Healthcare encounters and return to work: a qualitative study on sick-listed patients’ experiences

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Background: Sickness absence is a complex phenomenon affected by aspects other than disease. One important factor that can affect sick leave is the individual’s experience of healthcare encounters. It is therefore essential to consider the quality of the encounter with health professionals and its impact on the patient’s rehabilitation and return to work. Aim: The aim was to explore how sick-listed patients in Sweden perceive their contact with healthcare professionals in primary healthcare and to analyse what they view as crucial components for returning to work. Methods: A qualitative approach was used. Data were collected by semi-structured telephonic interviews with patients who were or had been on sick leave. The transcribed interview text was analysed according to qualitative content analysis. Findings: The analysis revealed two themes that highlight important areas for persons on sick leave in their healthcare encounters. The theme ‘Trust in the relationship’ contains categories describing the patients’ feelings of participation, and of being believed, confirmed, and listened to, and also dedication on the part of healthcare providers. Healthcare encounters that were characterised by professionalism, knowledge, continuity, and a holistic approach seemed to create trust. The theme ‘Structure and balance’ contains the participants’ views on important factors that could support the return-to-work process. All participants stated the importance of follow-up and a plan for rehabilitation. Sick leave itself can make a person passive, and participants in this study asked for support to balance activity, exercise, and work demands, which could facilitate their return to work. Conclusion: Healthcare professionals can facilitate sick-listed persons’ rehabilitation back to work by providing a clear structure in the process and support in occupational balance. The healthcare encounters must build on a mutual trust.

Key words: primary healthcare; sick leave; work ability

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Introduction

Sickness absence is a complex phenomenon affected by aspects other than disease (Whitaker, 2001). People’s ability to work is not separated from life outside work (Ilmarinen, 2009) and can depend on
many interacting factors (Sturesson et al., 2013). As people have a variety of illnesses and different types of work, different assessments (Stigmar et al., 2010; Wynne-Jones et al., 2010) and different interventions to accelerate return to work are needed.

Sick leave is often prescribed in primary healthcare in Sweden (Löfgren et al., 2007; Engblom et al., 2011) and is used to allow time to get healthier and to improve the ability to work. On the other hand, absence because of sickness can lead to negative health effects; work can be therapeutic and an early return to work might be beneficial (Waddell et al., 2007).

One factor that can affect sick leave is the individual’s experience of healthcare encounters. An early review article (Stewart, 1995) indicates that effective physician–patient communication can improve patient health outcomes. However, in healthcare, this is often considered merely a matter of good manners and is not given attention to in the discussion of outcome. Healthcare professionals’ interactions and relations with patients can influence their work ability and their possibilities of returning to work (Svensson et al., 2006; Lynöe et al., 2011). Feeling wronged, with factors such as indifference and disrespect in healthcare encounters, prevents return to work (Wessel et al., 2013). Feeling supported, believed, and listened to can facilitate return to work (Östlund et al., 2001; Müssener et al., 2008).

Therefore, it is important to consider the quality of encounters with healthcare professionals and its impact on the patients’ rehabilitation and return to work. Better knowledge is needed about aspects of the encounters that might be perceived as crucial components to enhance the rehabilitation process. This knowledge could be used to optimise the quality of the encounter between the patient and the primary healthcare professionals and ease the return to work in the sick leave process.

The aim was to explore what sick-listed patients perceive as important in their contact with healthcare professions in primary healthcare and to analyse what they view as crucial components for returning to work.

**Method**

A qualitative approach was chosen, as it is appropriate to use when the aim is to describe and understand human or social events and phenomena.

**Settings and participants**

This study was conducted in Sweden in 2011. All the interviewed individuals were recruited from an earlier intervention study of occupational therapy support for general practitioners in assessing work ability in sick leave cases (to be published). A duration of three months after an encounter with the healthcare centre, a follow-up was conducted through a postal questionnaire including both closed and open-ended questions, on their experiences of their contact with the professionals. In the questionnaire, participants could make a mark and write their name and phone number if they were willing to elaborate their experiences in an additional telephonic interview. During the contact by telephone, a verbal agreement was given to participate and time for an interview was adapted to suit the participant. To get several health centres represented, interviews from both the intervention group, 10 participants, and the control group, 11 participants, were conducted consecutively. As our aim was to find out what the sick-listed patients perceived as important in their contact with healthcare professions in primary healthcare, we did not separate the analysis from the two groups. The informants were strategically selected, aiming for inclusion from different healthcare centres and from both the sexes. With a view to finding informants who could provide rich, informational stories, those who had written about their experiences in the open questions, were selected (Figure 1).

The participants’ sick leave periods were handled by their primary healthcare centre in the smaller region in northern Sweden, representing city, rural, and urban regions. They had met different professionals at the healthcare centre. Some of the participants had only met physicians. Some patients had met a physician and other professionals such as a rehabilitation coordinator, an occupational therapist, a physiotherapist, or a social worker, and some patients, during their appointments, had contact with a team consisting of a physician and rehabilitation staff. Different diagnoses had caused the participants to take sick leave. Patients were from both the public sector and the private sector: one was self-employed and some were unemployed (Table 1).

**Process/data collection**

Data were collected by semi-structured telephonic interviews conducted by the first author (M.S.).

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One interview was conducted face to face, because the participant did not have a telephone of her own. The participants were given the opportunity to choose a suitable time for the interview to be held. The participants were assured that their participation was voluntary and would not affect their contact with their healthcare centre. The interview started with verbal information about the aim of the study, and participants were told that they could withdraw at any time. An interview guide was assembled by the research group, designed to give a deeper understanding of the participants’ experiences of healthcare encounters, with questions covering areas such as: which professions they had met, what happened at the healthcare centre, what was important, what was missing, what support they had received, and what support they would need to facilitate a return to

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work. The questions were open ended to encourage a narrative flow and started with, ‘Can you tell me…? ’ ‘How did you experience…?’ ‘What do you…?’ and so on. Each interview lasted 20–60 min. Of the 21 interviews, 19 were recorded and were transcribed verbatim by the first author (M.S.), and 2 of the interviews could not be recorded owing to technical problems, and therefore notes were taken during and after those 2 interviews.

Data analysis

The transcribed interview text was analysed according to qualitative content analysis, as described by Graneheim and Lundman (2004). This method is useful in analysing written or verbal communication in a systematic way (Krippendorff, 2004) and is a useful way of exploring peoples’ experiences or reflections (Downe-Wamboldt, 1992). To become familiar with and understand the content of the material in context, the recordings were listened to in their entirety, and transcripts and notes were read repeatedly by the first author. After discussion within the research group, sentences and phrases with information relevant to the research topic were identified and sorted into meaning units by the first author. To reduce the text, each meaning unit was condensed, but still included its essence. In a number of meetings in the research group, the findings emerging from the interviews were discussed, and the condensed meaning units were labelled with a code. The codes were interpreted and compared for differences and similarities, and then sorted into categories that corresponded to the meaning of the material, the topic, and the aim. Through further abstractions two themes were formulated that indicated relationships between the categories. Throughout the entire analysis, the categories and the themes were compared with the original transcripts until consensus among the authors was attained. Quotes were identified to clarify and to increase credibility. Finally, a model was formed that describes crucial components of the sick-listed patients’ shared experiences of their contact with professionals in primary healthcare.

Ethics

The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 2010-177-31M).

Results

The analysis revealed two themes that highlight important areas for people on sick leave in their healthcare encounters. The first theme ‘Trust in the relationship’ contains categories describing feelings of participation and of being believed, listened to, and confirmed, and also dedication on the part of healthcare providers. The second theme, ‘Structure and balance’, contains the participants views on factors that can support the return-to-work process (Figure 2).

The themes and the corresponding categories, with descriptive quotations in italics, are presented below.

Trust in the relationship

The theme involves important factors that create trust between the sick-listed patients and the professionals. Healthcare encounters characterised by professionalism, knowledge, continuity, and dedication seem to create trust. The theme contains a mutual trust; the interviewees related that it was necessary that the healthcare professionals show respect and trust in the patient. This was reflected if the sick-listed patients felt believed and listened to, and if they were confirmed and invited to participate in the decisions about sick leave and rehabilitation.

So I would feel more trust in them, if they gave me more of their time and if they listened to me.

(Interviewee 5)

But just this thing, about being heard and believed in, the most fundamental, and if that would not have happened I don’t know how it would have turned out.

(Interviewee 14)

The informants described the importance of being able to easily make a timely appointment and having adequate time in the meeting, which made the sick-listed patients more confident. The informants felt insecure if the healthcare professionals did not have answers for them. Informants who had problems with their medical certificates, or who experienced lack of understanding and of treatment, interpreted this as lack of knowledge by the profession.

They should know how to fill out a certificate – so that it holds.

(Interviewee 7)

The interviewees described the importance of being made to feel welcome and being carefully examined; this could strengthen the feeling of being believed and taken seriously, which supported the trust. Some of the participants described feeling ashamed of their limitations and their inability to work. This was reinforced by the feeling of having to prove their impairments.

I was so incredibly vulnerable; it felt really as if I was being accused.

(Interviewee 18)

Some of the informants expressed that they expected a holistic perspective in healthcare. Those who had met several professionals expressed satisfaction, because that enabled them to convey a whole picture, which seemed to strengthen trust. One participant stated that, because of the team approach, he knew that the healthcare professionals had the information they needed, which could be used to complete the medical certificate. Another participant expressed that teamwork signified collaboration between the different health professions, which gave a shared understanding (ie, she did not have to explain everything to everyone), and therefore the professions were prepared for the encounter.

What I perhaps thought was good was that it was three different persons [physician, social worker, occupational therapist] with three different professions that together got a more comprehensive view of my situation.

(Interviewee 7)

Possibly, if there had been some other solutions with other persons and actors, then this would have gone swifter, so to speak, that I had been listened to.

(Interviewee 19)

A woman who did not have the opportunity to meet with a team described feeling clearly that parts were missing, and she said: I know that different professionals have their own way of mapping their areas of interest.

In the relationship, communication is vital. The informants had experienced mixed messages with contradictory information; for example, a physician conveyed a need for the patient to be on sick leave. One participant narrated that the physician suggested a period of sick leave for the patient; however, after the physician had discussed it her supervisor, she changed her mind and did not want to write a certificate and could not explain why. Some of the participants reported that their physician had considered it medically justified, but expressed doubts on the grounds that the Swedish Social Insurance Agency would not accept the sick leave period.

Then he [the physician] also added that it is very difficult to be sick-listed today, which is the last thing you wish to hear, well, that the Social Insurance Agency will chase you as well.

(Interviewee 19)
One participant recounted that the professionals at his healthcare centre used a strict and clear language, which he appreciated. Positive feedback from the healthcare personnel on patients’ progress in regaining work ability was seen as a supportive factor.

(My physician has been able to tell me that she thinks that I have done a great job; to get this credit also fantastic. (Interviewee 14)

Another participant had experienced that one of the professionals had used inappropriate language and feigned friendship, which she considered as unprofessional and as having a negative effect on trust.

(They should not be too familiar, in a way, at least not when it comes to how and what one says – that I think is really important. (Interviewee 15)

Structure and balance

This theme contains the participants’ descriptions of factors that they considered as supportive for the possibility of returning to work, which can be associated with the process. Some participants requested that the support for rehabilitation and return to work have a clear and visible structure in the process. Participants expressed several needs, such as understanding what will happen, and knowing what to expect, what the next step is, and who is doing what. All participants stated the importance of follow-up and planned appointments, and some participants highlighted their need for feedback on assessments.

(To get back to me with the result of the evaluation, a clear feedback… and also to link this to some kind of plan. (Interviewee 16)

Those who had experienced a clear plan that created an image of the process ahead of regaining work ability expressed their satisfaction and had returned to work. The participants who described feeling they did not have control ended up just waiting; they did not know what they were waiting for, felt left out, and were uncertain how to find the way to return to work.

Then it is good that they get in touch, take hold of one, and ask…. Can we plan something new… THAT is what I want. (Interviewee 8)

In the interviews, it became apparent that the rehabilitation process to recover and regain work ability does not progress by itself. The interviewees wanted to be involved in their rehabilitation process. On the other hand, many of the participants reported that they required support to get the process moving forward. Some of the interviewees had experienced, during their sick leave period, absence of self-propulsion. The participants had found it difficult to arrange appointments with the healthcare professionals. Some participants were very satisfied that those appointments were arranged by someone from the healthcare staff, but there were also participants who were expected to arrange the appointments for themselves, which was not easy, and because of their lack of initiative, this procedure took considerable time.

Some participants had experienced expectations from the physician that the patient should arrange meetings with the employer and ask for work solutions that would facilitate return to work. Several participants described how, being on sick leave, it is difficult to have a discussion with the employer and make demands in/at the workplace. The informants’ contact with their employers varied a lot: some had employers who were very supportive, whereas others felt completely invisible to their employers. One of the informants expressed that the professionals at the healthcare centre need to be aware that the patient has gathered his or her last strength to manage an encounter with the healthcare service, and that the impact of the disease results in lack of strength and energy. Among the interviewees there were those who found it difficult to arrange workplace training or find a job that was more suitable to their limitations. Some participants had received assistance from personnel at the healthcare centre with their contacts with the national insurance agency or with their employer, which they perceived as supportive for their rehabilitation; others had experienced lack of cooperation between authorities.

What I feel disappointed about is that I end up in between the healthcare and the National

Insurance Agency, and I have to be some kind of person who mediate between these two.

(Interviewee 7)

The participants described the sick leave period as an opportunity for rest and recovery. During the sick leave they also had to regain their ability to work, and it often required training and activity to increase their capacity. Many participants stated that sick leave in itself can result in inactivity, and therefore they requested support in ways to become active or to exercise.

According to the interviewees, patients on sick leave may need assistance to find balance in their everyday activities, including balance between rest and the level of activity, and support to sort between different kinds of activities.

Be in charge, in some way – now we will do this. And then it is that, and the hard thing is to, somehow, not just leave people at home to sit and watch movies all day.

(Interviewee 18)

Furthermore the participants expressed that it could be beneficial, in the return-to-work process, to get support in balancing demands at work and time available.

I need help, I need structure, and then to start slowly. I have tried on my own, but I’ve not managed.

(Interviewee 7)

No clear patterns could be identified between participants’ experiences related to the healthcare centres, including if they were in the intervention or in the control group. There was also no pattern found in terms of age, sex, employment, diagnosis, or length of sick leave in relation to the participants’ experiences.

Discussion

The novelty of this study is the clarification of the patients’ need of structure in their sick leave process. The healthcare professionals should have an articulated plan that allows the patient to understand what is expected and what will happen, which can show the pathway back to work. The findings also indicate that some patients may need support to move forward in their process of returning to work. Furthermore, additional support can help the patient to achieve occupational balance in the efforts to promote return to work.

Traditionally, encounters in healthcare are characterised by asymmetrical power relations between the healthcare worker and the patient (Edlund, 2001). This study on sick-listed patients’ experiences with encounters in primary healthcare illuminates the importance of trust in the relationship between the patient and the healthcare personnel. These findings of our study agree with previous research. In 2001, Östlund et al. wrote about supportive relationships in the rehabilitation process. They found that to be ‘trusted’ and to be ‘listened to’ were two supportive qualities in encounters with rehabilitation agents. More studies (Klanghed et al., 2004; Müssener et al., 2008; Lynöe et al., 2011) confirm that positive encounters with professionals in the rehabilitation process are characterised by supportive action and respectfulness. Despite this knowledge, there is very little discussion in clinical work how the encounters in healthcare can affect the patient’s return-to-work process. Translating research into practice is difficult, and it often takes a very long time (Fixsen et al., 2005). Awareness of the problem and system readiness are significant for accomplishing changes in work practices (Greenhalgh et al., 2004; Guldbrandsson, 2007). Implementation of evidence-based practice requires organisational support, and the environmental context in healthcare has to be taken into account (Solberg, 2000; Halladay and Bero, 2000). Healthcare professionals interacting with sick-listed patients have an impact on patients’ ability to return to work (Lynöe et al., 2011). This requires that more attention must be paid to the organisation of the primary healthcare providers’ need for support to take this knowledge into account.

Mutual trust in healthcare encounters

The findings of this study make it important to stress that the patients’ trust in healthcare staff and the patients’ feelings of being trusted can promote the process of returning to work. Trust is a fundamental dimension in the healthcare system and therefore warrants serious consideration (Meyer et al., 2008; Slettebø et al., 2012). The results show that the area of competence is particularly vital to trust, and shortage of information in
the medical certificate may be perceived as a lack of knowledge and damaging to the trust. Proximity and continuity create better conditions for trust (Mainous et al., 2001). If the patients do not trust the medical assessment and treatment, they tend to continue to consult the healthcare service for new or other answers. The sense of trust in the healthcare personnel can affect the patient’s adherence to recommended interventions (Safran et al., 1998; Martin et al., 2005; Levesque et al., 2012). Adherence is defined as the extent to which a person’s behaviour corresponds with agreed recommendations from a healthcare provider (World Health Organization, 2003). This is of crucial importance to recover and regain the ability to work and then to return to work. The patients who felt that they were not listened to and not believed focused on continuing to prove their disability, and this limited the focus on how to re-enter work, whereas those who experienced that they were believed, confirmed, and involved felt supported in their rehabilitation process. Trust can form a power relation between personnel and the patient that can be beneficial to getting things done; however, it can also be a risk, as trusting someone makes one vulnerable (Grimen, 2009). The relationship between healthcare professionals and patients must be based on mutual trust (Nordin et al., 2013).

In a study by Müssener et al. (2008), informants reported that, if the professionals departed from their role as experts and were ‘involved in a more personal way’, it ‘seemed to enhance a feeling of being encouraged’. Having a personal relationship has been found supportive in a confidence-inspiring alliance between patients and health professionals (Nordin et al., 2013). Our study shows that there may be different attitudes to and experiences of what is perceived as professional and what is perceived as personal. An increasing personal approach from the staff side seemed to disrupt the respondents’ trust for the personnel in our study.

When the patient visits the healthcare centre in the course of sick leave, he or she is experiencing problems with health conditions that can affect the ability to work. The patients’ work conditions and context of their lives is crucial to the impact their illness has on their ability to work (Ilmarinen, 2009). This knowledge indicates a biopsychosocial approach for understanding hindrance and the potential of rehabilitation and returning to work. The framework in the International Classification of Functioning, Disability and Health (ICF) is based on a biopsychosocial model. Healthcare professionals’ use of the different components in the ICF may contribute to a more informative description of limitations on the patients’ ability to work (Stigmar et al., 2013). Some of the participants in our study expressed satisfaction with, or a need for, a more holistic methodology in the healthcare encounters. Those who had met with several health professionals also reported positive experiences. Nordin et al. (2013) found that contact with several health professionals favoured the patients’ participation in rehabilitation programmes. With regard to reducing long-term sickness absence, reports of intervention studies with multidisciplinary approaches show more positive results in terms of effectiveness and cost-effectiveness than studies of single-modality interventions (Gabbay et al., 2011). The feeling of being thoroughly assessed and receiving enough time–space seems to strengthen trust. Previous studies have indicated that other healthcare professionals such as physiotherapists or occupational therapists also have knowledge that can supply the assessments that describe the extent and limitations of the person’s ability to work (Stigmar et al., 2013; Sturesson et al., 2013).

Structured process: a support for return to work

An individual’s rehabilitation process during the sick leave period requires planning and progress. The sick leave period has to advance and lead to regaining work ability. Some of the participants had experienced that healthcare personnel supported them to proceed in the process. Some felt that they were expected to arrange and coordinate the planning by themselves, whereas most of them ended up just waiting for something to happen.

Many of the participants described the consequences of their disease as a lack of energy and the capacity to act, to not be able to act as the project manager for ‘project rehabilitation’. This makes it difficult to move the rehabilitation process forward with all it implies: the need to keep in contact with several different professionals in healthcare, to keep in contact with the employer, and to keep in contact with the national insurance agency. The requirement of cognitive ability to maintain contact with authorities and to fill in

forms to get compensation can become paradoxical, if the individual is on sick leave for an illness that comprises cognitive impairment. One of the main findings in MacEachen’s et al.’s review (2006) was that the complexity of the return-to-work process, with different actors, may be facilitated by an intermediary player who can coordinate communication and planning. Placing responsibility for the process on the sick-listed person, who has neither the strength nor the knowledge to navigate the system, whereas the different central actors remain passive, can promote procedural injustice (Ståhl et al., 2012). The return-to-work process involves the employer, the healthcare system, and the national insurance system, and these systems have different foci, which can be confusing for the patient (Andersen et al., 2012). Lack of understanding of the process limits the possibilities for the patient to act. The patient’s ability to determine and verify his or her situation is usually called empowerment. A structured process may facilitate the patient’s empowerment and ability to take control over the return-to-work process. The empowerment process as support for return-to-work benefits from an interactive approach (Larsson, 2007). The results show the importance of the patient of being involved, but we cannot expect all the patients to be able to coordinate, make plans, and advance in their return-to-work process without support.

Balance and imbalance

Sick leave is occasioned by a reduction in work ability because of disease, and the work activities are limited. Patients on sick leave may also experience a loss of control over their daily activities, such as self-care and/or recreational activities (Holmgren and Dahlin Ivanoff, 2004), and a mismatch between the various activities and rest, which causes an occupational imbalance. Occupational balance is a concept often used in occupational therapy (Townsend and Polatajko, 2007), and it deals with the right amount and the right variation between occupations (Wagman et al., 2012). Wagman et al. (2012) identified three perspectives of occupational balance in relation to: occupational areas, occupations with different characteristics, and time use. ‘Occupation’ means the activities a person undertakes with some consistency and regularity. These activities could include the basics such as self-care, including rest, or productivity, such as going to work, or carrying on with leisure activities (Townsend and Polatajko, 2007). The results in this study indicate the importance of both support for occupational balance and balance in the support. Well-balanced demands from the professionals can be beneficial for the patient in their rehabilitation process (Müssener et al., 2008).

Methodological considerations

This exploratory study’s strengths are that it contains sick-listed persons’ narratives from eight different healthcare centres and includes participants with different kinds of health problems and from various work sectors. The first author conducted the interviews and transcribed all of them, which resulted in an intimate knowledge of the material’s content.

More women (70%) than men participated in the study. Among those on sick leave in Sweden, two-thirds are women, and of those who consented to the interview through the questionnaire, 71% were also female. It is notable that almost half of the participants had university education, though more sick leaves are started per worker in jobs requiring shorter education than in jobs that require longer education (The Swedish Social Insurance Agency, 2012). That educational level of the participants can have an impact on studies is known from earlier studies (Novo et al., 1999; Kho et al., 2009). Among those who were available for interviews 37% had a university degree, and the selection criterion of choosing those who had responded to the questionnaire’s open questions might have contributed to including more participants with more education. All of the participants were fluent in oral Swedish. The participants were not asked to provide demographic data related to their ethnicity or country of birth, and therefore it is not possible to describe ethical aspects of their experiences in more detail. This may have been a weakness as ethnic aspects can effect power relations, patients’ and professionals’ attitudes, values, and approach to sickness absence (Swedish Council on Technology Assessment in Health Care, 2003; Müssener et al., 2008). Further studies must be conducted to determine the impact of ethnicity in sick-listed patients’ experiences of healthcare encounters.

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This study used a retrospective recall approach and the participants had to recall their experience of the healthcare encounters. There might be a risk for memory bias; however, on the other hand, some of the participants at the time of the interviews had had recent appointments, and there was no participant who had not been in contact with the healthcare centre in the last four months.

Another limitation might be that the interviews were conducted by telephone and the participation might therefore have felt impersonal. On the other hand, it could have created a feeling of being listened to but not exposed and made it easier to speak freely.

To increase trustworthiness of the findings, we used investigator triangulation. Three of the researchers are occupational therapists (M.S., A.H.F., B.B.) with different backgrounds and experiences, and one is a public health researcher (C.E.). Our background and pre-understanding was important in formulating the right questions, but also influenced the interpretive process. Data analysis followed a structured, analytical process and was performed in an interactive process where the first author ensured credibility by repeatedly discussing with the research group. To increase the trustworthiness, two interviews were coded and discussed in a group of researchers and Ph.D. students participating in a qualitative research course. Transferability is indicated by similar findings in other studies focusing on encounters between sick-listed persons and healthcare personnel (Östlund et al., 2001; Klanghed et al., 2004; Müssener et al., 2008; Nordin et al., 2013).

Conclusion

The healthcare encounters must be built on mutual trust. Persons on sick leave need predictability and a feeling of control in their return-to-work process. For the patients to move forward in their rehabilitation, the healthcare professionals must provide individual support of the structure and occupational balance. This study emphasises that more attention has to be paid to the healthcare professionals’ interaction with patients. It is also important that the organisation of the primary healthcare supports the implication of this knowledge to reach an optimal outcome.

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