehabilitation process. *Disabil Rehabil*. 2003; 25 (15): 867-874.
- [30] Saeki S. Disability management after stroke: its medical aspects for workplace accommodation. *Disabil Rehabil*. 2000; 22 (13-14): 578 - 582.
- [31] Shaw L, Polatajko H. An application of the Occupation Competence Model to organizing factors associated with return to work. *Can J Occup Ther*. 2002; 69 (3): 158-167.

- [32] Shaw L, Segal R, Polatajko H, Harburn K. Understanding return to work behaviors: promoting the importance of individual perceptions in the study of return to work. *Disabil Rehabil.* 2002; (24): 185-195.
- [33] S. Smout S, Koudstaal PJ, Ribbers GM, Janssen WG, Passchier J. Struck by stroke: a pilot study exploring quality of life and coping patterns in younger patients and spouses. *Int J Rehabil Res.* 2001; 24 (4): 261-268.
- [34] Taylor SJ, Bogdan R. Introduction to qualitative research Methods: A guidebook and resource. 3rd ed. New York: John Wiley and Sons Inc; 1998. pp. 88 -116.
- [35] Treger I, Shames J, Gianquinto S, Ring H. Return to work in stroke patients. *Disabil Rehabil.* 2007; 29 (17): 1397 - 1403.
- [36] Theorell T, Westerlund H, Oxenstjärna G. Coping och sjukskrivning. I: Marklund S, Bjurvald M, Hogstedt C, Palmer E, Theorell T, editors. Den höga sjukfrånvaron - problem och lösningar. (Coping and sick-leave. In: Marklund S, Bjurvald M, Hogstedt C, Palmer E, Theorell T, editors. The high absence due to illness – problems and solution. Stockholm: Arbetslivsinstitut; 2005. pp. 163 – 177.
- [37] M. Vestling, M, Ramel E, Iwarsson S. Quality of life after stroke: well-being, life satisfaction and subjective aspects of work. *Scand J Occup Ther.* 2005; 12 (2): 89 - 95.
- [38] Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *J Rehabil Med.* 2003; 35 (3): 127 - 131.
- [39] Vahlne L, Westerhäll, Bergroth A, Ekholm J. Rehabiliteringsvetenskap. (Science of Rehabilitation). Lund: Studentlitteratur; 2009. pp. 21-29, 185-199.
- [40] Wolfenden B, Grace M. Returning to work after stroke: a review. *Inter J Rehabil Res.* 2009; 32 (2): 93 - 97.

Table 1. Sample characteristics (N =12)

Age at time of interview	Gender	Origin of stroke	Time since the stroke when returning ¹	Time since returning ¹ when interviewed	Walking ability	Profession ²	Cognitive function ³
57	Female	Infarction	3 months	4 months	Independent	White-collar worker	Preserved
43	Male	Infarction	2 months	4 months	Independent	Self-employed	Moderately impaired
51	Female	Haemorrhage	17 months	8 months	Independent	Blue-collar worker	Severely impaired
49	Male	Infarction	4 months	3 weeks	Independent	Blue-collar worker	Preserved
53	Male	Haemorrhage	18 months	1 month	Wheel-chair	White-collar worker	Severely impaired
54	Female	Infarction	1 month	1 month	Independent	White-collar worker	Preserved
56	Male	Infarction	1½ month	3 months	Independent	Blue-collar worker	Preserved
61	Male	Infarction	2 months	3 months	Walkingstick	White-collar worker	Preserved
53	Male	Infarction	7 months	5 months	Independent	White-collar worker	Moderately impaired
57	Male	Infarction	2 month	1 month	Independent	Self-employed	Preserved
56	Female	Infarction	1 month	3½months	Independent	White-collar worker	Moderately impaired
49	Male	Infarction	4 months	2 months	Independent	White-collar worker	Moderately impaired

¹ Nine informants started with and three informants without vocational training at the work place. ² Profession was classified in accordance to the Swedish socio-economic classification (SEI) (26). ³ Cognitive function was classified in accordance to neuropsychological assesment.

Table II. Findings showed as sub-categories, categories, and theme.

Subcategory	Category	Theme
Getting social and societal support	Multiple arrangements and strategies are necessary for returning to work	<i>Striving for optimal function at work creates mixed feelings of appreciation and frustrations</i>
Using one’s own willpower and efforts are essential		
Emphasizing social aspects	Work as an activity holds multiple subjective meanings that are important for the motivation for returning to work	
Emphasizing intrinsic aspects		
Emphasizing financial aspects		
Struggling with feelings of lack of control versus confidence	The return-to-work process is a source of many and mixed feelings	
Having trust in and fear for future work situation		