How to avoid long-term sickness absence: the advice from women with personal experience

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**Objective.** The aim of this study was to describe women's perceptions of what can be done to avoid extended sickness absence with following suffering and passivity.

**Methods.** Qualitative interviews were conducted with 82 women who had been on sickness absence (60 days or more) or were receiving disability pensions. The data were analysed using phenomenological methods.

**Results.** To be able to get back to work was found to be equivalent to breaking away from the prospect of isolation and loneliness. To support this, four parties were identified along with suggestions for their actions: the healthcare professionals, the woman who is on sick leave herself, the employer, and the social insurance official. Most interestingly, the family and close relatives were almost not mentioned at all. The results are connected to a theoretical model of distress in terms of enduring and suffering.

**Conclusions.** It is necessary to look more carefully at how women on sickness absence use the resources in the world (like their families) to get well. More generally, the task is to understand why society deals insufficiently with women who need time off and cannot keep up with their duties because of illness.

**Keywords.** Prevention, qualitative method, rehabilitation, sickness absence, women's health.

Introduction

As a central part of their professions, primary care practitioners have to understand and be able to manage people in distress. Sick-listing and rehabilitation are procedures that predominantly involve distressed individuals. Women are reported to be more on sick leave than men, both according to frequency and number of days.1 The most common diagnoses given as reasons for women's sickness absence are musculoskeletal disorders and psychiatric diseases.2,3 However, there is today a large body of evidence from research that indicates that sickness absence is a complex phenomenon. Besides illness, sickness absence has been found to be associated with a wide range of factors, including individuals' attitudes towards the design of the sickness insurance system.5 A fact that often has been neglected is that the personal devastation from disease does not come only from bodily dysfunction but also from the realization of its consequences. A woman on sick leave suffers when she realises that the illness has influence on not only important parts of her body functions, but also means links to others and the external social world are lost. Sickness absence can thereby by itself add additional suffering to women with long-term illness, e.g. as a vicious circle of pain and indifference.6

Morse and Carter have proposed a theoretical model of distress in terms of suffering and enduring,7 which in the model are introduced as distinct concepts describing the subjective experiences during different stages in a disease process. Enduring is described as a reaction to an overwhelming life-situation when the individual has no choice but keeps going and gets through the situation. This state is characterized by absence of emotions, maintained control, and strong focus on the present. When the individual is strong enough, i.e. has sufficient energy and resources to risk being overwhelmed by the distress of suffering, she starts to acknowledge the phenomenon that has been endured and realises the consequences it will have on her self and her future life. This state of suffering is characterized by strong emotions, a preoccupation with what has been lost, how life used to be and what the future will bring. She becomes fully aware of the extent of change brought by illness: facing and coming to term with the
impact of hurt and loss. The individual moves back and fourth between the state of endurance and suffering until she has “suffered enough” and accepted the past as being an integrated part of her future. With this acceptance, she will find herself to be a different person than before (a reformulated self) with new perspectives and values, and from there she will be able to move on. Over time she will rejoin life, diminishing the impact from illness and making a place for a changed self.

Little is known about the thoughts and wishes women on long-term sick leave have themselves about possibilities to support them in their distress. Knowledge in this area is important for primary care practitioners in order to help them prevent a further expansion of female sickness absence. The specific aim of this study is to describe women’s on sickness absence own perceptions of whom the important supportive actors in her environment are and what different actions these actors can do to help avoid the vicious circles leading to unnecessary suffering, passivity, and lasting sickness absence.

Methods

Subjects
A random sample of 100 women in the age group 30–49 years who had been on long-term sick leave during 1994 were invited to participate. They were selected based on their sickness insurance status in 1994. They lived in two semi-rural municipalities in the county of Östergötland, Sweden. There was no selection by symptoms or diagnoses. Long-term sickness absence was defined, for this study, as absence from work due to sickness for 60 days or more or receiving a disability pension. From this group, there was an initial dropout of 18 women. At the time of selection (1994), the women had a mean age of 42 years (range 30–49 years). At the time of the interviews (1996), 84% were married or cohabiting, 8% were divorced or separated, 4% were single, and 4% were widows. The main self-reported diagnoses stated as the cause of their absence from work were musculoskeletal disorders leading to chronic pain (60%) and psychiatric disorders (16%), principally depression.

The majority had little education, e.g. 47% had only elementary school education. At the time of the interviews, 40% worked at least part-time (11/33 of these women worked full-time), whereas 59% received some kind of sickness benefit. The remaining women were unemployed, studying, or worked at home taking care of children. 70% of the women’s husbands or cohabitants were in full-time employment.

Collection of data
The data collection was conducted in 1995–1996 by two social workers at the Social Medicine Clinic, Linköping University Hospital, Sweden. A letter was sent out to the study group. In the letter, the intention of the study was presented. A few days afterwards, the women were contacted by telephone. The data collection, comprising a questionnaire and the interviews analysed in this study, took place at the Social Medicine Clinic. Only in exceptional cases, such as for medical reasons, did the meeting take place at the local primary care centre. The women were reimbursed for their costs in connection with participation in the study.

The interviews were semi-structured and consisted of six open-ended questions about the women’s thoughts regarding sickness absence in general and their own experience of being on sick-leave. The women themselves decided what topics were relevant when answering the broad questions.

Analysis
The interviews were audiotaped and transcribed. Phenomenological methods were used for the analyses. We wanted to explore the women’s own thoughts and explanations: the unreflected life-world.

All parts of the interviews where the women talked about their needs and wants of instrumental and emotional support during sickness absence and what determinants made the absence last were included in this analysis. The material was first analysed by two researchers with different backgrounds: a sociologist and a physician. This first phase of the analysis was focussed on identifying the perceived needs for support. Having two different interpretations for the same interviews helped control subjectivity in analysis and interpretations and to ensure confirmability. Data were examined to identify themes, explore categories, and develop concepts in order to make sense of the data. The results from the two different researchers’ analyses were then compared and discussed. Finally, a second order of analysis was performed together with a third researcher, a medical anthropologist, to clearly define and validate the paper’s argument. This phase focussed on integrating the results on concrete advice regarding support structure and actions into a coherent small-scale theory.

The presentation of the results here is complemented by quotations from the interviews. The purpose is to give the reader an understanding of how the results are drawn from the data and analysis. The numbers indicate from what interviews the quotations have been drawn.

Results
In terms of support structure, four important actors were identified: healthcare professionals, the employer, social insurance officials, and the woman on sick leave herself. But equally interesting was that family and relatives were in the present data only occasionally mentioned. Regarding supportive actions, it was found to be important that the woman receives psychological and social support, i.e. that everyone in the woman’s surroundings express a conviction that the woman will return to work.
“That everyone takes you seriously. Both the employer, the physician, and people around you.” (11)
“...inside then it is crucial that you have someone who supports you. And that you have a safe surrounding that can help you back again.” (2)

To further enhance enduring, more co-ordination between the supportive actors in the women’s environment was asked for. Meanwhile, it was also important that the woman herself be in charge and decide what the rehabilitation would consist of.

“Collaboration between the different authorities, and the one who is sick of course, ... that they listen to the one who is sick and what it is she wants and what she believes and that they try to make things as easy as possible. Be flexible and think of different solutions. Try and examine.” (23)

“It is me who should decide myself what I want to do! No one else should do that. Especially not the employer!” (21)

According to the women, time was the single most important threat against enduring during the sickness. The women were clear that all problems leading to work incapacity should be dealt with immediately.

The scenario leading to the most suffering was if the sickness absence would lead to a situation where the woman is left alone and forgotten. To avoid suffering and passivity was thus necessary to break away from isolation and loneliness.

“I think it is important to not get isolated at home ... not to get isolated and abandoned at home. You have to have contacts with life outside home. And how that should be avoided, that I do not know, but you should not be left alone at home.” (55)

“The important thing is to not be forgotten. It is what often happens. You stay at home and get depressed. No one calls you from work and asks you how you are doing. You just go there. You just go to your physiotherapy and somewhere to talk and ... then you go home and you just stay there.” (53)

A summary of the practical advice to reach recovery and avoid sickness absence provided by the women is presented in Box 1.

**Discussion**

**The determining parties**

The aim of this study was to describe the advice women, with personal experience of the situation, can offer about what can be done to avoid extended sickness absence with following suffer and passivity. Four actors were identified along with suggestions for what they could do to protect the woman from negative effects of sickness absence. None of these actors included the family or the closest relatives, even though these social institutions have long been reported to be the most important mediators of support and help for women in situations of distress. Also the family contract, that is, the division of labour and responsibilities between men and women in the family setting, has in previous studies been presented as a significant factor in the outcome of rehabilitation.14

There are at least five possible explanations why these women did not report their families to be important:

The women did not relate their illness and incapacity to work to circumstances at home. The links made in the literature between women, work, family and rehabilitation may be different than has been assumed in earlier research.

The women did not see any possibility to change the circumstances at home.

The family was considered to be the private sphere where they did not want anyone else to bother.

It was considered more socially correct to attribute their illness and incapacity to work to circumstances at the workplace.

The involvement of their families was found so self-evident that the women did not bother to mention it in the interviews.

The present data do not allow us to discriminate between these explanations, but suggest that more careful investigations are warranted in future research of how women in rehabilitation programs use the resources in the world (like their families) to get well.

The women reported too that there needs to be more co-operation between the different actors involved in

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**Box 1** Summary of the practical advice women with own experience provided on how to deal with long-term sickness absence

**Advice to healthcare professionals, the employer and social security officials regarding sick-listed women:**

Everyone she meets should be positive about the possibilities the woman on long term sick leave has with regard to a return to work.

All practitioners the woman gets in touch with should take what she says seriously.

Health care providers should furnish the women with immediate rehabilitation.

The woman should meet a co-ordinated health care and social insurance team during the rehabilitation process. Efforts should be taken from all actors to help the woman to remain in control.

**Advice for the women themselves:**

The woman should find someone to talk to about her situation.

The woman should take actions necessary to avoid losing social contacts when she is ill, especially concerning the workplace.
the process of sickness absence for them to recover. The role co-operation, informal and formal, between different welfare state agencies plays in rehabilitation has not received the attention it deserves, neither from researchers nor policy makers. For instance, the women in this study seldom mentioned the social insurance office that formally had the responsibility for co-ordinating their rehabilitation. In a study of social insurance officials, these officials were found to be ambivalent to their co-ordination tasks and insecure in the meeting with clients.  

This may be one reason why the women in our study seldom mentioned them as resources in the rehabilitation process. They simply did not know what type of support to expect from them.

**To suffer and lose control**

From healthcare practitioners, employers, and social security officials, the women mainly asked for more sympathy and personal commitment. A recent study has shown that identification of a low sense of coherence (interconnection between life goals and daily activities) by psychological tests can predict sickness absence in women.  

Similarly, tests showing a low internal locus of health control (influence over own health) have been found to be associated with a lower probability to return to work after a long period of sickness absence.  

Furthermore, interview studies have indicated that women who are on long term sick leave often report a feeling of being supervised by those involved in the process of sick-listing and rehabilitation.  

Those results can be seen as consistent with the findings that report these women have both a low sense of coherence and internal health locus of control. Thus, there seems to be that the structure and process of sick-listing and rehabilitation failed to deliver sympathy and personal commitment, but instead reinforced a low sense of coherence and low internal health locus of control among women on long-term sickness absence. The paradox here is that policies for sickness insurance aim at counteracting passivity and providing the individual the possibility of gaining a substantial responsibility for and influence over the rehabilitation process.  

However, healthcare practitioners and those in the rehabilitation community apparently have not successfully adopted these policies.

An alternative explanation for the apparent frailty of these women is that during the state of suffering, emotions are expressed and the control over the situation seems to be lost. But only when the woman shows her suffering it is possible for others to comfort and help her. In this situation, the women in the study noted that their employers, health-care workers or social insurance officials have not taken them seriously. Instead of getting relief they also start to suffer from the fear of being left alone, misunderstood and forgotten. Efforts should be taken to inform people in their surroundings to act on signs of suffering in order to help these women remain in control of their life situation.

**About the study and future research**

There was a small group of women who could not express any ideas or did not think anything could be done about their health status. This way of perceiving health has been documented before. Not everyone has the ability to put her perceptions into words. But non-responsiveness can also be interpreted as a state of endurance, when all her energy is needed just to keep ordinary life going. Moreover, the present data, collected in 1996, only reports experience from Sweden. Since then, many efforts have been made at national, regional and international levels to solve the problem of increasing sickness absence costs and to avoid the personal suffering those results. Interestingly, the layperson suggestions regarding long-term sickness observed in this study are in line with more recently reported recommendations from national expert commissions. What is striking is that here too little attention is paid to the patient’s family as a rehabilitation resource or even as a factor to include in analyses and program planning.

The commission results also illustrate the human consequences of sickness absence. For example, they report too female enduring, with regard to the support women receive and the commitments they feel that they have to other at home and in the workplace. While legislative change may help improve the situation of women like these, there are other issues that both the policy and research community needs to take into account.

Long-term sickness absence can be seen as a gender issue and it is this aspect of the problem that has not received the attention it should. To start, we have to look more carefully than we have at how women on sickness absence use the resources in the world (like their families) to get well. More generally, the task is to understand why society deals insufficiently with women who need time off and cannot keep up with their duties because of illness.

**Declaration**

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Conflicts of interest: none.

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