



Naked in the eyes of the public: A phenomenological study of the lived experience of suffering from burnout while waiting for recognition to be ill

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Abstract

Although there has been a focus on problematic issues related to health care services and complaints made by patients, individuals who suffer from medically unexplained syndromes continue to report being epistemically marginalized or excluded by health professionals. The aim of this article is to uncover a deeper understanding of the what-ness of experiencing being naked in the eyes of the public while waiting to be recognized as ill. Therefore, a phenomenological approach was chosen to inductively and holistically understand the human experience in this context-specific setting. Semi-structured interviews were conducted with two men and six women between 25 and 65 years of age, who had been on sick leave for more than 52 weeks. Their symptoms were consistent with Exhaustion Disorder (ICD-10, F43.8A). The meaning of the interviewees' lived experience was explored using a life-world approach to phenomenological reflection and writing. The participants described their experience of encountering the general practitioner as taking part in a battle. Feeling distrusted by others seemed to result in disconnection from their habitual lifeworld, which in turn triggered a shame reaction. Additionally, the study showed a possible distrust related to several communication levels within the health care system, which influenced the recovery process negatively. Lack of experienced support can lead to exacerbated feelings of distress. Accordingly, the psychosocial experience of being ill might be as important as its unknown aetiology. Therefore, in the context of these interpersonal relations, both norms, values, and attitudes, and issues of power need to be considered and addressed properly.

KEYWORDS

burnout, epistemic marginalization, experience, health care, shame

1 | CONTEXTUAL SETTING

I'm in the middle of chaos. I don't understand myself, can't recognise myself. Cannot fathom why things are as they

are. I hardly know who I am. I just want to sit here and be left alone. It's a bit scary. And when my husband gives me a compliment I'm unable to accept it. I hear what he's saying, but it doesn't register because of my own self-

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image. In a process like this, everything just disappears. That's why the little girl starts to appear, when I'm standing there completely naked. There is no way I can beat it. Everything just caves in. (Emma)

Emma (fictive name) is one of the participants in the study. Her story is not unique. She is experiencing "burnout" and has been on sick leave for more than 1 year. Burnout is a generic name for a state of physical fatigue, emotional exhaustion, and cognitive weariness because of prolonged exposure to unavoidable stressors.¹ During the sick-leave period (52 weeks) the Norwegian Labour and Welfare Organisation (NAV), the employer and the general practitioner (GP) are supposed to cooperate to provide for a time-efficient recovery process while the patient is granted sick-leave compensations. After the sick-leave period, the patient can apply for work assessment allowance (AAP), which is paid by NAV. From what the first author has seen in her clinical practice as a psychotherapist, there seems to be a mismatch between the needs of the patients who experience burnout or other medically unexplained syndromes and what the health care system provides. In the following, we will first address the context in which the encounters between patients and their communities take place.

In the West, this context is coloured by the social and political norms set by the biomedical model and evidence-based medicine (EBM). The biomedical model and EBM are rooted in the positivist paradigm. Within this paradigm, knowledge is achieved exclusively by what is objectively measurable and directly observable, and little space is left for reflections about subjective factors and underlying mechanisms. "Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients."² Recommendations made within clinical guidelines are graded according to the strength of the evidence on which they are based. Clinical guidelines are thus presented as practical tools, in which the available evidence is synthesized and interpreted to guide choice of diagnosis and medical treatment. In the industrialized society of today, an increasing number of individuals experience long-term absenteeism from work because of fatigue- and pain-related diseases that are not yet medically explained.³ This fact might challenge the care for these patients because of the lack of medical explanations and thereby lack of clinical guidelines.

In Norway, medically unexplained syndromes are placed in a "grey zone," which can result in a delay in receiving a diagnosis. Since a diagnosis is the key to various social privileges, important implications related to these syndromes might arise. A diagnosis is also a recognition of being ill. In encounters between doctor and patient, the evidence-based norms might influence the relationship negatively. Research has shown that individuals suffering from medically unexplained syndromes experience not being taken seriously within the health care system and often report disbelief and lack of support from their communities.⁴ This fact may cause severe problems for individuals with these syndromes because AAP and social security benefits are not readily granted without a known biomedical diagnosis.⁵ Issues of legitimacy may in turn contribute to elevated distress and suffering

and an aggravation of the physical symptoms.⁶ However, often, the experienced symptoms are attributed to psychological factors leaving these individuals to cope with their situation on their own.^{4,5,7}

Although some authors have focused on problematic issues related to health care services and complaints made by patients^{8,9} and others have drawn attention to the epistemic aspects of these complaints,^{10,11} patients continue to report being "epistemically marginalized" or excluded by health professionals.^{12,13} Epistemic marginalization may be understood as under-inclusion of the first-hand experiences and perspectives of those who suffer from medically unexplained syndromes because of the ontological stance taken by health care providers. Unsupportive encounters may seriously affect the way in which the individual attributes value to himself or herself as a human being with subsequent increased distress. The lack of societal recognition may in turn threaten vulnerable individuals' sense of self and social identity and elevate vulnerability.^{14,15} These patients have articulated feelings of shame and guilt associated with their pain.^{16,17} Shame is a feeling of worthlessness and involves self-blaming and criticism in a stable and maladaptive manner.^{14,18} To summarize, lack of support from society and medical professionals may lead to exacerbated feelings of distress. Shame has, in a cross-sectional study among people on sick leave, been found to be related to prolonged sickness absence¹⁹ and thus might contribute to restrain the recovery process. So far, we have focused on the term medically unexplained syndrome. In what follows, burnout will be used to represent medically unexplained syndromes in general.

Most of the empirical work on burnout is conducted within a social psychological framework where burnout is thought to relate to an individual's capacity to meet society's expectations about personal achievement.²⁰ The majority of the empirical work consists of cross-sectional designs and randomized controlled trials.²¹ These studies tend to miss much of the complexity, ambiguity, and ambivalence of the burned-out individuals' lived experience and to a minor degree appreciate that these individuals are coping with more existential changes in their lives.²² The present study will contribute to fill this gap by starting to uncover what it is like to suffer from burnout while waiting to be recognized as ill. From what Emma in the initial quotation said, she "lost herself," and everything that she knew about herself felt changed. The little girl inside her was stuck in chaos, feeling terribly scared and naked. By conducting a phenomenological study, we will enhance the work of previous researchers by inductively and holistically exploring the interviewees' experience in their context-specific settings. The aim is to uncover a deeper understanding of the what-ness of experiencing being naked in the eyes of the public while waiting to be recognized as ill.

2 | THEORETICAL PERSPECTIVE

We are inspired by the philosopher Maurice Merleau-Ponty's phenomenological approach and his theory of human existence as basically a bodily, intersubjective, and situated existence.²³ When we experience burnout, one immediately present sensation can for

instance be the perception of fatigue and pain. The experience is located in the person's embodied, intersubjective relations with others as much as it also occurs "in" the body.²³ The unity of the mind and the body is paramount; to be is to have a body that constantly perceives the situation we are part of.

Further to Merleau-Ponty, our consciousness is underpinned by an "intentional arc" that projects around us our past, our future, and our human milieu.²³ The intentional arc describes our relation to the world and focuses on the unity of the interaction between the individuals and their worlds. Out of this intersubjective field, "figures" emerge. The configuration of a figure against a ground displays the meaning, and meaning is achieved only through relations in the field. Thus, the relationship between the ground of the field and the figures that emerge is what gives meaning to the whole.²⁴ Thus, what we perceive is at any given time perceived from the specific point of view of a perceiving and situated individual. As perceiving subjects, we are always in a reciprocal connection to the context we, at any time, are engaged in. Perception is intimately linked to possibilities for action and is inseparable from the consciousness it has—or rather that it is—of reaching the thing itself.^{23 p.374} As such, the body is situated and intends towards emerging figures that stand out from the ground in its environment. Thus, perception is the realization of my access to the world via my perceiving and interrelational body that cannot be separated from my world. This unity can be seen as the seat of personhood. In illness, it is the intentional arc that "goes limp" because in illness, our bodies are no longer able to pursue our projects as we did when healthy.^{23 p. 136}

The person's world is phenomenologically both relational and personal in that the person and the world coexist. In this coexistence, we direct ourselves towards anything, in or outside ourselves, and display a behaviour in relation to that object and thus are self and world coconstituted.²³ Burnout is lived in the context of family and society and the perception of burnout is encountered in the intersubjective and social realms of the participants' lives. When something is perceived, it cannot be experienced without it being apprehended in terms of a meaningful world. For Heidegger, "world" and "lifeworld" are synonyms.²⁵ The person's lifeworld is their experience of being human.^{26,27} Ashworth has described this notion further to encompass several parameters, including a sense of self, embodiment, relations to others, spatiality, temporality, projects, discourse, and mood as atmosphere. These parameters constitute a whole and are to be taken as parts of a lifeworld, which are not separable into rationally distinctive bits; the lifeworld is therefore indivisible.²⁶ Thus, all experience is within the lifeworld, and this is for each of us "my real, subjective world."^{23,28,29}

3 | METHOD AND DESIGN

3.1 | Recruitment procedure and interviewees

The first author contacted 10 colleagues from the Oslo area (Norway) and asked if they could help to recruit participants for the project. They were given written information about the project and a handout

for their clients with contact information. Eight volunteers, two men, and four women made contact. They were invited to a personal information meeting. The aim of this meeting was to present the project and make sure that they fulfilled the selection criteria. These criteria were individuals between 25 and 65 years who had been employed at least at an 80% position and had been on sick leave for more than 52 weeks prior to the interview. In addition, their burnout symptoms should be consistent with exhaustion disorder according to ICD-10, F43.8A. All the volunteers fulfilled the selection criteria and agreed to participate in the project. They were informed about the further process and their role as interviewees. In addition, they were invited to keep a personal diary during the fortnight prior to the interview, which they were free to refer to during the interview.

3.2 | Data generation and analysis

The focus of the interviews was the participants' lived experience of their encounters with their GP and NAV. We applied a phenomenological research method. This approach is especially relevant when the aim is to explore burnout as a lived phenomenon.^{30,31} The existential phenomenological research approach emphasizes the individual lifeworld. This approach can be seen as a method to explore human phenomena that can, in turn, be recognized as true for all humans. During the interviews, an important consideration was to meet the participants in reciprocal humanity, while being aware that the interaction would influence the dialogue.

The first author conducted the interviews and transcribed the audio-recorded interviews verbatim. Then, the transcriptions were analysed. The intention was to allow any emotions, patterns, and themes related to the interviewees' experience to emerge from their descriptions of the situation, rather than being based on predefined themes. In this process, our aim was to explore and elaborate on the participants' pre-reflective and lived experience of burnout. As the interviewer and first author is part of the field, it is challenging to be able to set aside one's own presumptions of how this phenomenon could be understood. When analysing the data, we, as a collaborative research team, intended to keep a stance of openness towards the participants' expressions of their experiences. Thus, the process of analysis and interpretation as a nonlinear style was concerned with the dynamic relationship between the part and the whole of the empirical material at multiple levels.³⁰

4 | ETHICAL CONSIDERATIONS

The project was approved by the Norwegian Centre for Research (NSD no. p469). Prior to the interviews both verbal and written information about the study were given to the participants in separate meetings and written informed consent forms were signed by all of them. They were given a copy of their transcript and had the opportunity to read and amend the transcript. All data were de-identified and stored in a secure manner according to the ethical principles required by the University of Oslo (UiO). In designing the study, the participants' vulnerable

situation, being on long-term sick leave, was given special consideration. Clear boundaries were set, based on a written informed consent about the context of the research project, the research process, and how the findings would be reported. We acknowledged that the research process could cause painful awareness of their situation, and consequently, each participant was informed about the opportunity to come in for a debriefing session after the interview if they experienced excessive emotions as a response to what was brought up during the interview. However, this situation did not occur.

In the next section, we will present some selected excerpts from the empirical material. When working through and analysing the transcribed material, some parts of the participants' experiences stood out—parts that touched us and awakened us. For us, it was important to try to understand the meaning inherent in the words used to describe these experiences. From there, we chose excerpts from the transcribed material that could illustrate our analysis. Our focus was to be transparent as researchers about the nature of the experiences or phenomena we were analysing that we finally ended up with discussing. All the names are fictive.

5 | DISCONNECTION AND A SENSE OF SHAME

5.1 | The “battlefield”

Through our analysis, the participants' experiences related to encountering their GP and the NAV stood out as especially vital to explore further. The participants told about spending a lot of energy trying to explain their condition without feeling heard. As Gunn, one of the participants explained:

With regard to my doctor it is a continuous battle. I don't feel that he respects me. Had the feeling he labelled me into a psychological pigeonhole. At first, I went there on my own, but now my husband comes along every time because I sense a big difference when he is there. (Gunn)

In this quotation, we were struck by how Gunn described her experience of encountering the GP as taking part in a battle. Health care is usually understood as a place where people can expect to get help, care, and comfort related to their illness and health condition. From what Gunn says, the battle seems related to her feeling of not being respected. The battle might, therefore, be understood as a disagreement with her GP related to what she terms psychological. Thus, the battle concerns an opposition between the GP's and Gunn's understanding of her illness. When the lived experience and understanding of one's own situation differs from the GP's understanding to such a degree as in this case, the GP's diagnosis is difficult to accept. Then, Gunn got the feeling of neither being seen or heard nor respected or understood. The kind of difference she is sensing when her husband joins her in the appointments is not described other than as “a big difference.” The difference made when bringing him along could be described as added supportiveness to counteract the

feeling of being epistemically excluded. The husband's presence might be understood as “forcing” the GP to listen to how she understands her own situation and accepting that she has knowledge about her illness and the health challenges she experiences. Yet another participant describes his experience when encountering the GP this way:

He asks me if I'm suicidal. He is focused on depression and antidepressants came up quickly. The focus became wrong quite early on in relation to what my needs were or what I needed help with. I'm sort of in limbo; a place in between where I am neither nor. What I define as important to discuss with the doctor somehow disappears. It seems as if there are happy pills outside in the waiting room. I became passive and indifferent almost. (Toivo)

Just like Gunn, Toivo also seems to disagree with the GP regarding diagnosis and medical treatment. In this situation, Toivo seems to experience being labelled with a diagnosis that he felt was the wrong one. Although he tried to explain how he experienced the situation, he seemed to feel abandoned by the GP. The doctor's strong opinion about what Toivo's needs were seemed to put him into a sort of middle position where he experiences being neither nor. This could be understood as the experience of feeling disempowered. Toivo seems to associate feeling passive and indifferent as a reaction to the GP's attitude that happy pills seem to be the solution to everything—and definitely to such problems that he himself presents with. In this situation, he might have felt unable to escape the neither-nor position. This experience might be interpreted as being neither able to recognize himself as depressed nor being able to influence the GP's opinion—in other words feeling helpless. Another participant tells about her experience of feeling “not being met” in the encounter with her GP.

People try to understand. And then you notice that they are a bit prejudiced. They're thinking ‘can't you just pull yourself together. How can that be so hard? But they don't get it. I was embarrassed and felt awful—can't even manage that, you know. I didn't have any physical symptoms that showed. I was just terribly tired. The GP listens to me, a bit impatiently and says “Ok.” I felt a strong scepticism emanating from her, with a very clear message about not wanting to put me on 100% sick leave. I started crying. It just felt so painful not to be met properly. It was a continuous struggle. (Nina)

Nina experienced the encounters with the GP as “a continuous struggle” that seems to be similar to what Gunn said and thus might touch upon each other in meaning. For Nina, the struggle seems to be related to feeling distrusted by the GP, when asking for permission to stay at home. Although Nina believes that people try to understand how it is for her, she seems to sense being prejudiced. When she became aware of the GP's scepticism, she might have felt pushed by the GP to stay at work, which she might have understood as an expression of “just pull yourself together.” When feeling seen as weak and unable to meet what she imagined that others expected of her,

thoughts about herself such as being worth less than others might have come to the fore. When stating that it felt so painful not to be met properly, it is nearby to understand this experience as feeling judged and evaluated as unable to cope with what “everyone” has to handle in their lives. The painfulness might then be related to feeling degraded as a person. The participants' experience of being part of a battlefield points out a possible disagreement over whether it is the patient who has the right understanding of how it is like to suffer from burnout, or if it is the GP.

5.2 | The “NAV directive”

As we will see, the battle continues. In the next excerpt, another participant emphasizes how her GP also provided an explanation to her suffering that she could not recognize as the right one. She says:

I felt that the doctor was really happy when I was sitting and crying in her office because at last she could prescribe Cipralext and call me depressed. I feel like I'm very stuck. I have called it indifference. But for how long can I stand feeling like this? (Tone)

Tone experienced her GP's reaction to her tears as like that of “being happy.” This happiness might be understood as a reaction of observing some symptoms that fit with an accepted medical diagnosis. At last, when her patient was sitting there crying, an obvious symptom of depression manifested, and the GP could not only relate to a diagnosis but also prescribe medication to help her. Alternatively, perhaps the happiness Tone sensed in the GP when crying could have been a feeling of relief when finally, being able to give her patient a “legal” diagnosis. In this case, a legal diagnosis might be understood as a diagnosis that would be accepted by NAV. Thus, diagnosing her patient as depressed would “cover” her back by being able to justify her patient's sick leave in front of the NAV system. Just like Gunn and Tiovo, Tone seems to disagree with the doctor regarding how her illness should be understood and diagnosed. When being diagnosed as depressed, Tone says that she feels stuck. In this situation when not feeling heard or supported by her GP, it is easy to relate the feeling of indifference to a sensation of helplessness. In respect to the sensed disagreement between herself and the GP, Tone further explains:

I am not being misunderstood, but I'm experiencing what it means not to be believed—actually a lack of trust. Three times, I have experienced refusals in decisions from NAV. And there I am, so sure I'm entitled to the benefits, but instead I'm given an account where everything seems a bit turned on its head. Feeling that everything is twisted and turned so they can refuse me AAP (Work Assessment Allowance). And it is tough to read what they write about me as well. (Tone)

Related to her applications for support from NAV, Tone says she is “not misunderstood” but knows “what it means not to be believed.” She seems to experience that NAV do understand her version of the situation. She recognizes however what she sees as a distorted

description of her suffering in the written rejections from NAV. Therefore, she interprets that they do not believe her. Thus, her experience of what it means not to be believed is not only a result of the rejections of the applications but is also related to how NAV confronts her with what she perceives as a twisted description of the situation she lives. Again, disagreement seems to be at the forefront. This time the disagreement is related to whether it is the patient or NAV that posits the “right” understanding and description of the situation. One of the other participants also described her experience of encountering NAV. She tells:

My doctor diagnosed ME, but this was not accepted by NAV. It was awfully frustrating and hurtful to experience such unprofessional treatment of my case from NAV. It felt degrading to be treated like that. As if I was a scoundrel. It is clear that when I am not seen or heard I almost give up. (Sonja)

Sonja's GP diagnosed her with ME. When NAV refused to accept Sonja's diagnosis, she experienced that not only her GP was refused by NAV but also herself was seen as trying to claim rights she did not have. It hurts when feeling distrusted—and seen as if she tried to deceive undeserved rights. Disagreement and distrust seem to be prominent in the participants' experiences encountering both GP and NAV. Instead of feeling supported the participants described feeling left alone, distrusted, degraded, and helpless. A pertinent question related to what seems to happen in encounters between patients and those who are supposed to help is how then to act when you need help? In the next excerpt, one of the participants shares his experiences related to this:

I think the doctor has had a directive from NAV. The woman at NAV has in reality confirmed it. I felt real pressure to be at work. It went as far as my boss telling me to do something. You're walking around here like a corpse. People are wondering what's happening with you. Why the heck are you here so much? It's not good for you. Can't you just go on home and get well. Dreading having to go to the doctor doesn't exactly help you get better. I felt like a little boy at school being told off. Going to see a doctor you know will tear at your soul isn't much good and you just cannot manage to do anything about it. (Hans)

Although Hans does not feel well, he still goes to work. Even when he experienced being seen as ill by both his colleagues and his boss, he cannot just take it as support because he needs to have the GP's “permission” to stay home and “get well.” He dreads going to see his GP, as he knows that it will “tear at” his soul. What he believes is that NAV and the GP have a sort of agreement, which he experiences as not supportive for handling his situation. When the GP and NAV agree that you are not entitled to being sick listed, you have to go to work to earn money for living. In this situation, Hans experienced that his boss and colleagues almost “forced” him to stay home to recover. When being exposed to these radically different opinions related to

his condition and literally being in the position of being disqualified and disempowered, it is understandable that it felt like being a little boy in the meaning of being without any authority related to his own experienced life situation.

The participants' stories seem to highlight possible distrust at several levels: between the patient and the GP, between the patient and NAV, and between NAV and the GP. The result seems to be that the participants feel neither seen or heard nor respected or understood. On the contrary, they seem to feel distrusted and disempowered. Such feelings are appropriate in response to how the lifeworld speaks to them in terms of being disqualified by others.

5.3 | Being a “no-body”

We shall now see how another participant describes her experience of struggling to cope with living the situation of being burned out.

Reality has become lost to me. This is very frightening. All the time there are things to relate to from outside. It is exhausting. There is no space for what is me. That's why it seems like I am shrinking into a reality that doesn't exist. I just can't cope with that part. I withdraw. (Sonja)

When Sonja says that reality has become lost to her, this might be understood as she experiences her being in the world as radically changed. Such a big change of being in the world is frightening as the life and living situation she was familiar with and once knew seems to have disappeared. In this situation with all impressions and expressions from what she names “outside”—an outside that might be related to others—the GP, NAV, and society as such, she experiences there is “no space for what is her,” and she feels to shrink. One way of understanding this is that the outside does not see her as she experiences herself to be and, by this, shrinks her into a feeling of disappearing as there is no space for being who and what she is. Being put into such a situation, she sees the best alternative as to withdraw. To withdraw might be her way to protect herself and taking care of herself. In the next excerpt, Nina expresses how she felt “forced” to go underground when not able to meet what she sensed others expected of her. As she has previously mentioned, she felt being pushed by her GP to stay at work and she felt forced to “pull herself together.” When feeling unable to do so, she seemed to feel negatively judged by others.

I was invited to lunch with a possible employer. It was a wonderful occasion on which to present myself in a good light for possible new commissions. There were around 20 people present. Very important people. At the beginning of my presentation, I had to start by saying what an uncomfortable situation this was for me. I didn't know why I was there. I was extremely tired and felt pretty awful actually. I sensed how the audience lost respect for me. I could have died on the spot. I was so exhausted. I wasn't able to defend myself. That's how I seemed to finish, and then I was put on

sick leave. That's when I went underground. That's what I've felt I did. So now I don't know how to get back. (Nina)

At the beginning of her presentation, Nina started with disclosing to the audience how uncomfortable the situation was to her. This might be an expression of her understanding that she wanted to be there but because of feeling extremely exhausted, she knew that she was not able to handle the situation as she wanted to. When disclosing how she felt, she might have become aware that the audience could see her as not good enough, which might be the reason why she sensed that they lost respect for her. It is nearby to understand that losing the audience's respect could have triggered Nina to feel embarrassed and unable to hide from the gaze of others. Thus, she seems to relate the sensation of losing the audience's respect to feeling that she could have died on the spot. In this uncomfortable situation, she might have wished to flee but felt stuck in front of the audience. Then, “dying” could be understood as a metaphor for wishing to disappear, and this was exactly what happened when she went underground. Nina is not the only one who wants to hide from the gaze of others. Here is how one of the other participants puts it:

When you experience hitting rock bottom like that, all your protective walls are knocked down and all your feelings lie exposed, leaving a lot of yourself seeping through. (Hans)

In this excerpt, Hans refers to what it was like when hitting “rock bottom.” His experience seems similar to how Nina described her need to protect herself by going underground. As Hans puts it, the protective walls he had built to hide his vulnerable self were no longer intact. In this situation, he seems to imagine being transparent to everyone and not being able to hide. Feeling vulnerable in this situation might be related to be seen as weak and helpless—in fact being exposed as unprotected and transparent. Thus, feeling “naked” seems to provoke an existential anxiety, as we shall see in the next excerpt.

During the first year on sick leave the GP proposed that I should join a project called “Quicker recovery” sponsored by NAV. The long bus fare and the treatment—it felt so shitty that I dropped out after just a few sessions. At this time, the worst of it was handling the so-called reality, dealing with people and feeling so incredibly useless and shitty. I feel like it shows on the outside and that it's something everybody can point at and see. That's when anxiety and fear come thundering in all directions, shapes, and variations, which is really, really shitty. I was at the point of despair. It was my whole life—all of me that I couldn't stand. And I am not able to do anything about it. My need to escape reality suddenly becomes acute. I am not able to stand how I am - and what I might do to myself. (Toivo)

Toivo tells that he was at the point of despair. When attending the treatment project, he was forced to be part of what he terms the so-

called reality. In this situation, Toivo felt “incredibly useless and shitty.” Therefore, he seemed to drop out. His experience seems to touch upon Sonja's experience. She felt unable to interact with anyone when she experienced that reality had become lost to her. Additionally, it is possible to understand the despair Toivo experienced as a reaction to how he imagined others could see how he felt. This experience seems related to how Nina might have experienced being unable to hide from the judging gaze of others.

When living through burnout Toivo's Lifeworld is changed. He seems unable to recognize himself and does no longer fit into the “so-called” reality. Toivo, just like Nina, felt unable to change the situation. Seeing himself as a useless and “shitty” person, Toivo was desperate to escape his life. This situation seemed to have elicited an existential crisis where he realized that he could harm himself. Finally, here is how another participant experiences her desperate situation.

I had cancer when I was in my thirties, and then I was received with open arms. Everyone does everything for you and gives you presents. However, when you get an illness like burnout there aren't many gifts around, that's for sure. You are just “a no-body” then. There is nothing left. I was so distraught about everything that if I hadn't had children and grandchildren I would have killed myself. I thought about that a lot. During the worst period, I kept thinking about how I couldn't stand this. First of all, feeling so ill and almost incapable of getting out of bed—and on top of that experiencing so much resistance. (Sonja)

In this excerpt, Sonja describes how she experienced the difference between suffering from cancer and suffering from burnout. When she had cancer, she felt like a “some-body”—a person who deserved presents. Suffering from burnout, she experienced quite differently—like being just a “no-body”. Being a “no-body” can be understood as feeling unsupported and left alone. Moreover, by being a no-body, no one cared for her as it is not possible to care for a “no-body”. As she puts it “there is nothing left,” which might be understood as there is nothing left of her life as she knew it and how she wants to live it.

To summarize, the participants experienced feeling rejected in encounters with the health care system and NAV. None of them saw themselves as being depressed and being diagnosed as depressed made them feel neither seen or heard nor understood or respected. Additionally, having to struggle to convince others that they were entitled to social benefits, they experienced themselves as distrusted and without any status or legitimacy, which seems to be related to the experience of being disconnected from their worlds. The disconnection might create an awareness of feeling seen by others as worth nothing and, then turning the gaze of others towards themselves, seeing themselves as a “nobody.” Seen as a nobody in the eyes of others seems to elicit a sense of embarrassment connected to themselves as persons. In the next section, we will discuss how the participants' experience of feeling undressed publicly and unable to hide their nakedness from the gaze of others can be phenomenologically understood.

6 | NAKED IN THE EYES OF THE PUBLIC

Without a known biomedical diagnosis, the participants' subjective health complaints were labelled and treated as psychopathological. This duality, related to understanding human beings as either mind or body, is due to the inherent norms, values, and attitudes that are coloured by the biomedical stance taken within EBM. Phenomenology understands human suffering differently. Merleau-Ponty points out that “there is no inner man (sic) ... Man is in the world, and only in the world does he know himself.”^{23, xi} Thus, the experience of burnout symptoms cannot be separated from the participants' world as it is encountered in the context of family as well as communities. This context is the intersubjective and social realms of the participants' lives. Their perception of pain is located in their embodied, intersubjective relations with others as much as it also occurs in their bodies. Thus, there is no access to any inner selves except through living in the social and cultural surroundings we at any time in life inhabit, ie, our lifeworld. Therefore, the psychosocial experience of being ill is even more important than the unknown aetiology of burnout.

The participants had experienced being ill for a long time. Feeling seriously ill without recognition of their situation triggered an existential anxiety. All except for one described the encounters with the GP as a continuous struggle, which triggered feelings of frustration, despair, and hopelessness. Seven of them felt pushed to go back to work either during the period of sick leave or after having been granted AAP. The world seems to say: “Can't you just pull yourself together? How can that be so hard?” The interviewees' subjective knowledge, however, is their bodily perception of being ill. Being aware of what they sensed in their bodies, they knew that they were not able to perform what was expected of them. Moreover, when feeling distrusted the participants' distress escalated and turned their experience of being in the world upside down. As the empirical material and the phenomenological analysis has shown, the participants experienced being disconnected from their lifeworld. This theme highlights how the participants' relation with both others and themselves felt disconnected. Without exception, they were transformed by the illness into persons who were unknown to themselves. They were not able to recognize themselves and hardly knew who they were anymore. At the same time, being fearful of their own alienness, seemed to elicit a feeling of losing control. Others also seemed alien to them. When sensing the strangeness and weirdness of both themselves and others, anxiety raised. When healthy, they had experienced the epistemological progression referred to by Husserl; I express myself, then others listen to me and then I am able to influence the situation.²⁹ Although the participants tried to voice their experience of being ill, they felt distrusted and no one seemed to care. Thus, they no longer experienced themselves as agents in their own lives. This experience seemingly triggered a need to withdraw from interactions with others to survive. The participants were, however, not able to protect themselves from feeling intruded and overwhelmed by the outside world. The distress they experienced in this situation seemed to result in a feeling of powerlessness, which

can be understood as the psychological situation, wherein the life-world speaks to them of social identity, their feelings of presence, their sense of agency, and inability to voice their experience. Thus, selfhood is a continuous background meaning of my feelings, thoughts, and behaviour, and the self as a fraction of the lifeworld is the way in which my actions and their effects are open to my awareness.

When we experience the inability to recognize ourselves as the person we used to be when healthy and to pursue our projects as we once did, the sharp awareness of “how do I appear” comes to the fore. In such situations, we suddenly become aware that others can see us as inadequate. Emma, in the introduction, described the disconnection with her world as feeling naked. Hans did not use the word naked in his description of how it felt like for him when all his protective walls had been knocked down, leaving a lot of himself seeping through. Thus, feeling disconnected from their world seems to elicit a loss of agency, which in turn leads to a loss of self-esteem.

Much of the literature on burnout recognizes that the sense of diminished self-esteem experienced is often accompanied by a sense of shame. While irrational, this sense reflects the persons' feeling of being “damaged” when not being met by others. It is the experience of feeling rejected and separated from others that triggers shame.³² Moreover, when seen by another person, we are intertwined into that person's world. In this situation, we may feel either affirmed or undermined by others. Thus, other human beings are a central part of our lifeworld because of their impact on our selfhood. This means that we can feel judged, which elicits an awareness of either shame or pride. The person who experiences burnout perceives her own difficulties in the first person. Others also perceive her as a physical entity with particular features, which in this case may be faking illness—in other words, acting as a scoundrel. She is then perceived by herself as seen through the eyes of others. The moment we become aware of the mere look cast by another that we interpret as alienating and uncomfortable is the moment we want to escape it. It is through the look of the other that we feel objectified and judged as “cheating.” Thus, shame might be triggered when we become aware of ourselves as objects seen through the eyes of the other.³³

Gradually the participants lost sight of a life worth living. As Sonja puts it, “you are just a no-body then. There is nothing left.” Although their basic need was to feel supported, shame might have hindered a supportive interaction with others. The feeling of being vulnerable and unprotected—in fact caught off guard in the eyes of the public—was not conjunctive with being able to take support from anyone. This fact might have counteracted resolving the existential crisis in which they felt stuck. Shame brings them face to face with themselves. This is what Sartre pointed out when discussing what he calls “bad faith”—the effort to flee from oneself.³³ The participants seemed to struggle to accept themselves as seen in the eyes of the others while simultaneously seeking to hide from themselves as well as the world. The need to withdraw from interactions with others and themselves became acute. It was however not possible to escape because

perception via their perceiving interrelational bodies could not be separated from their worlds without literally leaving the world. As Toivo said, he felt neither able to stand the person he had become—nor what he might do to himself. Three of them explicitly considered suicide as a way out when being aware that there was nothing left worthwhile living for.

7 | THE EPISTEMIC INJUSTICE

The study uncovered that the participants sensed being distrusted by the GP when labelled as depressed. This fact seemed to worsen the participants' situation. The GP's mission is to take care of the patient and cause no harm. Therefore, we were struck by how the participants experienced the encounters with the GP using terms as a continuous battle or struggle. The interviewees expected support and being taken care of by their GP. These expectations were obviously not met, neither in the relation between the GP and patient nor between the patient and the NAV system.

In the encounter with the GP and NAV, all the participants spent a lot of energy trying to explain their condition without feeling seen or heard. Their stories show how they as “knowers” of their own bodies were ignored and distrusted. As previously mentioned in the introduction, this set of reaction to illness constitutes a form of injustice that is uniquely epistemic and is done to the patient in their capacity as knowers. Often such injustice is caused by biases and negative stereotypes³⁴—in this case about burnout as a medically unexplained syndrome. From what the participants have shared in this study, we have seen how incommunicable the syndrome is and how invisibly fatigued the participants are. The discrepancy between the perceived ease of a task and the great challenge it poses for the person who experiences burnout creates doubt in the mind of the observer. An observer often sees the person when she is at her best because when the symptoms are bad, she is in bed. This fact does not really convey the subjective sensation of severe illness. The complete certainty of the lived experience of burnout and the complete doubt it generates when viewed from the outside makes it similar to distress. The distress and sense of loss of control in addition to the panic of dreading living with burnout for the rest of one's life are internal and invisible. The outsider, in this case the GP and NAV, can never know if the patient is really feeling the pain or merely behaving as if she does.

In illness, the norms of feeling and action shift considerably and are quite different to the norms when healthy. Persons who have not experienced burnout themselves have no reference parameters. Therefore, the ability of a healthy person to understand the constricted experiential space of the person who experiences burnout is limited because of the lack of a shared experiential background. The shared norms of normal functionality disappear. Thus, when normal and pathological experiences diverge, communication suffers, which is clearly highlighted in this study. The participants feel neither seen or heard nor respected or understood. On the contrary, they seem to feel distrusted, disqualified, and disempowered, which might result

in feeling helpless and embarrassed. As this study shows, the problem of sharing the experience of burnout and the normal sceptical challenge can undermine the quality of clinical care and knowledge.

The study also shows that there seems to be distrust related to several communication levels. The first level is between the GP and the patient; the second is between the patient and caseworkers at NAV. There also seems to be third level which Hans termed the "NAV directive" related to how the GP seemed "induced" by NAV to push the participants to go to work. According to the participants' experience of feeling distrusted, the study seems to indicate that the norms, values, and attitudes inherent in the biomedical and societal system affect the encounters between the GP, NAV, and the patient in a negative manner. Moreover, the study also seems to indicate that political decision making is based on the norms inherent in the biomedical model, which in turn determine what is recognized as illness. Therefore, we suggest a need for reviewing what norms, values, and attitudes that are needed to improve the outcome of medical care. Additionally, issues of power need to be addressed properly and considered in the context of these interpersonal relations.

CONFLICT OF INTEREST

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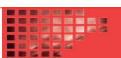
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