



ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: https://www.tandfonline.com/loi/idre20

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To cite this article: Isa Moldvik, Christian Ståhl & Ulrika Müssener (2020): Work ethics and societal norms influence sick leave and return to work: tales of transformation, Disability and Rehabilitation, DOI: 10.1080/09638288.2020.1728398

To link to this article: https://doi.org/10.1080/09638288.2020.1728398

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Published online: 23 Feb 2020.

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Work ethics and societal norms influence sick leave and return to work: tales of transformation

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ABSTRACT

Purpose: This study's purpose was to explore how people on sick leave manage societal norms and values related to work, and how these influence their perspectives of themselves throughout the rehabilitation process.

Materials and methods: This was a longitudinal interview study with a narrative approach, comprising 38 interviews with 11 individuals on long-term sick leave. Data collection was conducted in two phases and analysed iteratively through content analysis.

Results: The results suggest that work ethics and societal norms influence individuals' views of themselves and the sick leave and rehabilitation process. Conforming one's personal values to the work norm can create internal conflicts and cause feelings of shame for not being able to live up to the established norm. The strong work norm may create unrealistic expectations, which in some cases may result in constraining the return to work process.

Conclusion: To transform a sick leave narrative into a positive one, societal norms and their influence on identity needs to be recognised. Stakeholders involved in the process can contribute to a positive transformation by not only supporting return to work, but also to acknowledge and help people manage their self-image as having a disability that limits their ability to work.

- ► IMPLICATIONS FOR REHABILITATION
- Stakeholders involved in the sick leave and rehabilitation process need to support sick listed individuals by acknowledging and helping people manage their self-image.
- Full RTW is not always the best option from a quality of life and wellbeing perspective.
- Treatment and support from stakeholders should be viewed as meaningful and legitimate, even if it does not lead to RTW.

Introduction

The evidence of the positive association between work, health and wellbeing has been gathering for decades, and suggests that being involved in paid work offers meaning to life in terms of social contribution, social recognition, self-fulfilment as well as fulfilling basic needs such as housing and food [1,2]. Sage [1] challenges this view by claiming that it is not the absence of work per se that causes the decline in wellbeing when a person is not working, but rather the loss of identity, respect and status associated with work in today's society. From this perspective, positive associations between wellbeing and work is explained by social status, contributions to society and the self-worth that work provides. This is maintained through the ideal of work ethic, where working is seen as the moral way of life and for many represents a central part of one's identity. Identity can be described as the meaning that defines who one is when they take on a certain role in society, belongs to a certain group or claims certain aspects of one's personality to define him/her as a unique person. Individuals have meaning that they apply to themselves when occupying a role such as that of a worker [3]. Korhonen and Komulainen [4] suggests that individuals on sick leave seek to restore a morally worthy identity as the society assumes that an individual on sick leave does not fulfil the social obligations of paid work. Not living up to the morally worthy identity can cause feelings of inadequacy, shame and stigmatisation. Considering this, it is relevant to investigate how people on sick leave manage societal norms and values related to work, and how this influences the sick leave and rehabilitation process.

Over the last decades a shift has occurred in return to work (RTW) research, from a biomedical model to biopsychosocial model, which recognises that other factors, regardless of the injury/illness, can influence RTW [5]. Among these factors are age, sex, socioeconomic status, work demands, RTW-coordination and multidisciplinary interventions [6]. The interactions with the stake-holders involved in the process, such as the health care system and case managers at the Social Insurance Agency (SIA) have also been suggested as important influences in the RTW process [7–9]. The literature on RTW is extensive and has investigated the issue from different perspectives, for example interventions to facilitate RTW, factors that promote and hinder RTW and the importance of

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ARTICLE HISTORY

Received 5 August 2019 Revised 7 February 2020 Accepted 7 February 2020

KEYWORDS

Sick leave; return to work; work ethic; societal norms; narrative; experiences

social interactions. Long-term sickness absence has been seen to decrease the likelihood of RTW [10]. To prevent prolonged sickness absence early RTW is promoted and several countries have developed policies to support return before being fully recovered [11]. It has been suggested that early RTW is effective in terms of reducing sick leave duration and the cost associated with it [12,13]. Different types of interventions for RTW have been developed, such as changes in the work environment-, equipment- and organisation [14] and psychological interventions [15]. Though they all share the common goal of improving RTW, the effectiveness of these interventions varies [10,14,15], and what is considered to be successful RTW is dependent on the involved parties' interests [12]. The main focus has been on reducing sick leave, while the impact on individuals' wellbeing and quality of life is often unclear [16,17]. Focusing on how norms influence the RTW process and how individuals and other stakeholders relates to such norms are less commonly explored, which is the focus of the present study.

Aim

This study aims to explore how people on sick leave manage societal norms and values related to work, and how these influence their perspectives of themselves throughout the rehabilitation process.

A narrative approach

This study used a narrative approach, which can be integrated in the research process at various points, or throughout the process as a whole [18]. It can be used as a theoretical framework, and as a method for data collection or analysis. Narrative theory allows researchers to approach the subjective aspects of human experiences in general, and especially regarding experiences of illness [19]. According to Frank [20] in order for the individual to understand and make sense of the illness situation, they need to recreate the events and actions through storytelling. Self-stories unify identities to the individual's life by gathering previous actions to a meaningful story. The narrative form contains several dimensions of past actions such as feelings, thoughts, values as well as actual events; hence, in order to understand a person's identity there has to be knowledge about their self-stories [19]. Ezzy [21] argues that narratives both reflect on previous experiences and shape actions in the future. As the name suggests, core-narratives can be described as the core of the story, the overall feeling and meaning of what the narrative conveys. Core-narratives offer the opportunity to account for events, as well as give shape to the narratives in terms how it feels and how it relates to oneself and others [22]. Core-narratives have by some been identified as genres that characterise the narrative. The genres are divided into categories such as heroic and tragic narratives [19,23,24]. Ezzy [23,24] uses these categories when investigating experiences of job loss and unemployment where the heroic narrative is characterised by a positive experience, where there is little or no doubt in oneself regarding the possibilities of obtaining one's desired future. The heroic individual is in control of the situation and has a clear image of how he/she actually is. A tragic narrative on the other hand is characterised by the discrepancy of where a person is and their desired future. The events are described as negative, with a lack of control over the situation and the fate of the individual is put it in the hands of others.

In his study of individual experiences with rheumatoid arthritis, Bury [25] suggests that illness, and especially chronic illness, can be seen as a disruptive event, where the structure of everyday life is disturbed and the individual is forced to alter behaviours and/ or assumption, both regarding oneself and their surroundings. To deal with the disruption the individual needs to cope with the effects of the illness and mobilise personal resources [25]. Coping is seen as a cognitive process where the individual learns how to tolerate the effects of the illness, whereas strategy is what the individual actually does to mobilise the resources [26]. Bury [25] suggests that a supportive social network can make a considerable difference in the course and management of illness. In the present study core narratives of sick listed individuals are theorised to have similar characteristics as of narratives of job loss and will be analysed in the term of heroic and tragic narratives. The concept of illness as a disruptive event can be applied to the sick leave process, where the underlying reasons for getting sick-listed can be viewed as a disruption, but also the sick leave itself. Although the cause of the sick leave does not necessarily need to be life-altering, the sick leave may be a factor that forces the individual to change their view of themselves, their work and/or their behaviour. In the Swedish system, where this study took place, various stakeholders are involved, such as physicians or other health care specialists, case managers from the Social Insurance Agency (SIA) and employers, as well as a more personal social networks, including relatives and loved ones. Both professionals and family and friends can be considered as part of individuals' social network.

Materials and methods

This study is a longitudinal qualitative interview study with a narrative approach. Semi-structured interviews were conducted with 11 individuals on long-term sick leave. Semi-structured interviews allow a certain flexibility and the opportunity to explore interesting topics that might occur during the interview, while still providing predetermined areas to investigate [27]. Conducting multiple interviews on different occasions with the same participants offers an opportunity to follow the process and explore changes over time. Serial interviews have been suggested to increase depth in interviews and develop the researcher-respondent relationship [28]. Participants were recruited by a combination of purposeful sampling and snowball sampling [27]. Adults aged between 18 and 65 years who had been on sick leave for at least 28 days (which were considered to be long-term sick leave), and who were able to communicate in Swedish were included in the study. The research took place in Östergötland, a county located in southeast of Sweden that comprises of 13 municipalities which differ in financial and educational level, both within and between different municipalities. Health care professionals and employers from the east, west and central part of the county were contacted and asked to identify participants on sick leave, among their patients and employees. This approach generated only a small number of participants, mainly because high workload of the health care professionals and employers did not allow identifying potential participants for the study to be a priority. As a consequence, contacts from the research group's professional network was used in order to find health care professionals and employers that could identify participants. The managers and the health care professionals were informed about the study, and in turn they informed possible participants about the study and provided individuals with contact details of the researcher. This approach entailed a limited control of how the professionals managed the request, including whether or not they actually approached participants, and if so, how many.

Table 1. Participants' characteristics, reasons for sick leave and changes in their 'narrative continuum'.

Participant	Sex	Age	Occupation	Reason for sick leave	Continuum
Harry	Male	45	Assembly manager	Stress-related symptoms	Tragic → Heroic
Patti	Female	57	Assistant nurse	Fibromyalgia	Tragic •
Anna	Female	59	Home health aide	Shoulder impingement	$\begin{array}{l} {\sf Tragic} \to \\ {\sf Heroic} \end{array}$
Peter	Male	35	Cinema worker	Knee injury	Heroic •
Mary	Female	60	Assistant nurse	Knee operation	Heroic •
Sandra	Female	49	Pre-school teacher/qualified researcher	Burnout	Tragic \rightarrow Heroic
Nina	Female	28	Social worker	Severe headache	Heroic \rightarrow
Sarah	Female	37	Assistant nurse	Hand operation	Passive ↔ Tragic
Joan	Female	35	Disability carer	Unknown	Tragic ↔
Emma	Female	42	Economist	Burnout	Tragic → Heroic
Daniel	Male	26	Farm worker	Broken ribs	Tragic ↔ Passive

The arrows show the directions of the transformation of the narrative. The dot symbolises a stable continuum. Passive relates to a narrative that can be found in the middle of the scale, being neither tragic nor heroic.

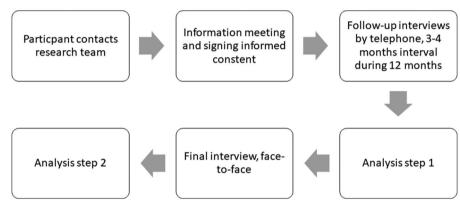


Figure 1. Flow chart over data collection.

The reasons for being on sick leave as well as length of the sick leave varied between the individuals, see Table 1. A meeting was set up between interested participants and a researcher from the research group, in which participants received both written and verbal information about the study. All interested participants were included in the study.

Data collection

The data collection was carried out in two phases, see Figure 1. The first phase was conducted January 2017 – October 2018, where semi-structured interviews were conducted by telephone every 3–4 months. An interview guide was used, which focused on individuals' contact with the various stakeholders involved in the process. The interviews ranged from 15 min to 47 min. All participants were followed over a 12-month period, and the number of interviews ranged from 2–4. In cases were only two interviews were conducted, it was due to difficulties in finding a suitable time for a follow-up. The first author conducted a majority of the telephone interviews, while some were conducted by other members of the research team.

After the first phase, a preliminary analysis was carried out to develop a new interview guide for the second phase of data collection. The second phase consisted of final face-to-face interviews, which were all conducted by the first author, at a location chosen by each participant, during December 2018. These interviews were also semi-structured, and the interview guide focused on aspects related to transformations in identity, abilities and values. The interviews ranged from 51 min to 2 h and 16 min. All 38 interviews were recorded with a digital voice recorder and transcribed verbatim by a professional transcription company.

Analysis

The analysis was conducted in two phases. The telephone interviews were analysed by gualitative content analysis, focusing on both manifest and latent content [29]. An inductive approach as described by Graneheim and Lundman [30] was used to identify areas that needed further exploration in the second phase of data collection. The analysis was performed in multiple steps. First, the interviews were read through several times to get an understanding of the whole interview. Second, meaning units were identified and extracted from the text and then condensed. The condensed meaning units were labelled with a code. The codes were compared to each other in terms of differences and similarities and divided into categories, and sub-categories when needed. The categories were reviewed and discussed among all authors and resulted in a focus on the process of the sick leave and rehabilitation, individual characteristics and aspects of responsibility. Thereafter, the material was reviewed to identify areas that needed further exploration in the final interviews. The purpose of the first analysis was to inform the second phase of data collection, and was used to develop the interview guide for the next phase. This procedure also served to identify a relevant theoretical approach to the second phase, similar to the process described by Swedberg [31], who suggests a two phased data collection

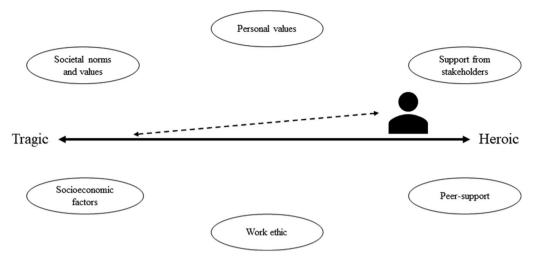


Figure 2. Example of an individual continuum. The ovals contain factors that influence the changes. The dotted line shows the movement on the continuum.

when developing theory. A first phase is usually more explorative and aims to develop research ideas, while the second phase is based on a first analysis where inspiration can come from theories, previous research and empirical findings. Although, we were not developing a theory, this approach was considered to be applicable to our project to provide direction for the analysis. This process identified narrative theory as a reasonable approach to the material, which informed the development of a revised interview guide to focus more specifically on transformations in identity, abilities and values.

The second phase of the analysis was based on the narrative approach identified after the first phase. In narrative analyses it is important to consider the narrative as a whole, as opposed to traditional open coding [22]. Hence, all interviews were read through several times to identify the core of the narrative (i.e., the meaning and the feel of the story), which in this case refers to heroic or tragic and in some cases transformation of the narrative. After identifying the core of the narrative, an iterative process followed. An adaptation of the questions from Srivastava and Hopwoods iterative framework [32] was used: "What is the material telling us?", and "What do we want to know?" By applying these questions in combination with the procedures of qualitive content analysis [30] previously described, the categorisation process moved back- and forth between data and theory and was influenced by both empirical findings and the concepts derived from the theoretical framework. All 38 interviews, initial telephone interviews and the final face to face interviews, were included in the second phase of analysis. All authors had experience in qualitative research and were involved in the analysis. The interview transcripts were read by all authors, categorisations were discussed, and consensus was reached regarding the interpretations.

Ethics

The study was approved by the regional ethics board (Dnr 2017/ 427-31). Written consent was obtained from the participants. All names have been replaced with pseudonyms to ensure anonymity of the participants.

Results

The results have been analysed in the context of a heroic – tragic continuum, and how the individual's narrative relates to that. An

overview of the participants is shown in Table 1, which presents pseudonyms, demographics, reasons for sick leave and how their continuum transformed over time. The following section contains general observations on core narratives and the two main themes 1), changes in the continuum and 2) the social context of the sick leave and rehabilitation process.

The core meanings of the narratives are viewed as either heroic or tragic. As respondents can transform their narrative over time, this is illustrated as a continuum with tragic and heroic narratives at opposite ends of the scale, as shown in Figure 2, where narratives can transform in either direction. However, a core finding is that it is not necessarily the *placement* on the scale that changes but rather the *perception of what heroic versus tragic entails*. When individuals' values and how they relate to societal norms change, the scale itself transforms and what the individual considers to be heroic or tragic. Since individuals have different perspectives there is no "one-scale-fits-all"; instead, different individuals have different continua. In the following themes the need for individual scales will be motivated by the respondent's different values, beliefs and experiences.

Changes in the continuum

This main theme contains two categories 1) Managing societal norms and values and 2) Identity work.

Managing societal norms and values

Several of the participants reported that they value work as very important, which affect how they view their sick leave and rehabilitation process. Their descriptions of themselves indicates that a high level of work ethic is shaped by upbringing and how work is viewed by society. Becoming sick-listed challenges their perceptions of work, which can lead to feelings of inadequacy and forces them to change their behaviour and, as a consequence, re-evaluate how they view work and its roles in their lives. The participants' priorities changed towards themselves or their families. However, there is a strong societal norm that citizens should work and contribute to society, which makes this change in priorities hard to apply, and could explain the difficulty of transforming the narrative from tragic to heroic. For example, Harry expressed that he constantly needs to be aware of how he acts and what type of work he does in order to be able to maintain his new perception of himself and of work.

But, pretty soon I started to notice that I winded myself up...getting into my old role/.../I need to think about that. Before I didn't know how to think, I still don't, I need to work on it all the time. Harry

Harry managed to transform his narrative from tragic to heroic, although the quotation indicates that it was not an easy task. It demanded a lot of work from his part and it is a never-ending quest to maintain the new perception of himself. Much like Harry, several respondents emphasise the struggle of changing their perceptions and maintaining them against such a predominant societal norm as the work ethic; they illustrate how participants experience shame for not being able to live up to the norm, and that accepting one's limitations also can mean having to accept defeat in relation to this norm. Joan was conflicted between the desire to prioritise her family and the desire to fit in to societal norms and expressed a desire to focus on her family with the little energy she has. Despite this, she still experienced a great deal of shame for not contributing to society by working and is sensitive to the community's opinion about her sick leave. The strong desire to fit in to the normative role caused her to return to work at a pace that instead set her back. Joan was conflicted between the desire to prioritise her family and the desire to fit in to societal norms. Another example of this is Patti, who returned to work and even though she tried to change her perceptions about work, including that she can contribute to her workplace in a different way, her narrative remained tragic since she experiences a great sadness for not being able to perform like she used to.

Respondents who express a high level of work ethic seem more prone to view their sick leave as a disruptive event. When Anna became sick-listed she experienced anger and confusion, causing her to question her identity. Identity and societal norms are related in the sense that individuals, in many cases, construct their identity to fit in to the acceptable norm.

You get the blues by it, or sad like 'What's happening now?, and God, have I gotten this old', you see? \dots So I think, I've gotten so old that I can't do this anymore, and so on. Anna

In Anna's case her injury and the following period of sickness leave is clearly a disruption to her everyday life. Peter, on the other hand, is placed on the heroic end of the continuum, which can be explained by the fact that his injury does not appear to be disruptive for him. Peter described his view on life as different from the normative view on work. He believes that society spends too much time working, his life-philosophy is that he should be able to do what he wants to do with his time. According to him, working is just a means to afford that lifestyle. His work motivation comes from a sense of self-fulfilment, rather than financial incentives. This relates both to societal norms as well as financial resources. Peter chooses a lower standard of living to live according to his personal values.

I don't like to work as much, it's one of the ideas I have, that we work way too much and put so much time on it./.../And that it's things that don't necessarily comes from yourself, and I think, I've always had trouble with that. Peter

As the quotation indicates, Peter does not need to change his behaviour nor his perception of himself and his attitude towards work. However, he was on sick leave several years ago, which he describes as shattering and having a large impact on his life. His previous episode of sick leave contributed to the change in how he values work. This serves as an example of how the heroic – tragic continuum transforms, and not simply an individual's placement on it. In other cases, there was a discrepancy between one's personal values. Patti believed that cutting down her hours and working less would contribute to her having more energy and being able to do what she desires in life, not only working and going home to rest. However, she believed that it was not possible due to financial reasons. In order for her to feel that she had the opportunity to care for herself she had to choose between a sufficient income or her health. This indicates that a full return to work does not always seem to be the most appropriate approach from a quality of life and wellbeing perspective.

 \ldots It's hard to explain, I feel that I've come a pretty long way, that I've accepted that 'This is me, I work like this', but then maybe, if I was able to cut my hours it could be a little more tolerable/ \ldots /I don't think I would manage a different job either \ldots full time Patti

Identity work

In order to transform the narratives from tragic to heroic the individual needs to cope with the effects of sick leave and/or the illness, which can be viewed as identity work. This can be seen as a way to maintain a sense of meaning and hopefulness about the future. If an individual lacks the resources required to make the necessary adjustments the narrative will remain on the tragic end of the continuum, or may move towards the heroic while risking to regress back to tragic. Societal norms and values are present in the process of working with one's identity. The individual's views of him-/herself relates to the desire to fit in to the norms of a strong, confident and hard-working individual, which is valued in today's society. When Patti returned to work, she no longer felt capable of performing her job in a satisfying way, causing shame and guilt for the extra burden she puts on her colleagues. Apart from having an impact on her behaviour it also changed her view of herself, affecting her self-esteem negatively.

I had to change a lot. I've slowed down, not doing any extra tasks and [I] don't attend any courses, I don't, no, I go to my job and do what I'm supposed to and sometimes not even that./.../Of course it affects me... but I think... what should I say, sometimes I'm completely at the bottom and think I'm the worst. Patti

Similarly, Harry described a negative self-image prior to his sick leave and did not feel confident enough to show people who he actually was. He portraited himself as strong and confident, which became a front that he needed to maintain. He used his sick leave as a time for reflection on who he really is.

If we put it like this, I had heard about self-image, that's about it. I was pretty lost and tried to show that, that I could perform and deliver, but I couldn't because I was heading down./.../And I didn't dare, dare to stand up for who I am. Harry

Much like Harry, Sandra used her sick leave for reflection and came to the realisation that her lifestyle had contributed to her sick leave. It became clear that she needed to make changes in her priorities to be able to handle her situation. This is not easy since her lifestyle is a part of what she values about herself. As stated earlier changing priorities is related to society's norms and also evident in the identity work. Changing priorities appears to be a common denominator in coping with negative effect of sick leave. Several participants believe that it is not worth giving all their energy to their job at the expense of their own health or their future desires.

Then I thought if it was worth working so much or, like there was not even a thank you, nobody thanks me for doing this, or then get sick listed and forgotten about. So the main thing is like, 'It's a job, nothing more'. Nina

For Sarah a form of normalisation was used to cope with the effects of sick leave. It was not seen as a disruptive event for her,

but the process was still viewed as troublesome as she was disappointed at the lack of contact from her employer. Her means of coping can be described as a form of 'distanced acceptances'. She accepted the situation but still distanced herself from it and became almost indifferent to the process. In the previous example with Patti, she stated that she has accepted her illness and created a new view on how she can contribute in other ways, with knowledge or by giving some sort of comfort to others. She describes it as an acceptance of how her life is now, her new normal.

And as the years pass and I can't do those things, you forget how it was to be a go-getter, well, you live pretty much in the present. Patti

However, due to her illness she does not have the energy to actually live by this, which makes her future uncertain and there remains a discrepancy between how she wants to live her life and how it actually is. As previously mentioned, struggling against society's expectations and norms might cause an aspiration for unobtainable goals, where in some situations return to work serves as an example of an unrealistic goal. What separates Nina's narrative from the example of Patti is that she manages to make changes in order to prioritise herself. She describes that her sick leave can be viewed as positive since it led her to gain an ability to listen to her body and say no when she believes that she needs to.

...dare to speak up and stand up for yourself, like, it's not bad to say no. Like, I'm doing this for my own good. So it's been, if you should see something positive in all this, I have needed to re-think and prioritise myself first. Nina

Another example of a narrative that described the sick leave as having a positive effect on her self-image was Emma. She described that being sick for a long period of time has caused her to view herself as sick: it became a part of her identity. When she started to get better this created an insecurity, who is she if she is not sick? By accepting the sick role, she stepped out of the work norm, and when trying to return she experienced difficulties to regain access to the work norm. She managed to change her negative self-image and poor self-esteem and gain a sense of self-worth, which was lost during her illness.

...when you're about to create a new identity, or it doesn't have to be new, perhaps it's as it should have been all along, like it was from the start, but you have to find your way back to it and that takes strength and energy and courage to get to something that you want to be./.../l can say that's it's extremely hard, it's something I still struggle with. Emma

Social context

This main theme contains two categories 1) Support from stakeholders and 2) The importance of social position.

Support from stakeholders

Support from various stakeholders involved in the sick leave and rehabilitation process can be a contributing factor in a heroic narrative. Employers who offer adjusted work tasks, flexibility and personal commitment are viewed as helpful. Conversely, not having a supportive employer, feeling alone in the process and not receiving the help that employees are entitled to causes negative emotions, especially when the participant must take on the responsibility that should be on the employers. In most cases a lack of support from the employer contributed to a tragic narrative but in Nina's case the lack of support from her employer serves as fuel for her to prioritise herself.

It's been equal to nothing. I haven't gotten any support at all, my boss hasn't called and asked me how I was feeling during this time ... So, I'm very disappointed about that. Nina

Even if the lack of support had unsuspected positive outcomes in her case it is still described in negative terms. Conversely, a supportive workplace may also have negative aspect related to it, as for Daniel, who described a close relationship with his employer as well as co-workers. He struggled with the desire to please his employer, because of their close relationship, and found it hard to say no; he constantly wanted to do a good job and not disappoint anyone. On the other hand, there is a lot of support. His employers know him very well and can tell when something is not right. This has helped him to listen to himself and not push beyond his limits.

A common denominator for the tragic narratives is a lack of support from health care personnel. Experiences of not being taken seriously or being accused of overexaggerating their symptoms is prominent in these stories. Being mistrusted causes feelings of helplessness and contributes to a tragic narrative. Patti has been denied sick leave by her physician, who she feels is not understanding. The lack of support reinforces the placement of her narrative at the tragic end of the continuum.

But I don't think I want to go back to my doctor at the health care centre, I feel that he doesn't understand me... That he doesn't have the empathy or, what should I say, doesn't listen to me. He was like 'Fibromyalgia is not a disease that you get sick listed for', he didn't listen to how I felt. Patti

Experiencing lack of support can manifest in different ways, like in the case of Harry, who believes that the health care system cannot help him; his experiences of contacts with health care professionals has lead him to believe that they have a predetermined pattern, and if you do not fit that mould you will not receive any help. As a consequence of these experiences, he started looking for alternative approaches of recovery. At first this caused him to feel hopeless and his narrative has a lot of tragic elements. However, his search for alternative treatments gave him a purpose and helped his narrative to transform to heroic. He described that he has learnt a lot about himself and that, in hindsight, being on sick leave was a positive experience.

I've found ways to deal with the stress, but somehow I'm still disappointed with health care/.../I felt that the health care wouldn't be able to help me, that I had to find my own paths. And I did, to some extent. Harry

Another participant who experienced mistrust and lack of support from the health care system was Joan, whose condition is still undiagnosed. She expressed that the health care system did not take her seriously, until she was seen by a new physician. Even if her current situation as well as her future is uncertain, feeling seen and heard from the physician helped her to see the future a bit brighter and contributed to a movement towards the heroic end of the scale. In other cases, health care services have had a contributing role in the transformation of the narrative. For example, Emma received counselling and viewed this as helpful in restoring her self-image. It appears that if the individual receives counselling or some form of behaviour therapy, the support is directed both towards the process of recovery and supporting change in self-image and values related to work. However, support from stakeholders seems mainly to be directed towards the process of returning to work, preferably full-time.

I mean with the rehabilitation plan, and the conversation and the meeting, it would never happened if I hadn't $\ldots\,$ if I hadn't written that letter. Anna

What becomes evident in the participants' narratives is that the view of the stakeholders' role and the level of support is specific to each person: some are described as helpful and supportive, while others are not, even within the same organisations.

It's not like at the Social Insurance Agency you get treated like this, depending on the case manager you get treated in different ways. Perhaps it also depends on who I am... Emma

Support from family and friends appears to be important in terms of emotional support and practical aspects. However, it is not clear whether or not it has any impact on changing the continuum. Support from stakeholders involved in the process appears to be more important than the support from family and friends. The importance appears to be in getting support from at least one of the stakeholders involved in the process, independent of which stakeholder is involved. The variations in responses to stakeholder support, as well as interventions, indicate the difficulty of a generalised RTW process. There appears to be a need for an individualised process and collaborative actions from the stakeholders involved in the process.

The importance of social position

Socioeconomic factors can relate to the level of support available, and as previously mentioned, a supportive employer may contribute to transformation of the narrative. Apart from emotional support, the possibility of adjusting work tasks appears to be important and, in many cases, translates as a supportive employer for the individual. Participants in white-collar professions appear to have better conditions for making the necessary adjustments when returning to work. Many of the participants working in blue-collar professions do not have the opportunity to be given adjusted work tasks. Patti expresses understanding for the lack of opportunities to make adjustments but at the same time there is a disappointment of not being able to make the work tasks easier, as she believes that her health would be improved as a result of adaptions. In the case of Sandra there is private insurance from her employer, which gives her access to several rehabilitation interventions that would not have been offered to her at a different employer. Having secure employment may make it easier to remain on the heroic side, than for someone who constantly struggles with insecure employment and/or low wages.

... I wanted a quick-fix so I could go back as soon as possible, because it was painful that I didn't have the finances to ... And I have three kids, not very young but still, I have to make ends meet. Harry

Several of the participants expressed a financial worry. Being on sick leave means a reduction in income and individuals with a lower education level often have less well-paid jobs. This could mean more financial stress than for someone with a higher level of education, office-work and the ability to adjust the work tasks. As previously mentioned, the financial situations might have an impact on decisions concerning one's health and returning to work. This might lead to low-income earners becoming more vulnerable, especially since low-income professions are often related to more strenuous work tasks. Worrying about the financial situation might lead to returning to work even though they are not ready, which may lead to a setback and, in turn, effect self-image negatively.

It's also about \dots if I would increase my hours and then have to cut back, it would be a failure to me, not because it is but I feel that it is. Emma

Discussion

The results strongly suggest that the work ethics and societal norms influence the individuals' views of the sick leave and rehabilitation process and play a role in the transformations of their personal continua between tragic and heroic narratives. Struggling toward goals set by society while not being able to obtain them can be viewed as especially tragic compared to those who strive for their own personal goals or have the resources needed to meet society's standards. Their experience of the process is a feeling of personal defeat. It is evident that it is possible to transform the narrative. With the right kind of support the stakeholders involved in the process can contribute to positive transformations of the narrative.

Transformative narratives

This study demonstrates that societal norms related to work highly influence how individuals view their sick leave and rehabilitation process. In previous studies such as Ezzy's study on job loss [23] and Polkinghorne's on transformative narratives [19], corenarratives have been divided into a dichotomous scale with specific characteristics to be met in order to be placed on the heroic or the tragic end. The results from the present study highlight the problem with this classification and suggests that it is rather the perception of what tragic/heroic entails that changes. In some cases, individuals have a normative view of the scale. They struggle when returning to work, or fail to return at all, resulting in feelings of defeat. Individuals who manage to identify the scale as normative and find ways to relate to this, or who question the norm rather than blaming themselves for not being able to live up to it, appear to be the ones who manage to create realistic goals for themselves. Peter is an example of an individual who has managed to guestion the norm and is able to remain a stable heroic position on the continuum. However, during a previous episode of sick leave he struggled with the effects of sick leave. This serves as an example of how the perception of the scale transforms and not simply the individual's placement on it. Since this perception differs between individuals there is a need for subjective scales. Movement on the scale is a complex interaction between structures and social support as well as individual factors. The results show a strong desire to fit in to the societal role of a worker, and those who do not fit in can experience, or simply anticipate, negative reactions from their community. This can cause self-stigma by accepting the stereotype and prejudice of not fitting in. In his research investigating experiences of individuals who had chosen to withdraw from paid work, Frayne [2] found that some people had taken the stigmatisation to heart, feeling worthless and isolated. This shows that an individual may still be affected by societal norms even after breaking from the norm. Self-image is defined by beliefs about how other people view unemployed people. This might also be the case with individuals on sick leave. A supporting social network along with the development of personal goals for recovery have been found to be protective factors to reduce self-stigma [33]. Having social support that encourages the individual to maintain their personal goals and values during the sick leave and rehabilitation process may facilitate a positive transformation towards the heroic end of the scale. A high level of self-esteem can make individuals more resilient and able to see that they should not blame themselves for not living up to norm. The ability to speak up for oneself and making sure to receive the help and support you need to recover is also important in transforming the narrative. A previous study investigating key factors for RTW in women with chronic pain found that their self-image, strength and desire to work were important. The study also supported the presence of a work ethic in the rehabilitation process [34]. However, they view work ethic as an individual factor, whereas we view it as a societal norm that sometimes causes individuals to stray from their personal goals. Although a strong work ethic may be helpful when it matches the individual's needs, it may have negative consequences when there is a discrepancy between societal and personal goals. Individuals who lack the abilities can be viewed as especially vulnerable. Another aspect that can contribute in the transformation of the narrative is financial resources, which is related to the social position of the person. Not having to worry about return to work due to financial reasons lets the individual focus on their recovery and their personal needs.

Rehabilitation goals

The main goal of rehabilitation in Sweden, as in many other countries, is RTW. Policies promoting early RTW have been found to decrease the duration of sick leave and the cost associated with it [12,13]. However, the results from the present study suggest that RTW does not necessarily equal success for the individual. It indicates that if the return is not in line with the individual's goal it may reinforce the tragic aspects of the individual's narrative, in the sense that they experience feelings of inadequacy and shame for not being able to return to work or perform as before their sick leave. A previous study suggested that therapists using an Acceptance and Commitment Therapy based approach to RTW found it beneficial to try to align personal values to work participation [6]. In the present study we can see the struggle involved in conforming one's own personal values to the societal values of work when abilities are lacking. The desire to confirm is strong and not taking part in the established norm may make people feel stigmatised and isolated. It is possible to return to work and still maintain a stance that does not conform to social values, but it demands a lot of resources to be able to do so. For a lot of people, especially with mental health problems, full recovery has not been made when returning to work, and they may lack the resources required to resist the pressure of such norms. As Frayne [2] points out a lot of companies search for a certain type of employee who is expected to act according to company values, which may further complicate the conflict between the individual, company and societal values. The risk of goals not relating to personal needs may result in relapse back to sick leave, which is neither beneficial to the individual nor to society, and may involve costs for the employer. With this in mind, perhaps more consideration should be given to the quality-of-life related outcomes when assessing successful RTW, in order to establish realistic rehabilitation goals. In this context it is relevant to question whether or not RTW is a realistic goal for everyone, and whether the desire to reach a gold standard within the sick leave and rehabilitation process is feasible. The results indicate the importance of tailored interventions where the individual's needs are considered based on his/her personal narrative. It is not likely that an individual in a tragic state has the same needs as someone in a heroic state, nor will they have the opportunities to assimilate the same interventions.

Social support has been suggested to make considerable changes in the management of illness [25]. This study supports this in terms of managing the sick leave process, however the support from friends and family does not seem to be as important as the support from stakeholders involved in the process. A possible explanation is that the stakeholder's opinions are perceived as more legitimate than those from relatives and loved ones. Another explanation is that people rely on their family and friends to be there for them through thick and thin, taking the support for granted and thus perhaps not reflecting on it in the same way. Studies have found that positive interactions with health care personnel and authority contacts are important for the sick leave and rehabilitation process and a positive experience may facilitate RTW [7,9,35], which is supported by the present study. Even though support is necessary and helpful in the rehabilitation process, our results raise the question of what such support should focus on. While current policies are heavily focused on RTW, the present study suggests that stakeholders also need to focus on identity, self-image and values, and acknowledging their validity even when they are not centred on work. Managing the changes in one's identity due to work disability is an important aspect of the individual's rehabilitation journey. It has previously been suggested that the rehabilitation process is mainly focused on the specific steps and that should be more focused on supporting the individual [34]. This is often overlooked since available interventions and supports are in line with work norms.

Socioeconomic factors

The importance of workplace-interventions is supported in the literature [13,14,36]. Respondents seem to associate a supportive employer with the opportunity to adjust work tasks. There are difficulties in adjusting work tasks in some professions and usually in blue-collar jobs. The budgets are strained, and employees need to be able to perform all various tasks involved, otherwise the burden will be greater on other colleagues. In today's labour market, managers express a difficulty in adjusting work tasks due to business pressure and needing their employees to be fully recovered on return, especially in low-wage professions [37,38]. A low educational level and financial worries have been found to be associated with early RTW [39]. Stepping out of the work-norm has financial implications and for some it is possible to do so because of financial security, perhaps from a partner with a good income or personal savings. It is harder for others who might need to provide for a partner and/or children. This can be viewed as a material reason for the work-norm being strong, and perhaps stronger among blue-collar occupations. White-collar jobs, such as a desk-job, usually provides more opportunities for adjustments. More control over work assignments has been found to give a higher level of opportunity to adjust the workplace and achieve a successful RTW [40]. Having a white-collar profession with high autonomy might make the situation feel safer and thus make it easier to view one's situation as heroic compared to those who constantly have to struggle. Perhaps it is also easier to adopt another view of work when there is the possibility of adjusting work tasks. On one hand, having a white-collar job and adjusted work assignments might add extra responsibility, making it hard to be on sick leave for a longer period of time, and perhaps returning too early. On the other hand, the employer may find the more skilled worker harder to replace and thus be more supportive during a longer sick leave period [39]. Individuals within white-collar professions usually have a higher education level and have strived and planned for their position for a great period of time. This might lead to identifying with one's profession to a greater extent and perhaps being more prone to view the sick leave as more disruptive and as losing one's identity.

Methodological considerations

In qualitative research the trustworthiness of the study is evaluated in terms of credibility, dependability, confirmability and transferability [27]. Recruitment of participants relates both to credibility and transferability [29]. In the present study, participants were recruited purposefully to ensure that they had experience of sick leave and were able to tell their story. The relatively small sample cannot be considered representative of all individuals on sick leave, thus making transferability difficult. However, the results indicated the importance of an individualised sick leave and rehabilitation process, which could be applicable to other individuals in similar contexts. The longitudinal approach is a strength of the study design. Conducting multiple interviews offers the possibility of following participants' processes and exploring changes over time. Serial interviews have been suggested as a good method for increasing depth in the interviews [28] and can also be viewed as a form of triangulation ensuring consistency over time [27]. A challenge was to get the participants to reflect over the changes they have made regarding selfimage and values. This required guidance from the interviewer, which can affect the dependability of the study. The interviewer aimed to let participants form their own stories, but it is important to note that, to some extent, all interviews are shaped by the interactions between the participant and the researcher. The dependability of the study was strengthened by the use of an interview guide, which was constructed and evaluated by the research group. The analysis followed the steps as described by Graneheim and Lundman [30] and Srivastava and Hopwood [32] to facilitate a systematic process, thus supporting the study's dependability. All authors were involved in the analysis process by reading the interview transcripts, discussing findings, and reviewing the categories. The members of the research group have several years of experience in the qualitative research field, which strengthens the study in terms of credibility. The researchers' various backgrounds in public health, occupational therapy and sociology also strengthen the interpretations of the results.

Conclusion

Conforming one's personal values to the work norm can create internal conflict and cause feelings of shame for not being able to live up to the established norm. The strong work norm may create unrealistic goals and expectations, which in some cases may result in constraining the RTW process. To transform a sick leave narrative in a positive direction, societal norms and their influence on identity need to be recognised. Stakeholders involved in the process can contribute to a positive transformation by not only supporting return to work, but also by acknowledging and helping people to manage their self-image. Treatment and support from the stakeholders, even though not leading to RTW, should be viewed as a meaningful and legitimate contribution to the process.

Acknowledgements

We thank Catharina Linderoth for performing telephone interviews with the participants.

The authors would like to thank the participants for sharing their stories.

Disclosure statement

The authors report no conflict of interest.

Funding

This study was funded by the Swedish Social Insurance Agency.

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