

Austerity and identity formation: How welfare cutbacks condition narratives of sickness

Niklas Altermark¹  | Åsa Plesner² 

¹Department of Political Science, Lund University, Lund, Sweden

²Stockholm Business School, Stockholm University, Stockholm, Sweden

Correspondence

Niklas Altermark, Department of Political Science, Lund University, Box 52, Lund 221 00, Sweden.

Email: niklas.altermark@svet.lu.se

Funding information

Forskningsrådet om Hälsa, Arbetsliv och Välfärd, Grant/Award Number: 2017-02098

Abstract

In recent years, Swedish sick insurance has become more restrictive. In this article, we analyse how people not being granted payments, despite being seriously ill, are affected. Scholarship on identity formation and sickness stress the importance of constructing narratives in order to come to terms with one's situation. Our analysis of 30 qualitative interviews with people diagnosed with ME/CFS shows that workfare politics conditions such identity formation and often prevents it from taking place. Interviewees describe extreme stress as a result of their contacts with the Social Insurance Agency (SIA), which results in a perpetual crisis that is renewed with each new denied application. In particular, the sense of not having a future means that it is hard to construct narratives to make sense of one's situation. To escape the perpetual crisis, some people have politicised their situation, constructing a narrative about themselves as suffering from oppressive politics. Others have escaped by not applying for sick insurance or other social insurances. But generally speaking, the most common effect of being denied sick insurance is an ongoing crisis that leads to deteriorating health.

KEYWORDS

austerity, ME/CFS, narrative, social insurance, welfare

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Sociology of Health & Illness* published by John Wiley & Sons Ltd on behalf of Foundation for the Sociology of Health & Illness.

INTRODUCTION

How are chronically ill people affected by being denied sick insurance? Research on experiences of becoming sick with chronic diseases have focussed on how people use narratives to make sense of their situation (Charon, 2006; Frank, 1995; Williams, 1984). This is described as central to identity formation; by telling stories about one's life trajectory, a radically changed situation becomes manageable. In such processes, the reactions of relatives, the health care offered and societal understandings of the disease in question will impact how people narrate their lives (Clark & Mishler, 1992; Hydén, 1997). Hence, narration as a response to sickness is socially situated. In this article, we claim that a central but neglected aspect of this social situatedness concerns relations to social insurance systems. Examining chronically ill people who are denied sick insurance, we show that the stress and insecurity associated with being declared 'fit for work' prevent members of this group from coming to terms with their condition, which in turn might lead to further deteriorating health and prolonged crisis.

This argument addresses a gap in the literature on illness and identity formation. Although much research has focussed on self-narration and sickness with respect to health care and societal attitudes towards different diseases (Iannello et al., 2018; McConnell & Snoek, 2018), there is a lack of studies that incorporate the central role of needs-based welfare systems into the analysis—despite a strong global trend of welfare state retrenchment and workfare policies which have made it harder to get financial support (Jensen et al., 2014; Starke, 2006; Swank, 2005). Analysing 30 interviews with people living with Myalgic Encephalomyelitis (or Chronic Fatigue Syndrome) (ME/CFS) who have been denied sick insurance, we show how this experience, and the ensuing crisis, becomes a central condition of self-narration.

The article is structured as follows: first we provide a background on Swedish social insurance cutbacks and relate it to research on stigma and welfare deservingness. Thereafter, we discuss the scholarly work on narrative and identity that we draw on in our analysis before presenting our methodology. The empirical analysis is divided into four sections, each one analysing how different stages of the crisis is described by the interviewees: first, the onset of illness; second, the crisis of being denied sick insurance; third, how this sparks a perpetual crisis; and fourth, how some interviewees find ways to manage their situation, either by opting out of the social insurance system or by reframing their experiences as results of oppressive politics. In the concluding section, we discuss the wider implications of our findings with respect to discussions about the relationship between agency and powerlessness.

Sick insurance policy and its effects

Sweden is known as a prime example of the Scandinavian welfare model, characterised by universal sick insurance, free health care and public services that are funded by tax payments. Today, welfare researchers specialising in Scandinavia agree that Sweden exhibits increasing deviations from this ideal (Blomqvist & Palme, 2020; Kananen, 2012; Pierre, 2016). Since the early 1990s, public spending has gradually decreased, whilst 'workfare' policies, premising social insurance payments on activation, have dominated social insurance reforms (Johnson, 2010; Kildal, 2001). Resembling how cutbacks have been legitimised in other contexts (León et al., 2015; Richards-Gray, 2020), these policies have been motivated by references to rising costs, overuse of welfare systems, allegations of widespread fraud and a strong focus on 'making work pay' (Altermark, 2020; Börjesson, 2018; Johnson, 2010).

This means that the Swedish social insurance system has gradually moved in a stricter direction since the early 2000s (Börjesson, 2018; Jacobsson et al., 2019). The latest step in this development was taken in 2015, when the social democratic government set a goal to reduce the average number of days that people are granted financial support (Socialdepartementet 2015). This drastically increased the number of people having their applications denied by the Social Insurance Agency (SIA) (Altermark, 2020). In particular, people with long-term illnesses and diagnoses that are not identified by biomedical tests were affected (see Altermark, 2020). There are no previous studies that describe the lived experiences of people who have been denied sick insurance payments in these years.

Internationally, there is a literature examining the effects of austerity, in particular concerning the consequences for sick and disabled people. There is strong evidence from different contexts that cutbacks are harmful for these groups (see Simpson et al., 2021) and more generally that politics affects health (Schrecker & Bambra, 2015). In particular, expectations of early return to work and ideas of overuse of welfare services have been described as sources of stigma, further complicating the process of rehabilitation (Garthwaite, 2014; Moffatt & Noble, 2015; Remnant, 2019). According to Goffman (1963), stigma arises in social interactions when certain people fail to meet the expectations of others since they are having attributes that are perceived as deviant and undesirable. Hence, norms about how people should look, function and behave attaches stigma to those who fail to meet these norms. With respect to welfare and sickness, prevailing norms about work as a duty towards society (see Börjesson, 2018 for an overview of Sweden), produces stigma of those who cannot work. With respect to the UK, Garthwaite (2015) has examined the implications of entering the sick insurance system. She notes that this does not necessarily lead to a negative identity, as participants can challenge the perception of sick people relying on welfare as passive recipients. Moffatt and Noble (2015) also examines stigma amongst people getting sick insurance, describing how being reliant on welfare is associated with shame. In contrast to these studies, the interviewees of our study all have in common that they have been denied sick insurance payments, which means that mechanisms of stigma and exclusion may play out differently.

The above implies that we understand perceptions of work and of people who are not working as produced and reproduced within broader societal and cultural frames. Here, Piven and Cloward (1993) famously argued that the workhouse of the 19th century and the workfare programmes of the 20th century both serve the purpose of degrading welfare recipients by forcing them to work. The trend of tightening eligibility criteria and downwards pressure on compensation levels, accelerating at the turn of the 20th century in Scandinavian welfare states, has similarly been interpreted as closely linked to ideas of welfare recipients as undeserving. Research on 'deservingness' highlights that it became harder to achieve the status of 'deserving' in European social insurance systems during the last decades of the 20th century (van Oorschot, 2000), which in turn risks undermining social policy reforms (Garthwaite, 2011). It appears as likely that this trend has accelerated in the Scandinavian context in the last decade, as welfare systems are remodelled to incentivise sick people to work whilst sick insurance costs have been increasingly questioned by politicians and in the public debate (see Baumberg, 2016).

The dividing line between deserving and undeserving welfare recipients can itself be interpreted as a product of politics. Ingram and Schneider (1993) argue that policy proposals often are motivated by the construction of target groups. Improvements in certain welfare systems require that users are depicted as deserving, whereas cutbacks are based on perceptions or descriptions of the affected group as 'undeserving' (see Baumberg, 2016; Garthwaite, 2011; van Oorschot, 2000). In this way, politicians can actively shape perceptions of groups in order to justify the policy.

Hence, a number of studies have shown that social insurance cutbacks are often accompanied by depictions of welfare recipients as idle and as fraudsters (Altermark, 2017; Goldberg, 2007), which on the one hand is likely to increase stigma and on the other hand requires that welfare systems take on a disciplinary function. These developments have also been found in Sweden (see Altermark, 2020; Börjesson, 2018).

The relationship between welfare rights and the duties of citizens to work are captured in the ideas of welfare contractualism, generally associated with Clinton's and Blair's governments in the 1990s (see Rhodes & Mény, 1998). The basic idea of this literature is that welfare can be understood in terms of a social contract, where the right to social security and support corresponds to the duty of the citizen to do everything in their power to work (White, 2000). This perspective marks a break with the idea of social citizenship, as espoused by Marshall ([1950]1992), where rights were perceived as unconditional. However, in the Swedish context, welfare has always been closely associated with the duty to work, not least in the vision of the 'folkhem' ('the people's home') which was mobilised to justify the construction of the 20th century welfare state (see Börjesson, 2018). Thus, the introduction of workfare policies in the early 2000s reactivated a central trope of Swedish welfare politics, further strengthening the link between the duty to work and the corresponding right to get support from social insurance systems.

In summary, although there is much research on welfare state reform and how people unable to work are portrayed and viewed, more studies are needed that focus on the lived experiences of losing one's social security payments. Garthwaite (2011, p. 372) has noted that such accounts are largely missing from public and scholarly debates, but that narratives of people relying on sick insurance can counter the vilifying discourse surrounding the group. Against this background, research that focuses on the effects of cutbacks in the everyday lives of sick people is needed.

Identity and narrative

Theoretically, we take the literature on the role of narration in the identity formation of sick people as our starting point. As stated in the introduction, research on experiences of chronic illnesses has pointed to the central role of narrative as a tool of sense-making. Bury (1982) argues that the onset of chronic illness constitutes a 'biographical disruption' in the life course of the individual, where social relations are transformed, future plans abandoned or revised, while the stigma towards chronically ill people affect the capability of the individual to mobilise resources to live their lives the way they want to.

Frank (1995) presents an empirical analysis of how sick people construct stories to understand their new situation. Like others in this research tradition, he understands narratives as connected to identity, where storytelling helps sick people make sense of how their identities transform. For chronically ill people, this entails entering what Frank terms 'the remission society'. He argues that widely held societal and cultural ideas of sickness are formed around a modernist idea of recovery, suggesting that 'sick' patients are on a journey towards recovery. Living in the remission society means defying that assumption. In this way, patients are performing 'identity work' (Goffman, 1963), which is necessary to come to terms with one's condition. Such processes consist of phases (Freidson, 1988; Grue, 2016), where previous studies have found that ME/CFS-patients typically go through periods of having their symptoms seen as medically unexplained (Guise et al., 2010). Patients with medically unexplained symptoms have been found to renegotiate their identities and struggle for status as legitimate patients in reflective and social processes (Lidén et al., 2015; Mik-Meyer & Obling, 2012; Nettleton, 2006; Rossen et al., 2019). These processes are

fraught with conflict and struggle, often involving strained relationships with health-care professionals (Kouyanou et al., 1998; Nettleton, 2006; Wileman et al., 2002). Rossen et al. (2019) found that patients with unexplained symptoms were left in a constant identity negotiation, implying that they did not enter the remission society (Frank, 1995).

Although not discussed by Frank or in the literature on identity work, we contend that social insurance cutbacks and workfare policies shape the experience of living in the remission society, as the presumption of recovery operates as a requirement imposed on the individual in order to be granted sick insurance. With respect to previous analyses of the identity work of ME/CFS patients, this implies focussing on identity formation as related to social insurance systems, rather than to health care. Our reasons for this focus follow from central ideas in these literatures. Considering the weight given by Frank to the sense of being in control over one's life (see Ståhl & Edvardsson Stiwné, 2014), it is notable that under a workfare regime, control will largely be related to whether one's applications for sick insurance are accepted. This is especially pertinent with respect to Frank's notion of 'narrative surrender', specifying what happens when individuals are forced to give up single authorship of their life story, for example, when the terminology of medical science provides knowledge about how one's body is functioning. Sick people surrender to the explanations, vocabulary and authority of medicine, which are incorporated into their storytelling. Obviously, this is not necessarily a bad thing, as it could mean improvements in patients' health literacy (Cartwright et al., 2018; Edwards et al., 2012, p. 176). Nevertheless, it is certainly a testament to how sick people depend on others, not only for care, services and help but also for self-understanding. While previous work has mapped tensions in such processes with respect to health care, there are not as many studies analysing identity formation with respect to social insurance systems.

Thus, our first theoretical proposition is that *workfare can be understood as a central aspect of the social situatedness of the identity formation of sick people not granted support*, with implications for what it means to exist in the remission society.

This implies that the opportunities of sick people to deal with their situation through storytelling are related to the government. Echoing Michel Foucault's (1982) proposition that the government is 'the conduct of conduct',¹ social insurance systems are designed to shape behaviour under a workfare regime by incentivising people to work. This way of governing is in turn reliant on categorisations, sorting people as 'fit for work' or 'sick', which applicants are inserted into as well as on wider societal norms about deservingness and un-deservingness. Seeing social insurance politics as part of the social situatedness of sick people hence implies understanding this group as entrapped in systems of power: norms and ideals about work, economic incentives and categorisations deciding on one's status in relation to welfare are regulating behaviour and affecting how people understand themselves.

Following from this, our second theoretical proposition is that *the social situatedness of identity formation and narration of sick people is imbued with power*. Both concerning how sick insurance is designed to shape behaviour through economic incentives and regarding norms and ideals that are upheld by discourse and reproduced by social insurance design.

In the analysis, we will devote some special attention to how social conditions shape individual perceptions of temporality. The struggles of sick people interacting with welfare authorities affect how they orient themselves towards their past, present and future. Considering the role of narratives for identity formation, this is central as narratives always contain a temporal aspect (see Ezzy, 2000). This idea is developed in Davies' (1997) discussion of how HIV patients make sense of their situation by relating to the future in one of three ways. (1) *Living in the future* means that people refuse to let go of their previous future plans and dreams, minimising

the effect of the biographical disruption brought about by being diagnosed. (2) *Living with a philosophy of the present* means that people draw on the disruption caused by their condition to achieve spiritual growth by consciously trying to appreciate the present. Lastly, (3) *living in the empty present* means being unable to compensate for the loss of projected future plans or replacing them. This group sees no future and cannot use a philosophy of the present to ameliorate the biographical disruption. This theoretical notion of the 'empty present' will be crucial in our analysis. It resembles how the Fennell four phases model describe the early stages of ME/CFS, with patients experiencing emotional turmoil before coming to terms with the chronicity of their illness in later phases (Fennell, 1995; Terman et al., 2020).

Hence, our third theoretical proposition is that *the temporal dimension of narratives can help us make sense of how power shapes the identity formation of sick people*.

Our primary reason to opt for these, rather than a more developed analytical framework, is to avoid shoehorning the stories of our interviews into pre-set analytical categories.

Methods and research design

Our material consists of semi-structured interviews with 30 participants who live with ME/CFS and who have lost financial support from the sick insurance system. ME/CFS is chronic and often has severe consequences for the living conditions of people falling ill. It is characterised by strong fatigue that is worsened after exhaustion. Currently, there are no treatments that are efficient and no clinical biomarkers that provide conclusive diagnosis. Rather, the condition is diagnosed on the basis of a set of criteria (Carruthers et al., 2011).

Chronically ill people with diagnoses that are not established with reference to biomedical markers have been disproportionately affected by cutbacks in Sweden (see Altermark, 2020). Here, it is worth noting that the condition shares a number of characteristics with other diagnoses, suggesting that our analysis may be relevant beyond this group of patients. First, like fibromyalgia, POTS and a number of diseases connected with long-term stress, there is a stigma attached to the disease (Boulazreg & Rokach, 2020; Terman et al., 2020). Popular understanding of the condition 'not being real' prevails, also among medical professionals and in spite of growing evidence of the biological basis of the condition (see Institute of Medicine, 2015). Secondly, the disease is chronic and often has life-altering consequences for the individual (Murray, 2016). Hence, the experience of living with ME/CFS certainly means living in the remission society. Previous research suggests that processes of biographical disruption and narratives play an important role for this patient group (Asbring, 2001; Dickson et al., 2008; Larun & Malterud, 2007).

Following approval from the Board of Ethical Review, interviewees were recruited with the aid of the leading Swedish patient organisation RME (National Patient ME-association, 2019), which spread our advert for interviewees in their social media channels. Inclusion criteria for the study were (1) living with ME/CFS and (2) having been denied support from the sick insurance system in the preceding 3 years. All interviewees were informed about the purpose of the study and their right to withdraw participation at any time during or after the interviews. They were also encouraged to take breaks or abort the interview if needed. This information was provided in written form and recounted before the interview. All interviews were conducted from May to September in 2019.

As concerns the demographics of participants, approximately two thirds were women. They were all between 30 and 63 years of age, evenly spread within this range. Some had been sick for a few years, whereas others fell ill over a decade ago. Comorbidities were common, especially

mental illnesses, but these debuted after ME/CFS. Only a few participants mentioned other somatic illnesses. The group of respondents was very diverse in terms of class background. As we shall see in our analysis, some interviewees had economic means that allowed them to withdraw from the social insurance systems to avoid contacts with the SIA, whereas others were struggling to make ends meet even before becoming ill. A majority of the participants used to have jobs that made them middle income earners by Swedish standards. People born outside of Sweden were underrepresented in the population of participants.

The interviews were conducted in Swedish by one of the authors, simultaneously taking notes. All but seven participants allowed the conversation to be recorded and then anonymously transcribed. The interviews were semi-structured, with the intent of capturing the experiences of interviewees. The conversations were structured around questions about the onset of disease, the experience of being denied sick insurance payments and how life took shape thereafter. Throughout, follow-up questions were asked. As interviews were focussing on narratives which may not follow linear paths, the thematic interview guide was often departed from. After data collection, the material was analysed iteratively, first separately by each author and then collaboratively, with respect to how the participants narrated their experiences. The theoretical propositions presented above guided the analytical process. Throughout, the software NVIVO was used to sort the material.

Our theoretical and methodological strategy has allowed us to conduct a thorough analysis of how the experience of losing sick insurance intervenes in processes of identity formation. The semi-structured character of interviews meant that participants were steering conversations, which is suitable when complex issues are dealt with. Furthermore, our theoretical and methodological choices allowed us to centre the experiences of participants. However, there are also some limitations that needs to be mentioned. First, the material does not allow us to generalise our conclusions to all people who have lost their sick insurance, as our participants were not selected randomly within this group. It is also likely that there is a bias in the material since people deeply affected by losing sick insurance may have been more motivated to participate in the study. Secondly, our study does not provide any comprehensive picture of how people are affected over a longer time span, as participants lost sick insurance in the 3 years preceding the study. For these reasons, our ambition has not been to make any strong causal claims concerning the effects of losing sick insurance, but to provide an interpretation of how the process of forming an identity after the onset of a chronic illness is related to austerity measures.

EMPIRICAL ANALYSIS

Chronic illness as disruption: Entering the remission society

The interviewees were encouraged to begin their narratives with the illness itself. Stories are similar here: the patient experiences loss of energy and function, and it becomes apparent to them that they are not having an ordinary flu. This is something else, something that affects their body, mind and life more deeply.

The situation is addressed by seeking medical attention. Interviewees expected to find out what was causing their condition and to be treated. However, as has been described in previous research on ME/CFS (Guise et al., 2010; Lacerda et al., 2019), the expectation that their illness would be understood and cured turns out to be wrong. For almost all patients, getting a diagnosis takes several years and a majority have met medical professionals who resist the

diagnosis. Several interviewees found out about ME/CFS by themselves and then suggested that their doctor referred them to a clinic specialising in ME/CFS. In Sweden, as elsewhere, there is no consensus within health care about whether, and how, ME/CFS can be treated. These findings are consistent with previous studies on the identity work of ME/CFS patients.

Most interviewees eventually found a doctor whom they trust and with whom they co-construct an understanding of their health status.² If they had not already, they learnt the method of 'pacing', which entails balancing one's daily activities to one's energy levels. This strategy has been rated as one of very few helpful interventions for ME/CFS patients (Goudsmit et al., 2012). For many interviewees, a new story is described as beginning here, in which the patient finds an identity as a member of the 'remission society' (Frank, 1995). Also, in this respect, the interviews are similar: patients come to terms with that they no longer will live their life as before and that health care cannot make the disease go away. Being diagnosed relieves some of the pressure of having unusual and contested symptoms and confirms their sense of being sick.

Thus far, our respondents' experiences are similar to Frank's (1995) analysis. Surrendering to the medical language means being validated as a proper and legitimate patient (Edmond & Keefe, 2015; Greville-Harris et al., 2016). Although the experience of having chronic disease is described as traumatic, respondents remain hopeful that a good life is possible.

Payment denial as disruption: Surrendering to the SIA

All participants in this study have been denied sickness payments even though their doctors consider them to be unable to work. Most have a period after diagnosis when they are granted sick insurance. Some participants report being suddenly and inexplicably declared 'fit for work' by the SIA and having their sickness payments revoked after having received payments for several years, whereas others were denied sick insurance as soon as the diagnosis 'ME/CFS' was confirmed. While the onset of disease and the diagnosis are depicted as possible to deal with, the narrative surrender required by the SIA at this point is recurrently described as unsurmountable.

Most interviewees figured that they had a fundamental right to financial security in case of sickness preventing them from working. To be denied sick insurance is described as a rupture, provoking strong emotions of distress, anger and worry, akin to Bury's (1982) description of a biographical disruption:

Interviewee 2: So, it says right there [in the notice of non-approval] that she [the caseworker] thinks that if I had all of these problems that my doctor describes, all of these limitations, well that can't be true because I'd be in need of constant assistance. And I mean. That sentence, it offended me to the point that I want to, I don't know, I felt, argh (...) I'm not a hateful and bitter person, but this?

In this way, the narrative surrender of understanding oneself as 'fit for work' is not possible, since it radically breaks with how participants experience the limits of how their bodies function. Many of the participants recount that they have tried to work and how their health worsened. The crushed expectation of social security support triggers a crisis that in a majority of our interviews appears as more serious and harder to deal with than becoming ill and being diagnosed in the first place.

Participants often describe this as a breach of the social contract. As noted in the introduction, welfare contractualism is based on the idea that social rights correspond to the duty to work

when one is able to. As interviewees experience themselves as unable to work, the withdrawal of social insurance payments means that the state fails to meet its obligations. As a consequence, the crisis of being denied sick insurance triggers at least two additional crises: one of personal finances and one of general trust in society:

Interviewee 6: Social services won't allow any assistance unless we sell the house and run out of assets. So, we're about to be kicked out with children due to all of this. (...) The emergency solution we're going to go with is getting a divorce. We think that my wife can manage the mortgage and the children on her wages, but not my debts. So, if I go sit on a bench in the park...

Several respondents expressed anger at being treated by the SIA as if their symptoms were not real. As mentioned above, this anger was often described with respect to their view of the social contract. They had fulfilled their part, but the state was not prepared to fulfil theirs:

Interviewee 1: So, the first feeling is getting really mad and frustrated and feeling, what the heck, am I worth nothing, and I sort of think they could look at my illness history, I've never been on sickness payment ever, except for when I fell off a horse 20 years ago. (...) And I feel like why don't you look back and realise, it's not like after 40 years you just come up with the idea that, oh, I want to be sick.

In this way, almost all interviewees express a strong sense of injustice. All participants report significant economic hardships and detrimental consequences for their quality of life and their family. Often, their lives are dominated by applying for sick insurance, overruling the denials of the SIA, whilst also trying to understand *why* they are being denied. The motivations of the SIA appear as difficult to decode, sometimes nonsensical given their health. As exemplified in the above quote, it is common that participants stress that they have always worked and never been overly reliant on welfare services. They have contributed, now they need support.

Similar exemplifications of a strong work ethics have also been observed by Ida Norberg (2019) in her study with a similar population in Sweden. We interpret such stories as a way of dealing with the stigma associated with being unable to work and applying for sick insurance by presenting oneself as 'deserving'. Garthwaite (2015) stresses that the stigmas of being sick and dependent on welfare overlap in the experiences of long-term sick insurance recipients. Layered on top of this, our interviewees suffer from having their needs disregarded, which is often interpreted as a questioning of their intentions and willingness to work. Hence, the stigma of being dependent is reinforced, whilst the need for social security remains unfulfilled.

Frank stresses the importance of regaining control over one's life through storytelling after falling ill. Our interviews expose how the denial of sick insurance payments introduces a radical lack of control, as the interviewees experience that their fate is determined by a state agency whose decisions are hard to comprehend. In Foucault's terms, they are embedded in a system of power, of norms and incentives, designed to encourage them to work. When they cannot fulfil this requirement, they face a situation characterised by stress and economic hardship.

In this way, the narrative surrender required by the SIA, declaring them fit to work, gives rise to a crisis that is harder to deal with than the disease. Whereas most participants are past the biographical disruption of being diagnosed with ME/CFS when we conduct our interviews, the disruption caused by being denied sick insurance strikes us as unresolved. The effects of the financial hardships, which for some mean selling their house, car and other belongings, having

to move or being economically dependent on one's partner, are creating great insecurity with respect to the future.

Stuck in perpetual crisis

Asked about life after being denied sick insurance, a recurring description in the material was a strong sense of being cornered, with no hope for change:

Interviewee 14: I'm taking it 1 day at a time. Looking forward has beaten the shit out of me, because all I get is being kicked around. I'm taking it month by month financially, though at the moment day by day—they took the entire amount [this month] so right now I'm in a fucking crisis.

The inability to reorient oneself towards the future reappears in most interviews. Since ME/CFS is chronic and the SIA is seen as impossible to convince, hopes for a better future are slim. Therefore, the kind of day-to-day living described in the quote should not be seen as a 'philosophy of the present', as specified by Davies (1997). Rather, this is the 'empty present' (Davies, 1997), where day-to-day living is a result of the fact that participants see themselves as trapped in a downward spiral. It is common that interviewees explain that they avoid thinking about what will come and how they will provide for themselves, not because of their disease, but as a result of the contacts with the SIA.

Hence, for most participants in our study, the crisis is ongoing, though many were denied sick insurance more than 2 years before the interview. For most participants, it is absolutely necessary to be granted support, which means that decisions need to be appealed and new applications for sick insurance are handed in. This means that the crisis is permanent: each new decision denying sick insurance, each appeal being disregarded, reactivates anxiety and strong feelings of insecurity about the future. At the same time, many describe that the efforts to appeal or apply for a new period of sick insurance are futile. Firstly, as mentioned above, because participants do not understand how the SIA justifies their decisions. The gap between their severe illness, in some cases meaning that they are unable to leave the bed for more than a few hours every day and a 'fit for work' decision comes forth as incomprehensible. Secondly, since they see the SIA as malicious and indifferent to reason. Despite this, a clear majority of the interviewees describe how they invest much time in getting new and better doctor's certificates, reformulating their applications and participating in mandatory meetings required to even be eligible for support.

In this way, the general picture is that the denial of sick insurance leads to a situation where our interviewees have profound insecurity with regard to the future, a strong sense of anxiety that is reactivated with every new decision and contact with the SIA and a threatening economic crisis of making ends meet. Our interpretation is that this creates a situation where people are prevented from narrating their own lives. When asked about life after being denied financial support, the accounts in our material often appear as a collection of fragments, concerning poverty, anxiety and consequences for significant others (see Thomas et al., 2020). In the theoretical vocabulary of Frank, the people in the midst of such situations are not storytellers, only wounded. People describe a form of day-to-day living of great pressure, where a common coping strategy is to not think about the future at all. The vital step of reorienting oneself towards the future and accepting one's situation is hence not possible.

Against this background, it is not surprising that mental health problems are common in the material. Several respondents stress that depression was not part of their clinical symptoms until they were declared fit to work:

Interviewee 7: The way things are now... I don't want anything more to do with them [the SIA]. I can't take it. At first, I wasn't depressed, but these days I'm so down and listless. It's a struggle just making it through the day. My sleep is much worse now, you just lie and think. And you know there's no point in going to the welfare office. (...) It's frightening. It's hard to keep away the thoughts that this is going to hell:

Within the group of participants responding in this way, suicidal thoughts were sometimes brought up:

Interviewee 10: I think about suicide every day even though I really don't want to die. I hope I won't do anything.

While our research design does not allow for estimations of the prevalence of suicidal thoughts among people with ME/CFS that are not granted sick insurance, we want to stress that the theme of suicide emerged alarmingly often: even though the interviewer never introduced the topic, respondents brought it up in about half of the interviews.

We described in our introduction that understanding patient narratives as socially embedded implies government and power. The aggregation of incentives to work, which for our interviewees is concretised as poverty, moral judgements concerning welfare dependency, stigma with regard to sickness as well as being questioned by the SIA, amounts to a situation that is extremely difficult to deal with. As a result, all interviewees state that their health has deteriorated as a consequence of the contacts with and decisions of the SIA. The permanent stress introduced by lacking control over the future makes pacing and rest, which is fundamental for ME/CFS-patients, almost impossible.

Escaping the perpetual crisis

The sense of a perpetual crisis reappears in almost all of our interviews. However, about 10 participants appear to have escaped it. There are two escape routes in the material, where the first one is to politicise one's situation. Some of our respondents had come to recognize that their denied sick insurance applications are an outcome of politics. Due to the fatigue that typifies ME/CFS, participants have limited resources to advocate for themselves. Some respondents had, nevertheless, taken to social media to share and process their experiences with the SIA. These participants expressed that getting in contact with others in similar situations helped them to reframe their experiences in terms of being subjected to oppressive politics. In these cases, the individualisation inherent to the contacts with the SIA, where sick people experience that they are blamed and punished for not being able to work, is replaced with a sense of belonging to a group that are disregarded in the welfare system. Here, our findings are similar to previous research on the benefits of online patient support groups (Petersen et al., 2020; Radin, 2006; van Uden-Kraan et al., 2008, 2009; Wentzer & Bygholm, 2013).

In the material, political activism ranged from simply participating in group discussions to managing and coordinating advocacy activism such as open letters. Seeing one's individual

hardships as part of a wider struggle against the SIA helped create some analytical distance towards one's own situation, as one of the respondents explains:

Interviewee 8: I've gotten mad [at the SIA] at times, but what good is that? With this illness, that just makes your health even worse. Get depressed, just sink into it, but that doesn't do anything either. So more and more I've been trying to laugh at it. Find the weirdness of it. I share stuff on Facebook to show regular people that this isn't a normally functioning governmental agency.

To return to Davies' (1997) theorisation of narrative and temporality, the politicisation of these participants reintroduced a possible different future. Even though many were pessimistic about actually changing the system, a better future could still serve a narrative function, as interviewees describe that trying to envision a fairer system helped them realise that their situation was not their own fault. In this way, seeing one's life as an effect of politics made it possible to reflect about one's experience in a new way. In addition, recognising oneself as part of a collective of people that are wronged is described as lessening loneliness and opening up for online contacts with other people in similar situations.

The second escape route from the perpetual crisis is to relinquish the expectations of having their health status acknowledged by the SIA. A few participants described ways of adjusting their household expenses so that they could live without financial support of the state:

Researcher: Sounds like you're doing better these days?

Interviewee 4: Yes, a lot better.

R: That's nice. What has made you feel better?

I4: My payments were withdrawn in November, and we discussed the household finances. My husband said that we can get by on your part-time pay so don't bother with the employment services office and all of that. Let's leave this behind and just look forward. I tried it anyway but realised that I won't get any help there. So, I deregistered a month ago. I tuned them out. (...) I have no regrets. I focus on my life and on making it the best I can and savouring it.

This allowed some participants to develop what Davies (1997) terms a *philosophy of the present*, that is, an acceptance of life as it is and a focus on appreciating the positive aspects of it. It also made it possible for these individuals to create narratives about their situation, not future-oriented, but with respect to the biographical disruption of becoming ill. People in this group emphasise appreciating 'the little things in life' and expressing acceptance with respect to living with ME/CFS. Naturally, this escape route is only available to respondents with sufficient economic resources; those who describe significant economic hardships explain that this way of solving their situation is not feasible.

In summary, our interviews show that being denied sick insurance creates a crisis where it becomes very hard to create meaning and understanding through self-narration. This results from the fact that participants face economic crisis, a disease that may worsen as a result of stress and a strong sense of powerlessness. In this situation, it is common to express that one has no future. Almost all participants have found themselves in this situation. Those that have managed to escape it have either started to view their living conditions as a result of oppressive politics or withdrew their claims to sick insurance. In the former case, the future is reintroduced in the form of a hope for a more just sick insurance system, which makes it possible for people to make

sense of their lives through narrative. In the latter case, participants live with a philosophy of the present, not reorienting themselves towards the future, but with more energy to make sense of and develop acceptance of their disease.

CONCLUDING DISCUSSION

Previous research on the identity work of chronically ill people shows that storytelling is central for identity formation. Studies have also showed that workfare policies produce mental distress and suffering (see Simpson et al., 2021; Thomas et al., 2020). Our main contribution is the insight that austerity policy may prevent people who are denied sick insurance from constructing narratives that help them come to terms with their condition. In addition to the hardships mapped in research on the identity work of ME/CFS patients with respect to health care, we show how social insurance systems introduce another set of challenges. To lose financial support from the welfare state initiates a new and often more disruptive crisis than the disease itself, made permanent by the recurring requirement of reapplying for sick insurance in hope of a better outcome.

With regard to the sick insurance policy in Sweden, our findings suggest that the remission society is supplanted by the workfare society, where the expectation of recovery and the active incentivising of people to work hampers the possibilities of chronically ill people to sustain themselves. Social insurance cutbacks are regularly justified with reference to the risk that generous welfare will make people passive objects of support. Activation through workfare is thereby said to counter long-term reliance on sick insurance. On the contrary, our findings suggest that stress and uncertainty regarding the future can result in deteriorating health, further decreasing the work capacity of the individual.

In addition, our analysis relates to broader questions concerning agency, self-narration and victimhood. There is a risk that accounts of repression and suffering like the ones our study is based on represent repressed groups as passive victims, denying them agency. Therefore, we want to stress that in our analysis, experiences of powerlessness do not amount to passivity. Narrative is an expression of agency, also when it accounts for the experience of not being allowed to understand oneself. Hence, we see the accounts of powerlessness and distress in our interviews as expressions of agency, where the interviewees are actively shaping stories about what they are subjected to. Thereby, they are challenging the dominating narrative that sick people need incentives to work and therefore are helped by stricter social insurance systems.

From a theoretical perspective, our study can be seen as an examination of Foucault's (1982) idea that power shapes subjectivity. As Butler (1997) has suggested, it is misleading to interpret such production of subjectivity as a linear and one-dimensional process where the workings of power determine identity. Although the divisions between 'fit for work' and sick or between the normative judgements of 'deserving' and 'undeserving', certainly are part of the social situatedness of our interviewees, people still relate to such ideals and social structures in an active fashion. Butler argues that this may be of special importance at the junctures where the social designation of subjects and their lived experiences do not add up. Our material exposes the rift between an externally imposed categorisation (of being 'fit for work') and how one experiences one's own situation (of being unable to work). Here, Butler (1997, p. 2) has suggested that 'the injurious address may appear to fix or paralyze the one it hails, but may also produce an unexpected and enabling response'. When interviewees politicise their situation by challenging the imposed labels, replacing them with a counter-discourse of being oppressed, it can be seen as this kind of enabling response.

Much of the literature on austerity and workfare has overlooked the experiences of people losing access to welfare systems. Our study suggests that a full picture of the effects of austerity requires that these are incorporated into analysis. We argue that research on patient identity and the role of narratives for sick people need to incorporate welfare politics as a condition of identity formation, not only concerning health-care policy, but with respect to social security more generally. Our study also demonstrates that research on social insurance benefits from centring the experiences of individuals living with chronic diseases.

AUTHOR CONTRIBUTIONS

Niklas Altermark: Conceptualization (Lead); Data curation (Equal); Funding acquisition (Lead); Investigation (Lead); Project administration (Lead); Writing—original draft (Equal); Writing—review & editing (Equal). **Åsa Plesner:** Conceptualization (Supporting); Data curation (Equal); Writing—original draft (Equal); Writing—review & editing (Equal).

ACKNOWLEDGEMENT

The study was funded by FORTE (2017-02098).

DATA AVAILABILITY STATEMENT

Data are archived and available in accordance with Lund University policy and Swedish Law. Details here: <https://www.sambib.lu.se/en/researcher/research-data-management/data-management/archiving-research-data?q=write-and-publish/researcher/research-data-management/data-management/archiving-research-data>.

ORCID

Niklas Altermark  <https://orcid.org/0000-0001-7114-1431>

Åsa Plesner  <https://orcid.org/0000-0002-9673-3545>

ENDNOTES

- ¹ This phrase only appears in the French original text, but the English version of *The Subject and Power* (Foucault, 1982) gives a good grasp of the argument.
- ² This may be a selection bias in our material. Enrolment in the study may be more likely for people who have progressed further in their processing of their illness, thanks to having a trusting partnership with their doctor.

REFERENCES

- Altermark, N. (2017). Hur legitimeras socialpolitiska besparingar? Konstruktionen av personlig assistans som ett "kostnadsproblem". *Socialvetenskaplig tidskrift*, 24(2), 107–126.
- Altermark, N. (2020). *Avslagsmaskinen: Byråkrati och avhumanisering i svensk sjukförsäkring*. Verbal förlag.
- Asbring, P. (2001). Chronic illness - a disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312–319. <https://doi.org/10.1046/j.1365-2648.2001.01767.x>
- Baumberg, B. (2016). The stigma of claiming benefits: A quantitative study. *Journal of Social Policy*, 45(2), 181–199. <https://doi.org/10.1017/s0047279415000525>
- Blomqvist, P., & Palme, J. (2020). Universalism in welfare policy: The Swedish case beyond 1990. *Social Inclusion*, 8(1), 114–123. <https://doi.org/10.17645/si.v8i1.2511>
- Börjesson, A. (2018). *(R)evolutionära idéer: Förändringar i svensk sjukförsäkringspolitik 1995-2015*. Förvaltning shögskolan.
- Boulazreg, S., & Rokach, A. (2020). The lonely, isolating, and alienating implications of myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare*, 8(4), 413. <https://doi.org/10.3390/healthcare8040413>

- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Butler, J. (1997). *Excitable Speech: A Politics of the Performative*. London: Routledge.
- Carruthers, B. M., van de Sande, M. I., De Meirleir, K. L., Klimas, N. G., Broderick, G., Mitchell, T., Staines, D., Powles, A. C. P., Speight, N., Vallings, R., Bateman, L., Baumgarten-Austrheim, B., Bell, D. S., Carlo-Stella, N., Chia, J., Darragh, A., Jo, D., Lewis, D., Light, A. R., & Stevens, S. (2011). Myalgic encephalomyelitis: International consensus criteria. *Journal of Internal Medicine*, 270(4), 327–338. <https://doi.org/10.1111/j.1365-2796.2011.02428.x>
- Cartwright, E., Hardon, A., & Manderson, L. (2018). Ways of caring. In *The Routledge handbook of medical anthropology*. Routledge.
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford University Press.
- Clark, J. A., & Mishler, E. G. (1992). Attending to patients' stories: Reframing the clinical task. *Sociology of Health & Illness*, 14(3), 344–372. <https://doi.org/10.1111/1467-9566.ep11357498>
- Davies, M. L. (1997). Shattered assumptions: Time and the experience of long-term HIV positivity. *Social Science & Medicine*, 44(5), 561–571. [https://doi.org/10.1016/s0277-9536\(96\)00177-3](https://doi.org/10.1016/s0277-9536(96)00177-3)
- Dickson, A., Knussen, C., & Flowers, P. (2008). "That was my old life; it's almost like a past-life now": Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology and Health*, 23(4), 459–476. <https://doi.org/10.1080/08870440701757393>
- Edmond, S. N., & Keefe, F. J. (2015). Validating pain communication: Current state of the science. *Pain*, 156(2), 215–219. <https://doi.org/10.1097/01.j.pain.0000460301.18207.c2>
- Edwards, M., Wood, F., Davies, M., & Edwards, A. (2012). The development of health literacy in patients with a long-term health condition: The health literacy pathway model. *BMC Public Health*, 12(1), 130. <https://doi.org/10.1186/1471-2458-12-130>
- Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science & Medicine*, 50(5), 605–617. [https://doi.org/10.1016/s0277-9536\(99\)00306-8](https://doi.org/10.1016/s0277-9536(99)00306-8)
- Fennell, P. A. (1995). The four progressive stages of the CFS experience: A coping tool for patients. *Journal of Chronic Fatigue Syndrome*, 1(3–4), 69–79. https://doi.org/10.1300/j092v01n03_11
- Foucault, M. (1982). The subject and power. *Critical Inquiry*, 8(4), 777–795. <https://doi.org/10.1086/448181>
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). University of Chicago Press.
- Freidson, E. (1988). *Profession of medicine: A study of the sociology of applied knowledge*. University of Chicago Press.
- Garthwaite, K. (2011). 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform. *Disability & Society*, 26(3), 369–372. <https://doi.org/10.1080/09687599.2011.560420>
- Garthwaite, K. (2014). Fear of the Brown envelope: Exploring welfare reform with long-term sickness benefits recipients. *Social Policy and Administration*, 48(7), 782–798. <https://doi.org/10.1111/spol.12049>
- Garthwaite, K. (2015). Becoming incapacitated? Long-term sickness benefit recipients and the construction of stigma and identity narratives. *Sociology of Health & Illness*, 37(1), 1–13. <https://doi.org/10.1111/1467-9566.12168>
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Penguin.
- Goldberg, C. A. (2007). *Citizens and paupers: Relief, rights, and race: From the freedmen's bureau to workfare*. The University of Chicago Press.
- Goudsmit, E. M., Nijs, J., Jason, L. A., & Wallman, K. E. (2012). Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: A consensus document. *Disability & Rehabilitation*, 34(13), 1140–1147. <https://doi.org/10.3109/09638288.2011.635746>
- Greville-Harris, M., Hempel, R., Karl, A., Dieppe, P., & Lynch, T. R. (2016). The power of invalidating communication: Receiving invalidating feedback predicts threat-related emotional, physiological, and social responses. *Journal of Social and Clinical Psychology*, 35(6), 471–493. <https://doi.org/10.1521/jscp.2016.35.6.471>
- Grue, J. (2016). Illness is work: Revisiting the concept of illness careers and recognizing the identity work of patients with ME/CFS. *Health*, 20(4), 401–412. <https://doi.org/10.1177/1363459315628044>
- Guise, J., McVittie, C., & McKinlay, A. (2010). A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *Journal of Health Psychology*, 15(3), 426–435. <https://doi.org/10.1177/1359105309350515>
- Hydén, L.-C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19(1), 48–69. <https://doi.org/10.1111/1467-9566.ep10934289>

- Iannello, P., Biassoni, F., Bertola, L., Antonietti, A., Caserta, V. A., & Panella, L. (2018). The role of autobiographical story-telling during rehabilitation among hip-fracture geriatric patients. *Europe's Journal of Psychology, 14*(2), 424–443. <https://doi.org/10.5964/ejop.v14i2.1559>
- Institute of Medicine. (2015). *Beyond myalgic encephalomyelitis/chronic fatigue Syndrome: Redefining an illness*. The National Academies Press.
- Jacobsson, K., Seing, I., & Hollertz, K. (2019). Fölsamhet som styrningsideal hos försäkringskassan—Ett hot mot rättssäkerheten? *Social-Medicinsk Tidskrift, 96*(5), 682–689.
- Jensen, C., Knill, C., Schulze, K., & Tosun, J. (2014). Giving less by doing more? Dynamics of social policy expansion and dismantling in 18 OECD countries. *Journal of European Public Policy, 21*(4), 528–548. <https://doi.org/10.1080/13501763.2013.866262>
- Johnson, B. (2010). *Kampen om sjukfrånvaron*. Arkiv.
- Kananen, J. (2012). Nordic paths from welfare to workfare: Danish, Swedish and Finnish labour market reforms in comparison. *Local Economy: The Journal of the Local Economy Policy Unit, 27*(5–6), 558–576. <https://doi.org/10.1177/0269094212445351>
- Kildal, N. (2001). *Workfare tendencies in Scandinavian welfare policies*. ILO.
- Kouyanou, K., Pither, C. E., Rabe-Hesketh, S., & Wessely, S. (1998). A comparative study of iatrogenesis, medication abuse, and psychiatric morbidity in chronic pain patients with and without medically explained symptoms. *Pain, 76*(3), 417–426. [https://doi.org/10.1016/s0304-3959\(98\)00074-8](https://doi.org/10.1016/s0304-3959(98)00074-8)
- Lacerda, E. M., McDermott, C., Kingdon, C. C., Butterworth, J., Cliff, J. M., & Nacul, L. (2019). Hope, disappointment and perseverance: Reflections of people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and multiple sclerosis participating in biomedical research. A qualitative focus group study. *Health Expectations, 22*(3), 373–384. <https://doi.org/10.1111/hex.12857>
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies. *Patient Education and Counseling, 69*(1–3), 20–28. <https://doi.org/10.1016/j.pec.2007.06.008>
- León, M., Pavolini, E., & Guillén, A. M. (2015). Welfare rescaling in Italy and Spain: Political strategies to deal with harsh austerity. *European Journal of Social Security, 17*(2), 182–201. <https://doi.org/10.1177/138826271501700203>
- Lidén, E., Björk-Brämberg, E., & Svensson, S. (2015). The meaning of learning to live with medically unexplained symptoms as narrated by patients in primary care: A phenomenological-hermeneutic study. *International Journal of Qualitative Studies on Health and Well-Being, 10*(1), 27191. <https://doi.org/10.3402/qhw.v10.27191>
- Marshall, T. H. ([1950]1992). *Citizenship and social class*. Pluto Press.
- McConnell, D., & Snoek, A. (2018). The importance of self-narration in recovery from addiction. *Philosophy, Psychiatry, and Psychology, 25*(3), 31–44. <https://doi.org/10.1353/ppp.2018.0022>
- Mik-Meyer, N., & Obling, A. R. (2012). The negotiation of the sick role: General practitioners' classification of patients with medically unexplained symptoms. *Sociology of Health & Illness, 34*(7), 1025–1038. <https://doi.org/10.1111/j.1467-9566.2011.01448.x>
- Moffatt, S., & Noble, E. (2015). Work or welfare after cancer? Explorations of identity and stigma. *Sociology of Health & Illness, 37*(8), 1191–1205. <https://doi.org/10.1111/1467-9566.12303>
- Murray, R. E. (2016). *A life lived differently: An exploration of how living with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) impacts upon people's identity*. Doctoral thesis. University of Huddersfield.
- National ME Patient Association. (2019). Medan livet går förbi. Att (försöka) leva med ME/CFS. *Medlemsenkät 2018/2019*. [With life passing by. (Attempting) living with ME/CFS. Member survey 2018/2019.].
- Nettleton, S. (2006). "I just want permission to be ill": Towards a sociology of medically unexplained symptoms. *Social Science & Medicine, 62*(5), 1167–1178. <https://doi.org/10.1016/j.socscimed.2005.07.030>
- Norberg, I. (2019). *Life in the hands of welfare bureaucracy: The impact of austerity on disabled people in Sweden*. University of Glasgow.
- Petersen, A., Schermuly, A., & Anderson, A. (2020). Feeling less alone online: Patients' ambivalent engagements with digital media. *Sociology of Health & Illness, 42*(6), 1441–1455. <https://doi.org/10.1111/1467-9566.13117>
- Pierre, J. (Ed.). (2016). *The Oxford handbook of Swedish politics*. Oxford University Press.
- Piven, F., & Cloward, R. (1993). *Regulating the poor: The functions of public welfare*. Vintage Books.
- Radin, P. (2006). "To me, it's my life": Medical communication, trust, and activism in cyberspace. *Social Science & Medicine, 62*(3), 591–601. <https://doi.org/10.1016/j.socscimed.2005.06.022>

- Remnant, J. (2019). Getting what you deserve: How notions of deservingness feature in the experiences of employees with cancer. *Social Science & Medicine*, 237(112447), 1–8. <https://doi.org/10.1016/j.socscimed.2019.112447>
- Rhodes, M., & Mény, Y. (1998). Introduction: Europe's social contract under stress. In *The future of European welfare: A new social contract?* Palgrave.
- Richards-Gray, L. (2020). Political discourse and gendered welfare reform: A case study of the UK coalition government. *Journal of Elections, Public Opinion, and Parties*, 32(2), 1–19. <https://doi.org/10.1080/17457289.2020.1760283>
- Rossen, C. B., Buus, N., Stenager, E., & Stenager, E. (2019). Identity work and illness careers of patients with medically unexplained symptoms. *Health*, 23(5), 551–567. <https://doi.org/10.1177/1363459317739440>
- Schneider, A., & Ingram, H. (1993). Social construction of target populations: Implications for politics and policy. *American Political Science Review*, 87(2), 334–347. <https://doi.org/10.2307/2939044>
- Schrecker, T., & Bamba, C. (2015). *How politics makes us sick: Neoliberal epidemics*. Palgrave Macmillan.
- Simpson, J., Albani, V., Bell, Z., Bamba, C., & Brown, H. (2021). Effects of social security policy reforms on mental health and inequalities: A systematic review of observational studies in high-income countries. *Social Science & Medicine*, 272(113717), 1–18. <https://doi.org/10.1016/j.socscimed.2021.113717>
- Starke, P. (2006). The politics of welfare state retrenchment: A literature review. *Social Policy and Administration*, 40(1), 104–120. <https://doi.org/10.1111/j.1467-9515.2006.00479.x>
- Ståhl, C., & Edvardsson Stiwne, E. (2014). Narratives of sick leave, return to work and job mobility for people with common mental disorders in Sweden. *Journal of Occupational Rehabilitation*, 24(3), 543–554. <https://doi.org/10.1007/s10926-013-9480-7>
- Swank, D. (2005). Globalisation, domestic politics, and welfare state retrenchment in capitalist democracies. *Social Policy and Society*, 4(2), 183–195. <https://doi.org/10.1017/s14747464002337>
- Terman, J. M., Awsumb, J. M., Cotler, J., & Jason, L. A. (2020). Confirmatory factor analysis of a myalgic encephalomyelitis and chronic fatigue syndrome stigma scale. *Journal of Health Psychology*, 25(13–14), 2352–2361. <https://doi.org/10.1177/1359105318796906>
- Thomas, F., Wyatt, K., & Hansford, L. (2020). The violence of narrative: Embodying responsibility for poverty-related stress. *Sociology of Health & Illness*, 42(5), 1123–1138. <https://doi.org/10.1111/1467-9566.13084>
- van Oorschot, W. (2000). Who should get what, and why? On deservingness criteria and the conditionality of solidarity among the public. *Policy & Politics*, 28(1), 33–48. <https://doi.org/10.1332/0305573002500811>
- van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Seydel, E. R., & van de Laar, M. A. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*, 10(2), e18. <https://doi.org/10.2196/jmir.992>
- van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2009). Participation in online patient support groups endorses patients' empowerment. *Patient Education and Counseling*, 74(1), 61–69. <https://doi.org/10.1016/j.pec.2008.07.044>
- Wentzer, H. S., & Bygholm, A. (2013). Narratives of empowerment and compliance: Studies of communication in online patient support groups. *International Journal of Medical Informatics*, 82(12), e386–e394. <https://doi.org/10.1016/j.ijmedinf.2013.01.008>
- White, S. (2000). Review article: Social rights and social contract – Political theory and the new welfare politics. *British Journal of Political Science*, 30(3), 507–532. <https://doi.org/10.1017/s0007123400000211>
- Wileman, L., May, C., & Chew-Graham, C. A. (2002). Medically unexplained symptoms and the problem of power in the primary care consultation: A qualitative study. *Family Practice*, 19(2), 178–182. <https://doi.org/10.1093/fampra/19.2.178>
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175–200. <https://doi.org/10.1111/1467-9566.ep10778250>

How to cite this article: Altermark, N., & Plesner, Å. (2022). Austerity and identity formation: How welfare cutbacks condition narratives of sickness. *Sociology of Health & Illness*, 44(8), 1270–1286. <https://doi.org/10.1111/1467-9566.13545>