

A narrative journey into the borderland of patient safety: Toward an expanded, relational concept of safety

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ABSTRACT

“Patient safety” is routinely defined in health services globally as “safety for patients against harm and risk of injury in health care.” (Danish Board of Quality in Health Care, 2022, p. 28; translated by the author). This is a standardized, broad, and general definition of

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what counts as safety. In this article, I argue for an expanded, relational concept of patient safety revolving around *experienced* patient safety. Recognizing safety as vital for all groups of patients, I follow a dialogical, critical-reflexive approach to focus on safety in a somatic hospital setting in Denmark as it is experienced by people with lived experience of mental distress. Safety in this context is often compromised, contributing to inequity in health for people with mental distress. I present and analyze the narratives of two experts by experience about their somatic hospital stay. As an analytical approach, I draw on Frank’s dialogical narrative analysis together with elements from Bakhtin’s theory of dialogue and Foucault’s theory of power/knowledge. Forefronting voices of those rarely asked and seldom heard, dialogical narrative analysis provides insight into how “patient safety” is enacted through situated negotiations of meaning in the narratives of people with lived experience. The storytellers are continuously struggling to fit in and to be seen as human beings, trying to resist public narratives on mental distress that threaten to limit their scope of action and who they can become. The discussion highlights how unintended emotional and psychosocial harm limit the benefits of patient safety for certain groups in society. In particular, shame, individualized responsibility, and internalized inferiority hinder equity in health. Building on my analysis, I suggest a collaborative, participatory approach for co-producing further knowledge through joint analysis with people with lived experience and nurses from somatic hospital wards.

Introduction

Patient safety is a concept that is well-established in health services globally and promoted by the World Health Organization (WHO), which launched its “Global Patient Safety Action Plan 2021-2030” (2021). The WHO defines patient safety as “framework of organized activities that creates cultures, processes, procedures, behaviours, technologies and environments in health care that consistently and sustainably lower risks, reduce the occurrence of avoidable harm, make errors less likely and reduce the impact of harm when it does occur” (2021, p. vii). The vision of the Global Patient Safety Action Plan is “a world in which no one is harmed in health care, and every patient receives safe and respectful care, every time, everywhere” (2021, p. viii).

In the healthcare system in Denmark, patient safety is officially defined as “safety for patients against harm and

risk of injury following the healthcare system's interventions and performances, or the absence of it" (Danish Board of Quality in Health Care, 2022, p. 28; translated by the author). This standardized definition entails the prevention of error and unintended harm in health care through systematic learning and analysis of harmful events. It is very broad and at a high level of abstraction, saying nothing of the time perspective (Does injury count if it appears after discharge?), subject matter (What counts as harm?) or power perspective (Who defines what counts as harm?). Furthermore, defining something by its absence leaves the meaning wide open. Sokol-Hessner et al. (2015), for example, identify the absence of respect and dignity as an example of unintended emotional harm.

Patient safety is promoted and monitored by the official Danish Patient Safety Authority (DPSA) and a well-established reporting system. In 2021, more than 326,000 unintended incidents were reported (DPSA, 2022). Both the DPSA website (2018) and the Danish public health website (2018; organized by the Danish regions, municipalities and the Danish Health Authority) enable, and even encourage, patients and significant others to report unintended incidents in an "open and reciprocal" way as recommended by Hor et al. (2013, p. 578). However, in 2021, only 2,664 of reports were made by citizens, equalling 0.8 % (DPSA, 2022).

Examples of relevant incidents given on the two websites include harm following medicine or surgical error, missing blood samples, and fall accidents during hospitalisation. Through their presentation on major public health platforms, examples such as these contribute to defining and delimiting public understandings of "what counts" as harm. As pointed out by Travaglia and Braithwaite, "What an error is, how it is defined, and what is included has been left exclusively to clinicians and researchers" (2009, p. 603). Moreover, as Travaglia & Braithwaite note (2009), the technical-physical examples given on the two websites reduce what counts as unintended harm to a clinical, instrumental measure which does not take the complexity of safety into account. Psychosocial and emotional harm are excluded, and, as a result, a wide range of serious adverse events are not registered in the incident reporting systems (Daumit et al., 2016; Kuzel et al., 2004).

Rexbye and Frappart (2022, p. 25) recognize the complexity of patient safety, pointing out that it does not exist in a vacuum, but as part of a multilevel interactional system comprising culture, performance, organization, work environment, structure, policies, and standards as well as individual factors. Travaglia & Braithwaite (2009, p. 600), too, understand patient safety, not as a well-defined technical problem, but as a "social mess" embedded in a complex setting with fuzzy boundaries and, hence, as a "wicked problem" (ibid) defying quick-fix solutions.

According to Hor et al. (2013), it is difficult to find *the patient* in the official definition of patient safety since

experienced patient safety deviates significantly from the official standards. Safety, they state, does not represent a fixed state of affairs, but is constituted through continuous, situated (inter)actions. This is an expanded, constructivist, and dialogical conceptualization that resonates with Rhodes et al.'s understanding of patient safety as "fluid, contingent, multi-dimensional, and negotiated" (2016, p. 270). On the basis of their conceptualization, Hor et al. (2013) argue for a person-centred, relational, context-sensitive approach to safety that pays attention to power imbalances and reflexively addresses how "patient safety" is enacted through situated negotiations of meaning.

As a registered nurse (RN), a postgraduate mental health nurse, lecturer in nursing, and PhD student, I draw both on professional experience and an international body of literature that classifies emotional and psychosocial harm as a severe and largely neglected problem in general (Lyndon et al., 2023; Sokol-Hessner et al., 2015). Emotional safety is vital for all groups of patients. However, I have experienced how the encounter with people suffering from mental health issues invoke discomfort and uncertainty and how they, accordingly, are treated differently or even dehumanized. I have also experienced how a focus on physical and technical safety is foregrounded in somatic as well as mental health contexts. Nevertheless, research points to the particular serious consequences of neglecting patient safety in the encounter between people with lived experience of mental distress and the somatic healthcare system. These consequences include increased inequity in health (Daumit & McGinty, 2018; Harris et al., 2015). As noted by Lyndon et al. (2023), physical safety is prioritized over emotional safety, "particularly among the most structurally and systematically marginalised patients," exacerbating stigma and shame (p. 3).

Rhodes et al. (2016, p. 270) refer to the "largely invisible and inaccessible (but taken for granted) architecture of safety." I consider the term "architecture" a useful metaphor for the taken-for-granted assumptions regarding safety within the healthcare system. The aim of this article, therefore, is to expand our knowledge of this architecture by exploring experienced patient safety in the narrative understandings of people with lived experience of mental distress and somatic hospitalization as they unfold in two in-depth individual interviews drawn from a series of eight. As my approach to producing and analyzing narratives, I use Frank's dialogical narrative analysis (DNA) (2010; 2012), which builds on Bakhtin's theory of dialogue (1981, 1984). The analysis focuses on how the storytellers draw on narrative resources to negotiate the meanings of patient safety and addresses the implications for the storytellers' struggles of being and becoming. In addition to Frank, I draw on Foucault's theory of governmentality to analyze critically how power is in play in the relational enactment of patient safety through technologies of self by which subjects are governed (1991). On the basis of the analysis, I critically reflect on how the of-

ficial definition of patient safety carries the risk of limiting the positive impact of patient safety measures on certain groups of patients. Building on this critique, I argue for an expanded, relational concept of patient safety in contrast to the standardized, technical definition. This concept construes safety as co-constructed through social interaction, storytellers as co-constructors of safety, and narratives as co-constitutive of reality.

First, I present methodological considerations and the narrative analysis. Then, on the basis of the analysis, I discuss the limitations of, and inherent problems in, the standardized, technical concept of patient safety. Finally, I reflect on how the expanded, relational understanding of patient safety underpins a collaborative, participatory research process in which people with lived experience and nursing staff co-produce knowledge and practice change.

Materials and Methods

Dialogical Narrative Analysis (DNA)

Frank views stories as performative, “artful representations of lives” (2012, p. 33), and as such, as vital and “breathing” things (2010, p. 3). In telling our story, we reshape the past and imaginatively project the future as we seek to create an open-ended identity (2012, p. 33). A story represents the storyteller’s subjective understanding of her life and identity; at the same time, it is *external*, as she intertextually draws on socially and culturally shared resources in the form of public narratives (Frank, 2012, p. 36). Therefore, narratives (and selves) are co-constructed bricolages, assembled from available “fragments,” contingently and “artfully rearranged,” but never truly one’s own (Frank, 2012, p. 35). As a dialogically engaged researcher, I do not consider myself an observer, but a witness, and the narratives presented below contribute to a collaborative witnessing that brings voices together to enhance their “evocative force so that these storytellers could hear each other and so that they could be heard collectively” as Frank (2012, p. 36) puts it. By “recovering the voices that illness and its treatment often take away” (Frank, 2013, p. xx), narratives make a powerful contribution to support social change. Furthermore, the teller “becomes a witness to the conditions that rob others of their voices” (Frank, 2013, p. xxi).

DNA builds on a Bakhtinian, holistic understanding of all human life as dialogic. Along holistic lines, Bakhtin conceptualizes every utterance as part of an intertextual chain to which the utterance belongs through its dialogic relations to pre-existing and future anticipated words (Bakhtin, 1981, p. 280; Phillips, 2011, p. 26). Meaning and “selves” are continuously negotiated and produced relationally through a polyphonic play of voices, and, therefore, are “unfinalizable” (Christensen-Strynø et al., 2021, p. 4). As Phillips and Scheffmann-Petersen point out (2020a, p. 1424), Bakhtin posits that people rework

multiple voices to create hybrid knowledge and multi-voiced selves by appropriating perspectives in a process of “re-accentuation.” So, when people invest voices with their own “accents,” these voices are made their own. Bakhtin says: “Prior to this moment of appropriation, the word does not exist in a neutral and impersonal language...but rather it exists in other people’s mouths, in other people’s contexts, serving other people’s intentions” (1981, p. 293). In the re-accentuation process, an ongoing negotiation of meaning takes place, carrying with it a potential for resistance.

Narratives represent individual struggles in all their ambivalence and unfinalizability (Frank, 2005, p. 972). Thus, DNA shows how identities are in constant and life-long transition, “always producing themselves through the combined processes of being and becoming, belonging and longing to belong” (Yuval-Davis, 2006, p. 202). DNA makes available individual stories from the margins of public narratives on mental distress, and I follow along the lines of Blix et al. (2013, p. 264) who, in their work with DNA, emphasize the importance of reducing narrative silences and letting stories “breathe” (Frank, 2010) to challenge the reproduction of established truths and deconstruct stigma.

Methodological and ethical considerations

From a social constructionist ontoepistemological standpoint, I follow Frank in viewing storytelling as a way of relating, sense-making, and knowledge-sharing that enables us to learn from storytellers (2013, p. 2). The recovery of one person’s voice may encourage others to speak through her narrative (2013, p. xxi). This approach supports the idea of a broad concept of “evidence” embracing embodied and experiential forms of knowledge. According to Frank, there is a “gap between the physical and existential suffering caused by disease and the suffering that results from socially organized conditions...including diffuse stigmatization and marginalization of the ill” (2016, p. 9). Furthermore, medical treatment, he claims, “too often increases patients’ suffering rather than reducing it” (2012, p. 37). This represents an ethical problem, not least regarding people with experiences of mental distress, whom we carry a moral imperative to protect from emotional harm given that their psychological health is already compromised (Reeves et al., 2018, p. 58).

This study was carried out in full accordance with the norms for ethical practice followed in the Zealand Region. The regional research ethics committee (EMN-2022-03833) was notified about the research project and had no reservations about it. All participants gave written informed consent in accordance with the Declaration of Helsinki. Ethical considerations are extremely important in this kind of research, and, as I will elaborate on in the following section, I am on a narrative journey where my ethical compass points to relational ethics, as I make a small contribution to bridging the gap identified by Frank

by bringing forth the stories of marginalized voices, often silenced and seldom heard.

Participants

I contacted an ambassador from a Danish anti-stigma campaign for mental health who spread the word about my project in a flyer saying “Do you have lived experience with mental distress and have you been hospitalised in a somatic hospital department? Would you like to help me in my project on communication?” Through her snowballing effort, I managed to arrange eight interviews in a few days out of which I will present two in this article. For instance, I was almost immediately contacted on the phone by Janet (participants’ names are pseudonyms), whose story is one of the two that you will read below. She had just been discharged from a somatic hospital ward and sounded upset and eager to make an appointment and tell her story. After our first short conversation on the phone, she thanked me, saying that telling me this first outline of her story had made her feel better. During the interview a few days later, she said that our initial conversation had encouraged her to contact the district mental health nurse for further support.

All eight participants are white women between their thirties and sixties. Three of them live in supported housing, two live by themselves, and three live with their partner and children. Five have been hospitalized due to physical illness and three as a result of their mental distress, i.e., self-harm and/or a suicide attempt. Despite the use of purposeful sampling (Morse & Richards, 2013, p. 221), my attempt to recruit people from different social categories regarding, e.g., age, gender, and ethnicity, did not succeed.

Active interviewing

The initial contact between the interview participants and me was by mail or phone. Here, I encountered my first dilemma relating to relational ethics. As I tried to express respect, trust, and humility, I was all too aware of my own identities as researcher and nurse, representing the same healthcare system that sometimes inflicts unintended harm.

I interviewed four of the participants in their homes and four online due to the long geographic distances. One of the planned online interviews ended up being on the phone because the internet connection broke down. The interviews lasted from 45 minutes to one hour, 45 minutes and varied in the way participants told their stories. Some spoke almost continuously with very few prompts and probes, while in other cases, I felt the need to give frequent prompts. The narratives moved back and forth across time and space; for some, the story covered one specific hospitalization retold chronologically and in a linear fashion; others told their story along more horizontal lines where similar incidents from different hospitalizations were recounted.

The interviews were non-structured following Holstein & Gubrium’s (2011) approach to “active interviewing” in which an interview is considered a site for interpretive practice resulting, not in answers, but in *stories*. However, I did bring a preliminary question guide to inform my prompts and probes, if necessary, which I would check at the end of the interview to see if any topics of interest were left unaddressed or to assist me if both the storyteller and I ran out of words.

In active interviewing, both participants are regarded as co-constructors of stories and, as such, deeply immersed in creating meaning. Meaning is not elicited, but *assembled* during the interview encounter, emerging out of the narrative interplay. Accordingly, the narratives unfolded through a relational exchange as we assembled meaning through mutual exploration. I found myself immersed in the conversation, contributing with comments, probes, and prompts on the basis of my personal and professional experience, intuition, and emotional, embodied sensitivity as a somatic and mental health nurse with an upbringing marked by parental mental health issues.

The interview method rests upon a social-constructionist, dialogical framework in which the story is recognized as a representation of storytellers’ truth with a small “t,” contributing to a co-constructed body of knowledge. Through a focus on social and culturally shared narrative resources, the method enables exploration of the contingent, socio-cultural, and historical dimensions of what we, in everyday life, tend to call our “own” perception of reality (Pedersen, 2021, p. 100).

Crafting the analysis

In order to select the stories and extracts that “call out as needing to be written about” (Frank, 2012, p. 43), I immersed myself in an iterative process of reading and assessing. In crafting this part of analysis, phronesis and intuition are vital components, supported by ethical values (p. 43). I selected only two of the eight narratives because I wanted the storytellers’ voices to be largely uninterrupted. These particular stories were chosen because they offer richness as well as diversity (Blix et al., 2013, p. 268) in relation to experienced patient safety. The two storytellers suffer from different mental health issues. Simone is in her thirties and has been hospitalized primarily following self-injury and suicide attempts, and Janet is in her sixties and was hospitalized due to a somatic injury.

I present very long, coherent excerpts from their two personal accounts. I want the stories to live and breathe by themselves, which is why my prompts and probes (in italics) are only partially included as examples of the co-creation of meaning, for instance, when Simone elaborates on her perception of darkness in response to my question. I deliberately chose not to provide a presentation of the storytellers in order to let their stories breathe by themselves (Frank, 2010) and to avoid finalizing the storytellers by adding a description of them. I am aware that

this choice means that the reader may lack situational information such as sensory and emotional details or background information such as sociodemographic and biomedical details.

With inspiration from Frank (2010), who does not offer a set way of practicing DNA, and Phillips and Scheffmann-Petersen (2020b), who apply Bakhtinian theory in analysis of patient-centredness, I have formulated the following set of context-sensitive analytical questions to “help thought move” (Frank, 2010, p. 85): i) Which tensions arise across different voices and from which narrative resources do they emanate? ii) How are knowledge and meaning negotiated through the re-accentuation of voices in which the storyteller appropriates perspectives as her own by investing them with her own “accent?” iii) How does the narrative create a tension between forces that finalize lives and unfinalizable meaning-making?

In the following section, I present and analyze Simone’s and Janet’s personal accounts (translated from Danish by the author), letting their stories of somatic hospitalization breathe.

Janet’s story: “I didn’t get to tell him that it’s because I’m a psychiatric patient that I react so unpredictably”

I fell on my floor, and they had a locksmith open the door. Then they drove me there. I was totally unprepared for being hospitalized on a somatic ward. I was not prepared for... other methods and, and, being.... So, when I got there and they gathered around the bed, I got terrified, because when they do that in a mental health setting, it means *something* is going to happen. You’ll get an injection or restraint, you know, something serious. I got absolutely terrified, and I didn’t behave properly. I screamed and shouted, to be honest. Then, the doctor wanted to calm me down and touched me, and then I got even more terrified. It was very anxiety provoking. Then they left.

When there were two days left, the doctor came by, and I apologized for my behavior. And then he said that he knew I was in pain and that he understood. It *really* did hurt. But I didn’t get to tell him that it’s because I’m a psychiatric patient that I react so unpredictably.

There was especially one elderly gentleman [nurse]. He was unpleasant. He claimed I didn’t need the medicine [pain relief]. He said I could do without it. That’s nonsense! He couldn’t know that. If the doctor meant that I should have it, then he can’t just skip a dose. He claimed that I didn’t need the two o’clock dose; that was too much, he said. His patients shouldn’t have too many pills, he said, implying that you could overdose or die

from it. The pain got so immense. I almost didn’t get through those hours. But I discovered that it didn’t kill me; I’m still here, obviously. But it was unbearable. I prayed to God. I prayed, and prayed, and prayed. Tears were rolling down my face. But I didn’t say anything. It was no use.

We talk about Janet’s experience with the level of information.

I was lying there alone, I didn’t know what was going on. I didn’t know the treatment.... Maybe I wasn’t aware of them saying it? I don’t know. They have to say it right away, you know. If they told me about the treatment, I didn’t notice it. It was a mess. I messed around.

It sounds as if you lacked some information?

I don’t think I had any [information].... But I possibly didn’t hear it. Perhaps I didn’t pay attention. I was on my own. I didn’t have any next of kin. I had to figure it out by myself.... Which questions I had to ask and the questions that were not answered. It sounds silly, but my mind goes blank when I’ve gotta ask questions. And you don’t wanna make things worse, do you? If you ask too many questions...are you the one to say...that the treatment isn’t working? And will they stop it then, or...what? You don’t know which way it’ll go. And perhaps you just don’t wanna...take any chances...in that situation.

Could you tell me a bit about how you felt when you came home?

I felt like I had escaped a trap, you know. I felt miserable. I was really...marked by the experience.

Analysis of Janet’s narrative

Insecurity is central to Janet’s story. Janet uses negations like “I didn’t know” and “I wasn’t prepared” or refers to abandonment with “I was alone,” and “then they left.” Janet is not given access to information in a person-centered way that fits her needs. Consequently, the responsibility for maintaining a patient identity is individualized. The story represents Janet’s attempt to ascribe meaning to her lived experience. Her being left alone, terrified, lacking information and psychological safety, causes problems in her interpretation of the situation, so she draws, intertextually, on the familiar and embodied experiential knowledge of being hospitalized in a mental health setting. When this attempt at meaning making is not sufficient, Janet is left in the dark, anxious and in pain, and she reacts strongly; in her own terms, “it’s because I’m a psychiatric patient that I react so unpredictably.” The use of the term “react” – not “reacted” – implies that it is habitual. By apologizing to the doctor, she re-accentuates voices from authority figures (teachers, parents, clinicians) that invoke “the calm, controlled, cooperative patient.” She “helps” the doctor by interpreting her behavior within the terms of the public narrative on

psychiatric patients as (always) reacting unpredictably and thereby reproduces the narrative instead of resisting it. The apology can be seen as a disempowering measure as she ascribes the responsibility for miscommunication to herself. She interprets her behavior in terms of her own mental vulnerability, rather than expecting the healthcare professionals to take responsibility.

In doing so, she internalizes the tensions between external factors (an unknown hospital setting, lack of information) and internal conditions (anxiety, insecurity). Her narrative, then, contains a movement from turning the tensions *outwards* (loud behavior), to turning them *inwards* (“I didn’t say anything. It was no use.”). Thus, power is reproduced through public narrative, restricting the space, resources, and safety to which Janet has access.

Nevertheless, Janet also demonstrates a will to contest the finalization of her identity. Contacting me in the first place and then contacting the local mental health nurse for support may involve an emerging resistance to marginalization. Furthermore, Janet re-accentuates a supportive, appreciative voice in using an exclamation and modal verbs to categorize the male nurse’s actions as wrong: “That’s nonsense! He couldn’t know that,” as well as in referring to the lack of information: “They have to say it right away, you know,” thus defending her patient rights. The process of re-accentuation implies a pathway to resistance in the form of an internal negotiation.

According to the narrative, Janet finds no other way of overcoming her existential and physical suffering than to pray, which contrasts with evidence-based biomedicine and health legislation as well as standard patient safety measures. When asked about the level of information, Janet moves from initial empowerment to internalized inferiority. Janet says “I don’t think I had any” which is a subjective, relative modality that places responsibility with the healthcare professionals, who by all accounts failed in their responsibility to provide person-centered information. But by using a subjective modality, “I don’t think,” instead of the categorical, objective modality “I didn’t get any,” she relativizes her own authenticity. Then, Janet further questions her own authenticity in saying, “but I possibly didn’t hear it.” Finally, Janet attributes full responsibility to herself by adding a stronger modality in saying: “Perhaps I didn’t pay attention.” This movement towards victim-blaming creates a tension between imagining herself as a victim (“I don’t think I had any [information]”) and herself as responsible (“I did not pay attention”).

By discursively questioning her own ability to be a responsible and attentive patient, Janet co-constructs an identity as inferior in terms of integrity, autonomy, and agency. Thus, Janet’s story does not support an opened narrative of what she can become, but reproduces society’s negative expectations of people with lived experience. She projects society’s mistrust onto herself as she scales down the trustworthiness of her own voice, in-

ternalizing the dominant public narratives’ mistrust in her judgmental ability. This self-doubt can be enhanced as a consequence of lived experience with a psychosis spectrum disorder which can affect one’s perception of reality and executive functioning such as memory, planning, and overview.

Furthermore, self-doubt can be enhanced through the healthcare professional’s attitudes. For instance, a discourse analysis of mental health journals in Denmark has demonstrated how patients’ utterances were often referred to using modality-markers like “allegedly,” which diminish the patient’s trustworthiness (Berring et al., 2015). The power of such mechanisms points to the need for co-creating an individual, person-centered practice that counteracts inequity in health and patient safety.

When Janet refers to asking “too many questions” by saying “you don’t wanna take any chances,” she reveals the magnitude of her uncertainty and powerlessness. “Chance” connotes something out of your control, closely related to coincidence, luck, and gambling. By using “you” instead of “I,” Janet normalizes chance-taking as common sense. At the same time, something is *at stake* when you have to take a chance, which is not compatible with the idea of “informed consent” or concepts of person-centered care.

Janet’s narrative representation contains dehumanizing events and psychosocial harm that indicate that her patient safety has been compromised. Stress, fear, and uncertainty can worsen her mental health, causing a setback for her personal and clinical recovery (Roper et al., 2021, pp. 25-28) and, potentially, future healthcare avoidance. Although there are “cracks” in Janet’s story allowing an alternative, empowered identity to shine through, her narrative demonstrates the powerful agency of the public narrative that individualizes and stigmatizes mental distress. In drawing on this public narrative as a narrative resource, she comes to see herself through a lens of self-stigma that reduces the societal space in which her integrity, self-worth, and self-respect are allowed to unfold. This compromises strong ethical and democratic values and, more specifically, the premises of person-centered communication.

Simone’s story: “When you have this huge feeling of shame, it doesn’t take much to make it all fall apart”

When I think of my encounter with somatic wards, I arrive with expectations and wishes about being taken seriously. But that’s not always the way I feel I’m met. I feel that my psychiatric diagnosis becomes the lens everything is viewed through, no matter what it is. That my reaction to information I’m given... it could be, uhm... I was at... I can’t pronounce that. Something with metabolism. It was a foreign doctor, and I didn’t un-

derstand anything he said. Then the nurse tried to... And I was, you know, my threshold when it comes to getting frustrated was very low. I could not... I was so frustrated. And that was attributed to my mental disorder. I spoke to others, who don't have mental health issues, and they claimed that my feelings were appropriate in that situation. That I wasn't the one who's supposed to have the big picture and being patient and understanding regarding the lack of sufficient communication.

I've had several suicide attempts, and in those cases, you aren't treated.... I'm not treated very well, and I've also heard from others that you don't...you're just a downright nuisance. "You did that to yourself!" It feels like you're an object. It isn't necessarily communicated directly to my face, but in their whole attitude towards me. Like, when I've taken an overdose, often I get confused and shaken. I was at the cardiologic department and had an EKG [electrocardiogram] taken. My hands were shaking, and I couldn't button my shirt, and a man yells at me: "Will you get that shirt buttoned!!" really rough. I couldn't manage at all.... It was so humiliating. And when I feel ashamed, it gets even worse; it [suicidal attempt] isn't something you do to bother people. It's precisely in order to disappear. I'm received in the same way in the emergency room, like...rolling eyes and "you are wasting our time." I have experienced that several times. "Is that you again"-ish.

I remember once I was wheeled in on a stretcher, and a nurse received me saying "Well, here's Simone once again. Unfortunately, we know her all too well." The ambulance driver looks down at me and he sees that I'm all.... And then he strokes my cheek. It was so lovely.... But I had to be left with *her*. And I just wanted to disappear. It was so uncomfortable.

Once I overdosed, and I had researched in advance.... And one of the doctors said to me "If you take so-and-so many grams next time, presumably you'll succeed." That was his attitude towards me. Yes. I think.... Powerlessness characterizes their encounter with us. So...I understand the powerlessness or whatever it is perfectly well, but it just isn't constructive in this context. Sometimes, you [the hospital staff] may have a need to detox, the staff has an urge to think out loud, "Oh no, here she comes again".... But if they just did that in the staff room, then you can tell.... It shines out of them that they are annoyed with me. And if you're like, kind of sensitive to that sort of thing, then you have to... you got...you've gotta not be a nuisance, and then you make yourself smaller than you really are because you catch the signals. "It's fuffy" [i.e., hard to get a grasp on]; it's really difficult to describe.

What kind of emotions do you bring with you after a hospitalisation like this? Does it stay with you? In an embodied way? Or what happens to it?

It depends on how you are met in the ward because if they still treat you like, with dis-respect or, you know, unworthy, then sometimes, I've gone out and tried [suicide] again right away. So, it's sort of a catalyst. But if they were caring and...with dignity, then I left there OK.... You know, ashamed of having done it again, but not with a catalyst for my sense of wrongness. Does that make sense? It doesn't take much to trigger that in me, that's for sure. Especially when I've done something bad which is a burden to the hospital that is already burdened. That makes me feel ashamed afterwards, but it's not something I can control when I'm in affect. And then, when you have this huge feeling of shame, it doesn't take much to make it all fall apart. But, yes, the level of darkness I find myself in matters a lot.

Would that be your own darkness?

My own darkness, yeah.

Yes.... Am I getting it right if I say that the way the staff take care of you, I'm probably repeating myself here, but that it actually contributes to either lifting you out of the darkness or making it even darker?

It can make it less dark, yes. And then it can... yes, alleviate the huge shame that I have inside of me, I think. That's just it.

Analysis of Simone's narrative

Simone's story is characterized by a theoretical vocabulary with the use of words like lens, objectify, and detox. In appropriating the voice of professional others, she reaccentuates professional, psychiatric knowledge, combining it with experiential knowledge to create a hybrid form of knowledge. This voice constitutes a psychologizing narrative resource which provides an objective distance to Simone's (painful) story and simultaneously empowers her by enabling her to co-construct her identity. By merging lived experience with professional knowledge, Simone creates a range of critical, objectivist, narrative resources that may support her in co-constructing an identity different from identities belonging to the public narratives which often construct people with lived experience as cognitively impaired, powerless, and passive. This identity frames Simone as a responsible, analytical, assertive expert-by-experience in contrast to public narratives about people with mental health issues. She thereby achieves the power to navigate in life, despite severe mental health issues that sometimes put her on the edge of "darkness" where she is dependent on the help of others to drag her back into the light. Thus, the re-accentuation process can be a powerful means to expand Simone's scope of action, supporting her enactment of an empowered, responsible, and critical service user.

Simone mentions her “huge shame” in a clinical, objective way, almost downplaying the implications of this feeling. This contrasts with the theoretical understanding of shame as a very powerful relational, degrading, and dehumanizing force. At the same time, the re-accentuation of the clinical-objective voice offers a framework which normalizes shame as closely related to the sense of feeling *wrong*, which is a well-known psychological consequence of childhood abuse and neglect (Jørgensen, 2023, Chapter 5). The internalization of this clinical voice brings empowerment through normalizing measures and thereby offers a strategy for resisting the degrading character of shame. But tensions arise across narrative resources, between normalizing shame (the clinical-objective voice), and shame experienced as powerful enough to determine where in the “darkness” Simone finds herself (the experiential voice). Simone’s account offers a glimpse of how shame operates to regulate identity, self-esteem, and her mental and emotional well-being which contrasts with the neutral tone of voice in her final words: “That’s just it.” Given the power that healthcare professionals possess in terms of triggering Simone’s internalized inferiority, this is a euphemism. The narrative dynamics reveal that the staff holds the key to regulating the level of Simone’s shame and darkness by their words and actions, thus having the ability to enhance Simone’s suicidal impulses.

Negotiating the meaning of shame is critical because it uncovers the need for shared responsibility between Simone and the healthcare professionals. Paraphrasing the Danish philosopher, Løgstrup (1956), the staff hold the life of the Other in their hand – with the ability to make the person either flourish or wither. Simone’s narrative unfolds the literal meaning of these ethical-relational dynamics and the power embedded therein. It does not exempt her from responsibility, but emphasizes that the neoliberal individualization of responsibility is incompatible with person-centred healthcare practices. Simone depends on others to take their share of responsibility.

Simone has been given the diagnosis of borderline personality disorder which, according to research and reports, carries the strongest stigma next to schizophrenia in the hierarchy of stigma (Jacobsen et al., 2010). The public narrative surrounding this diagnosis contributes to finalizing the person affected. A Danish anti-stigma campaign visualizes psychiatric diagnoses as a cardboard box you’re put into. Within the terms of this metaphor, the borderline diagnosis would constitute a narrow, solid box, completely closed (One of Us, n.d.). The diagnosis is characterized by deregulatory emotional behavior. Simone challenges prejudice towards it by re-accentuating the objective voice. As she negotiates an open-ended narrative, she contests the finalization of her identity, opening up the possibility of an alternative identity and life path. Furthermore, the objective voice provides a distance to the emotional imbalance that is central to the borderline diagnosis. In her appropriation of the normative expecta-

tions of emotional neutrality, she creates a tension between the subjective and the external.

Simone distances herself from emotions and almost objectifies herself as she adapts her narrative to resist a stereotypical assumption about personality disorders. So, when empowerment is added to the equation, the diagnosis becomes a box that you get to *stand on* to improve your self-understanding (One of Us, n.d.) – but it’s still a box, provided to you by the public narratives, yielding its power over a life lived with mental health issues.

When Simone speaks of the staffs’ need for detox, she could be referring to a theoretical concept used in mental health nursing a few decades ago called “psychodialysis.” Psychodialysis represented a way of detoxing from emotional overload due to the internalization of patients’ suffering (see, e.g., Belin, 1999, p. 389). Simone re-accentuates a professional voice as she legitimizes the staff’s need for “ventilating” their negative assumptions towards the mentally ill. Ventilation, then, becomes a euphemism for legitimizing condescending and dehumanizing attitudes, suggesting a brutalized practice culture. In this process of re-accentuation, Simone uses a narrative resource of theoretical/professional explanation, and her acceptance of the staffs’ behavior makes her seem even more professional than the professionals. But she also questions her own acceptance, confessing the emotional discomfort that follows from being subject to the staff’s “ventilation”: “then you make yourself smaller than you really are because you catch the signals.” In doing so, an internal tension emerges between making allowance for staff and her own integrity and empowerment. The degree of (self-)stigma and the complexity of shame together lead to Simone adjusting her expectations to health care, thus restricting her access to patient safety and ability to make a complaint or self-report unintended harm.

The ambulance driver’s gesture can be seen as an unexpected, person-centered voice representing acknowledgement, compassion, and humanity in a hostile environment, enacted through a brief, but caring, encounter. During the interview, Simone reproduced the incident with the use of verbal and non-verbal elements serving to underpin the positive quality of the memory. The stark contrast between the coldness of the nurse and the compassion shown in the driver’s gesture was obvious. The nurse represents an othering and marginalizing voice which places Simone outside a community. This cements the public narrative on mental distress as alienating by reproducing an “us” and “them” narrative. The driver’s embodied and emotional reaction is a story within the story, handing the imaginary of a space of possibility to Simone. Thereby he creates, albeit briefly, the idea of an open-ended narrative, which adds unfinalizability to what Simone can become in opposition to the narrow public narratives. The story indicates that a life lived with mental health issues may sometimes entail that you have to journey through the dark. But it also suggests that you do not

necessarily have to explore the dark all by yourself; even darkness comes with the possibility of encountering compassion, care, and understanding.

The tensions between life as imagined and as experienced, resting in the hands of the nurse, put Simone's life in perspective. To know somebody well usually carries affirmative connotations, but here, the nurse uses it sarcastically. The utterance "Here's Simone again. Unfortunately, we know her all too well" functions as alienating and abusive, with degrading and even infantilizing connotations by using the third person, "her," and the negation, "unfortunately."

In Simone's narrative, responsibility for her emotional and psychosocial safety is left for her to carry. Her narrative reproduces and re-accentuates a clinical, but also a neo-liberal, instrumental, recovery-voice, individualizing responsibility for her own recovery and safety. However, Simone creates a tiny crack for the light to shine through by contesting the idea of individualized responsibility and confirming the staff's role in creating safety: Their appreciative attitude can make the darkness less dense and "then it can... yes, alleviate the huge shame that I have inside me, I think. That's just it."

Discussion

My analysis has unpacked the ongoing negotiation of the meaning of *experienced* patient safety and the multiple ways in which it deviates from the official, standardized, and technical understanding of patient safety. In doing so, it supports the article's main aim of building a strong argument for an expanded, relational concept of patient safety. In the following, I will pave the way towards this concept. I problematize and discuss central aspects of the standardized, technical concept of patient safety, contrasting it with *experienced* patient safety. By highlighting the unintended harmful effects of internalized emotional conflict, I show that an expanded notion of patient safety goes far beyond the conventional understanding of (i) conflict as solely externally and aggressively enacted and (ii) patient safety as a merely physical-technical measure.

Patient safety unwrapped

As I mentioned in the introduction, the official discourse of patient safety serves to define and delimit the nature of what counts as unintended harm to measurable physical and instrumental errors. Travaglia & Braithwaite criticize the reduction of "the embodied patient who experiences the error to a set of procedural classifications" (2009, p. 603), viewing it as a way of maintaining biomedical hegemony. In Denmark, despite a rather transparent incident reporting system, control, with respect to defining and determining what counts as error, is not democratic, but closely tied to clinical,

administrative, and governmental staff's "symbolic and cultural power" (Travaglia & Braithwaite, p. 603). Therefore, as they put it, emotional harm is at risk of "being pigeon-holed as not worthy of reporting as an incident." It represents a severe patient safety risk if incidents that patients may have experienced as intensely problematic and/or causing long-term adverse emotional effects are not recognized or reported by clinicians (Travaglia & Braithwaite, 2009, p. 604). These points are echoed by Sokol-Hessner et al. (2015, p. 551) who stress that the most vulnerable may be particularly reticent in reporting adverse emotional and psychosocial effects "because of the historical neglect of these harms"—and consequently, these events may be significantly underreported. My analysis of Simone's and Janet's narratives confirm the impact of dehumanizing experiences on mental health and trust in healthcare systems.

It is worth noting, though, that the non-governmental Danish Society for Patient Safety *does* mention emotional harm on its website, but only with respect to the LGBT+ segment. This may marginalize an already marginalized group (as well as marginalizing emotions *per se*) by discursively labeling LGBT+ persons as sensitive: "We are aware that LGBT+ persons can feel and experience the absence of respect and dignity when receiving health care treatment" (Bach, 2020). It exemplifies the above-mentioned points on the operation of power in the act of discursively defining who is counted in, thus limiting the access to safety for those who are counted out.

In Denmark, as I noted earlier, patient safety is defined as "safety for patients against harm and risk of injury following the health care system's interventions and performances, or the absence of it" (DSKS, 2022, p. 28). The idea of defining something by its absence is interesting and may discursively contribute to the messiness. Who, then, is responsible for the content and limitations of this absence? The narratives point out several absent elements of care, but none of them counts as unintended harm. Speaking up about the absence demands stamina and symbolic capital (Travaglia & Braithwaite, 2009) as well as responsiveness from healthcare staff and leaders, both shown by the narratives to be in short supply.

Absence and its consequences for patient safety

Simone's story serves as an example of the paradox of suffering caused, not by disease, but by "socially organized conditions [...] including diffuse stigmatization and marginalization of the ill" as noted by Frank (2016, p. 9). The hospital stay induces iatrogenic harm and compromises, not only Simone's safety, but also the work environment of healthcare professionals as it potentially generates moral distress, shame, and brutalization. Staff members' "Oh no, here she comes again" attitude paradoxically serves as a catalyst to making Simone come back again and again. Simone's story reveals a potential

for conflict that could be (and sometimes is) turned outward and expressed in terms of aggression and lack of cooperation. Depending on where in the darkness Simone finds herself, this conflict may also be turned inward and internalized. Nevertheless, even if it leads to repeated incidents of self-harm, it will not be reported as unintended harm, but as readmission, providing the nurses the opportunity to say “Yes, unfortunately, we know her all too well.” Or as Simone puts it: “Is that you again-ish.”

Janet’s suffering is intensified due to lack of information, a crucial element in the Danish health legislation where information forms a foundation for consent, specifying the healthcare professionals’ responsibility to provide personalized information that fits the patient’s individual needs (Declaration of Health Law §16,2). This demands careful, person-centred, relational work, and the lack of it induces harm, putting patient safety at risk and the patient to work as she compensates for an obligation that, according to the legislation, indisputably belongs to healthcare professionals.

My analysis uncovers four senses in which people with mental health issues are vulnerable: first, with respect to their mental health issues, second, to societal stigmatization, third, to iatrogenic traumatization, and finally, when psychosocial harm is not taken seriously as they are “being rendered invisible within the very field ostensibly created to protect them” (Travaglia & Braithwaite, 2009, p. 605). This multiplicity of vulnerabilities may serve to reproduce and maintain inequity and mistrust in the healthcare system reducing the often already reduced stamina and symbolic capital that is necessary to navigate the system – or the opportunity to make a complaint.

Patient safety is grounded in standards and guidelines, but my analysis shows that it does not “automatically flow from enacting these guidelines” (Iedema, 2011, p. i83). Safety is highly context-specific and must be worked at from moment to moment in what Iedema calls the “in situ creation of safety” (2011, p. i83), which entails placing reflexive, mindful, person-centered communication at the center. Mindfulness, Iedema claims, “happens when clinicians and patients become able to think and act with one another and, at times, *for* one another” (2011, p. i84). This, I would like to emphasize, implies mutual trust and recognition, where, as I see it, healthcare professionals must take responsibility for the first step in bridging what Cheryl Mattingly (2014, cited in Frank, 2016, p. 11) calls an “ontologically consequential divide” across patients’ earlier healthcare experiences and internalized inferiority. Alternatively, we run the risk of forcing responsibility upon the vulnerable person herself. And, as stated by Kuzel et al. (2004, p. 338), a relation that “has caring as its imperative will erode” if we do not acknowledge the ramifications of fear, humiliation, and dehumanizing experiences. Therefore, I locate mental health service users in the borderland of patient safety with its fuzzy boundaries drawn along discursive lines, on which I will elaborate in the following section.

The dirty business of boundary maintenance

The storytellers are continuously adjusting in order to fit in, to be seen as humans, to fight the public narratives. They keep the hurt and the shame on the inside as they conform to public narratives that individualize responsibility, marginalize, dehumanize, and stigmatize people with lived experience. The narrative encounters are framed by the *negative* of dialogue (Frank, 2016, p. 11) where staff members’ perspectives, in subtle ways, exclude the storytellers’ perspectives whenever expectations of mutual, dialogical recognition are not met. Moreover, the encounters demonstrate what Yuval-Davis refers to as the “dirty business of boundary maintenance” as we judge whether a person belongs “inside or outside the imaginary boundary line of the community of belonging” (2006, p. 204). “Stories revise people’s sense of self, and they situate people in groups,” Frank claims (2013, p. 33). I follow Blix et al. in adding that “stories also situate people *outside* of groups” (2013, p. 272).

The above points, I think, underscore the existential severity of these harms. For the storyteller, the stakes are high – underpinning the “endemic, structured disconnection” between the involved persons (Frank, 2016, p. 12). Also, they draw attention to the asymmetrical power dynamics and the frailty the harms entail, and they highlight the importance of re-distributing moral responsibility in favour of the more vulnerable.

Along Foucauldian lines, the processes of re-accentuation sketched out in the analysis come with a price; they constitute a space for power to unfold. The voice that is made one’s own possesses power and agency by setting the boundaries for ways of being, knowing, and doing. Thus, immanent tensions arise “between empowerment and self-discipline” (Phillips & Scheffmann-Petersen, 2020a, p. 1469) due to the dominance of a particular recovery-based approach to mental health. This approach individualizes responsibility and operates as a disciplinary technology of conduct, as pointed out in recovery-critical circles (see, e.g., <https://recoveryinthebin.org/neorecovery-a-survivor-led-conceptualisation-and-critique-mhrn2019/>). These subtle, disciplinary, neoliberal measures contribute to finalizing and disabling people with lived experience and do not address the foundational socio-cultural terms and power dynamics that play a substantial role in developing and maintaining mental health issues (see, e.g., Roper et al., 2021). In Simone’s case, it means that she takes on responsibility, not only for coping with a life heavily marked by mental distress linked to an upbringing with abuse and neglect, but also for explaining and forgiving the stigmatization, dehumanization, and iatrogenic re-traumatization she encounters. These are forces that intensify her sense of shame and her feeling of being *wrong* and enhance the darkness she sometimes disappears into.

In closing, I address the call made by Hor et al. (2013) for a mindful, reflexive, and collaborative reconceptualization of patient safety. The dialogical approach followed in

the study presented in this article not only constitutes an analytical lens, but also a critical, normative principle based on a constructivist onto-epistemology. In the wider doctoral research project of which this study is part, I embrace this approach by inviting the storytellers and nurses from somatic wards to participate in the dialogical co-production of knowledge. This knowledge includes concrete suggestions for how to take account of the voices of storytellers in clinical practice and thus contribute to transforming practice on the basis of principles of social justice.

The main site of co-production is a series of collaborative workshops. A set of workshops were held with nurses as co-researchers, using creative, collaborative methods such as memory work, photo elicitation (Pedersen, 2021), and creative non-fiction writing (Høgsgaard, 2018). In order to *let stories breathe* (Frank, 2010) and enable dialog across perspectives, the nurses engaged in joint analysis of their own embodied, emotional experiences and extracts from the eight narratives. Following this set of workshops, storytellers, nurses, and management came together to work across their different perspectives in a final workshop. In addition, I engage in frequent discussions with the managers of the somatic ward to cultivate organizational reflexivity. The planned publications will revolve around analysis of the processes of co-production and of nurses' perspectives on the encounter with people with lived experience and the implications for their work environment.

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