Epistemic injustices in clinical communication: The example of narrative elicitation in person-centred care.

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Abstract

The increasing popularity of the term "person-centred" in the healthcare literature and a wide range of ideals and practices it implies point to the need for a more inclusive and holistic healthcare provision. A framework developed in a Swedish context suggested narrative elicitation as a key practice in transition to person-centred care. Initiating clinical communication by inviting people to tell their stories makes persistent yet often subtle problems in clinical communication visible. By drawing upon an observational study on narrative elicitation and vignette-based focus-group interviews with nurses, our aim is to trace "credibility deficits" (Fricker 2007) as well as "credibility excesses" (Medina 2011, 2013) in narrative elicitation. We argue that narrative elicitation may be one way to tackle epistemic injustices by giving voice to previously silenced groups, yet it is not enough to erase the effects of "credibility deficits" in clinical communication. Rather than judging individual professionals' success or failure in eliciting narratives, we underline some extrinsic problems of narrative elicitation, namely structural and positional inequalities reflecting on narrative elicitation and the credibility of patients. "Credibility excesses" can be useful and indicative to better understand where they are missing.

Keywords: Narrative elicitation, patient narratives, person-centred care, epistemic injustice, credibility deficits and excesses.

Introduction

current situation.

The increasing popularity of the term "person-centred" in the healthcare literature (Håkansson et al. 2018, Summer Meranius et al. 2020) and a wide range of ideals and practices that it implies point to the need for a more inclusive and holistic healthcare provision in contemporary western societies. While patient groups mobilise and vociferate their discontent towards healthcare institutions and professionals that fail to hear their voice (Bradby et al. 2020), a myriad of models and interventions seek ways to encourage patients to construe and express their idiosyncratic experiences of illness and make use of their own capabilities and resources. One framework developed in a Swedish context suggested three clinical practices such as narrative elicitation, developing partnership and documentation of lifeworld goals as crucial in transition to person-centred care (Britten et al. 2017, 2020; Ekman et al. 2011, 2015; for a recent criticism, see Hardman and Ongarao 2020). This framework has shown to increase both patient and organisational outcomes, such as improved quality of life, decreased length of hospital stay and economic costs (Britten et al. 2017, 2020; Summer Meranius et al. 2020). Initiating clinical communication by inviting people to tell their stories, as in similar narrative-based approaches (Kalitzkus and Matthiessen 2009, Launer 2002) has been considered one way to capture the person's wishes, goals and capabilities and commence the partnership between the clinician and the person (Britten et al. 2017, Ekman et al. 2011, 2015). Narrative elicitation has the potential to be democratising, especially for those have long been afforded less time and attention than those who are more privileged, powerful and skilled to make their voice heard in clinical communication. Patients' positive evaluations have shown that "being listened to" can be an important outcome of such changes in clinical relationship building (Thórarinsdóttir and Kristjánsson 2014, Wolf et al. 2017) since through this form of communication patients can verbalise previously latent, subconscious, unheard experiences and their relevance for their However, amidst persistent yet often elusive problems in clinical communication (Bradby *et al.* 2020, Hamed *et al.* 2020, Kukla 2007), narrative elicitation is not sufficient per se to erase the effects of "credibility deficits" (Fricker 2007) and redress epistemic injustices. Even when sought, patients' narratives may fail to be heard or immediately intelligible for the interlocutor. In this article, by drawing upon an observational study on narrative elicitation and vignette-based focus-group interviews with nurses, our aim is to trace "credibility deficits" (Fricker 2007, 2013) as well as "excesses" (Medina 2011, 2013) in narrative elicitation. Rather than judging individual professionals' success or failure in eliciting narratives, we underline some extrinsic problems of narrative elicitation, namely structural and positional inequalities affecting narrative elicitation and performances.

This article is structured as follows. In the following section, we will review the relationship between narrative turn in healthcare and its potential and limits to redress epistemic injustices. Second, we will briefly describe our methods and methodological approach. This will be followed by the presentation of three theoretically chosen cases and a discussion of narrative elicitation as empowerment and reflexive action.

Narrative and redressing epistemic injustices in clinical communication

Since the 1980s illness narratives have been paid salient attention (e.g. Frank 1995, Greenhalgh and Hurwitz 1999, Hydén and Brockmeier 2008, Kleinman 1988, Mattingly 1998, Mishler 1984) in order to advocate a transition from overemphasis on professionals' voices and biomedical evidence in the clinical encounter to the quest for practice that seriously takes patients' knowledge and experience into consideration (Barry *et al.* 2001, Bury 2001). This transition has been considered more than a technical and procedural change, a search for ways of mending traditional medical history taking. Rather, it has sought to highlight narrative as a fundamental way of giving meaning to experience (Bruner 1986, 1987), understanding the point

of view and personal experience of one's informants (Mattingly and Lawlor 2000) while being aware of the social transformation of illness in clinical relationships (Clark and Mishler 1992). The narrative turn has also been criticized by scholars for its way of transforming the person into "an isolated actor who experiences and narrates a matter of private and privileged experience" (Atkinson 1997: 335, see also Paley and Eva 2005). Patient narratives are elicited in given social contexts, often in clinical environments and in dialogue with health professionals. Patients often have recourse to socially shared resources of rhetoric and narrative (Frank 1995; Bury 2001). Thus, patient narratives can be seen at the juncture of expressing unique experiences of illness and deploying collective ways of representing and meaning making. In Arthur Frank's words, "real things happen to people, but *narrative resources* conduct people's interpretations of what happens" (italics added, 2009: 191). Frank also pinpoints "narrative surrender" that implies the transformation of an individual story into a medical one. What is at stake in this conceptualisation is not only medicalisation of certain distresses, but it also involves differing levels of epistemic injustice, i.e. wronging the patients in their capacity as subjects of knowledge (Fricker 2007).

Drawing upon a feminist legacy that seriously interrogates the persistent and hierarchical forms of knowing and ways of producing knowledge (McKinnon 2016), Miranda Fricker (2007) refers to two different types of epistemic injustice: *testimonial injustice*, as caused by prejudice in the economy of credibility and *hermeneutical injustice* as caused by structural prejudice in the economy of collective hermeneutical resources. In the case of testimonial injustice, what the speaker expresses or asserts is not believed by the hearer because the latter is prejudiced in their judgement. In Fricker's terms, the person has a "credibility deficit" i.e. cannot be believed on the basis of her position in the hierarchy. For instance, ill persons are often vulnerable to testimonial injustice because of the presumptive attribution of cognitive unreliability and emotional instability (Carel and Kidd 2014). The credibility deficit argument has been

elaborated and extended in its interactive nature (Medina 2011). There is an intimate relation between credibility "excesses" and credibility "deficits" (Medina 2013) as they are equally important in shaping epistemic injustices. Credibility has no distributive nature, i.e. the one is not believed "less" because the other is believed "more", yet it is crucial not to "ignore the role of credibility excesses for some people in producing credibility deficits in others" (McKinnon 2016: 440) as these patterns of credibility are contextual and infused in the social imaginary. People with similar medical conditions may have different levels of credibility depending on wayward indicators, their abilities to express their symptoms and distress; some patient groups are often pushed to low levels of credibility such as mental health patients (Gosselin 2019), or those with medically unexplained symptoms (Werner and Malterud 2003).

Hermeneutical injustice, on the other hand, makes "itself apparent in discursive exchanges between individuals" (Fricker 2007: 7) and occurs in communication where

a subject who is already hermeneutically marginalized (that is, they belong to a group which does not have access to equal participation in the generation of social meanings) is thereby put at an unfair disadvantage when it comes to making sense of a significant area of their social experience. (Fricker, 2013: 1319)

Hermeneutical injustice in the case of clinical communication may make itself visible in at least three ways. First, illness experience is often perplexing and confusing (Carel and Kidd, 2014) and requires that persons gradually make sense of this incipient experience by restoring their sense of self in new ways and forms (Bury 2001). This is a process entailing time, effort by all parties in clinical communication, and hermeneutic resources to make the very experience expressible and to some extent intelligible for the other. Second, patients with the resources and skills associated with social and economic advantage in a given society may actively seek to supplement their own care and decision-making (Sinding *et al.* 2011) by enhancing their inquiry

(Kukla 2007), familiarising themselves with medical language (Wardrope 2015) and restoring a narrative in dialogue with medical experts and vocabulary; whilst some others, by vulnerability, lack of support or resources or previous negative experiences, may simply tend to defer to the medical experts' narrative and decision-making (Kukla 2007). Third, yet untraditional approaches like narrative elicitation and focusing on lifeworld goals may seem at odds with their previous experiences in healthcare settings where they were invited to reply to structured, often close-ended questions (Launer 2002, Naldemirci *et al.* 2020). Put bluntly, a person who has never been asked to tell her story openly may hesitate or fail to reply to questions inviting a narrative.

Narrative elicitation, by attempting to give voice to silenced and marginalised groups in clinical communication, *ideally* can tackle epistemic injustices. On the one hand, the premise that every patient has a story may be corrective of "pre-emptive testimonial injustice" (Fricker 2007: 130) where certain individuals and groups are not (or rarely) asked for information and contribution, such as cases of "heart sink" patients (Mathers and Gask 1995; Sharpe *et al.* 1994) and racialized people (Bradby *et al.* 2020). On the other hand, being encouraged to tell one's own story, articulate a lifeworld goal (not necessarily a medical one) and make this documented in the records may be a gateway to more inclusive communication, self-knowledge and awareness in both the patients and professionals. The patient's narrative can be emphasized and deployed as a corrective to epistemic hierarchies in medical encounters. Yet, there is the need to rethink the social inequalities and the complex workings of power that spawn epistemic injustices. Credibility deficits as well as credibility excesses can also risk shaping the contours and the imaginative possibilities of narrative as the means of reinvigorating a humanistic approach to healthcare delivery.

Methods and methodological approach

Drawing upon insights of a study about the implementation of person-centred care in a Swedish context (Britten et al. 2017) where narrative elicitation is closely linked with personcentredness, our aim was to critically examine how narrative elicitation unfolds in practice (Naldemirci et al. 2020). Therefore, we strategically chose an internal medicine ward in a Swedish hospital where PCC has been implemented since 2010. In this ward, registered nurses were expected to elicit the patient's narrative during the admission interview by using a form including narrative-inducing questions. ÖN (also referred to later as the researcher) did 13 days of fieldwork spreading over three months and observed 14 admission interviews and the preparation for two interviews that were interrupted because one was an emergency case and the other was a case of infection. The study was approved by the Regional Ethical Board of Gothenburg. The researcher participated in the staff meeting before the start of each shift, and asked nurses if they agreed to be observed. When a new patient arrived, the researcher informed the patient about the study verbally and with written information, by strongly emphasising that the study would not affect the care they received. Two patients did not want to participate in the study and the researcher did not observe these admission interviews. Both the nurse in charge of the interview and the researcher asked for and received consent for the researcher's observation of the interview. The researcher was present only during the admission interview and left the room if the patient needed privacy. Identifying details were redacted.

As admissions were unpredictable and their frequency sporadic, the researcher could loiter in the field during his long waiting times and make sense of the warp and weft of everyday life on the ward. During coffee and lunch breaks, and while helping with practical work, he could ask questions to clarify some details of the admission interviews. The participating nurses were eager to explain, elaborate and clarify some information for the researcher who is a non-native Swedish speaker. The researcher's presence on the ward and interest in narrative elicitation led to more collaborative research and continuous feedback from the participants. The researcher

took notes during the admission interviews and subsequently wrote down each case for the critical interrogation of the research team. The research team asked questions about the details of the cases, challenged the researcher's subjective and situated interpretation while inviting him to see other possible interpretations, helped anonymization of some details without changing too much essential information. As a registered nurse, AW (last author) checked the medical information. In addition, the participant nurses' engagement in the research made it possible to develop vignettes based on the observed cases which depicted strategies and difficulties in narrative elicitation. ÖN and AW conducted five focus group interviews (n=53) where these vignettes were discussed in depth and interrogated by the nurses. Not only was this a strategy for respondent validation for the emerging themes but it also paved the way for a collaboration with the participants in order to design pedagogical workshops about narrative elicitation (see also Naldemirci *et al.* 2020).

The selection of three admission interviews for further exploration in this article sought to illustrate the relation between narrative elicitation and credibility deficits and excesses. We chose three cases with significant variations in their duration and in the emotional effects they caused on the professionals (Naldemirci *et al.* 2020). The first is a case of "credibility excess", not only because the patient (Johan) was a skilful narrator embroidering the many details and vicissitudes of a long life, but as an older but not frail, middle-class, native Swedish man, he was also successful in expressing some wishes and goals, easily intelligible for a younger native Swedish nurse. The second case (Ali) was chosen, among others, to mark some pitfalls of narrative elicitation with people whose stories were marked by migratory experiences, differing narrative and linguistic skills. Ali's case illustrates credibility deficit in such an admission interview, by trying to dispel the confusion about the so-called "multicultural patients" who are often exposed to the language barriers in clinical communication and implicit norms in institutional settings. The third case consisted of a typical "difficult" patient (Anna) whose co-

existing social problems (Sharpe *et al.* 1994) were steeped in severe illness; she was rapidly moving from having a credibility excess to a credibility deficit since her story also became a "typical" story to dodge within the professional boundaries. To support and nuance our analysis, we also refer to nurses' critical reflections from focus group discussions on the complexity of these cases. All names are pseudonyms and the information which would identify the case or the research participants were omitted or changed.

As storytelling "is animated and transpires somewhere, in relation to some audience, for some purpose" (italics added, Gubrium and Holstein 2009: 81), it is crucial to underline the role and situated understanding of the researcher who arrived as "additional audience" in these narrative performances. The researcher's interpretation of the selected cases was subject to a continuous self- reflexive endeavor and the research team's interrogations. Therefore, the following cues are provided, not to make a confession about possible biases of the researcher, but to elucidate why these cases were chosen and analyzed in the ways they were. In the first case, the researcher was an additional "young" listener to an older man's life story. He was welcomed by the narrator to witness his skilful performance, and as touched by the story as the nurse in the end. As a non-native Swedish speaking, single and migrant person, the researcher came to ponder the potential privileges of white, (middle) classed and couple-normative tropes and plots in narrative elicitation by the professionals who may share similar backgrounds. The researcher's migration background and previous fieldwork with older migrants (Naldemirci 2013) has informed both the choice and interpretation of Ali's interview, especially about Ali's hesitant way of speaking Swedish and formulating a goal. However, it is worth noting that five of the observed interviews were with patients whose mother tongue was not Swedish. Discussions about language barriers and cultural differences were common during focus group discussions. Anna, on the other hand, was another native Swedish speaker and had a working class background. She was also a good storyteller, yet her account's detailed constitution and coda was informative for the researcher but difficult to manage for the nurse in the limited time and within his professional boundaries. All three nurses were white and native Swedish speakers; Dora had more interest and experience in narrative elicitation, while Helen and Adam were relatively new on the ward and had less experience.

Findings

Narrative skills and "personal chemistry"

Nurses on the ward were accustomed to working against the unpredictable rhythms of new admissions from the emergency room. When Johan, a man in his late 80s, stepped into the long and silent corridor with food trolleys waiting to be taken away, Nurse Dora was about finishing her shift after a long but relatively calm day. Dora was one of the nurses who openly emboldened her colleagues to think about narrative and as she knew the researcher's interest in the topic, she was very keen on brainstorming with him. She welcomed and accompanied Johan into an empty single room that she had just cleaned and disinfected carefully. Johan was cheerful but apparently in pain, holding his right arm on his chest. He had a pacemaker fitted three weeks ago. Dora decided to take her time and conduct the admission interview. As dinner had already been served before his arrival, Dora first served him some tea and sandwich.

After a short while, Dora started the admission interview by asking him how it felt to be back on the ward. If "narrative competence" is the ability to acknowledge, absorb, interpret, and act on the stories and plights of others (Charon, 2001), Dora was almost a virtuoso. She took a seat, avoiding unnecessary follow-up questions and adding economically some "hmm"s to show that she lingered in Johan's story. He was a good storyteller, and his story was coloured by happy turning points and the vicissitudes of a long life that drastically changed after his beloved wife's passing. Johan told Dora about his travels with his wife around the world after his abrupt but wilful decision to retire. Dora did not interrupt but added some very brief and appreciative

remarks about the places Johan visited, as she enjoyed travelling with her boyfriend every time she could take a vacation. In a moment of silence, she wanted to come back to Johan's life as it was now and his goals. Johan was silent first, Dora, after a glimpse at her notes, gently reminded him of his hobbies he had just juxtaposed during his almost one-hour monologue. Johan wanted to return to his model ship hobby, which he had started after retirement but had to stop because of long travels with his wife.

Johan successfully paced his storytelling, by adding colourful details without overdramatising the tone, in a touching and chronological plot. Dora seemed interested in the story and noticed very early Johan's eagerness to relate to her. Besides the tropes of long happy marriage, economic wealth, and adventurous journeys around the world, Dora came to notice Johan's mourning very early and deployed narrative elicitation almost as a means to therapeutic ends (White and Epston 1990).

Long session. Dora comes back to the expedition room. She is exhausted, and already working overtime. She takes a seat in front of the computer, and me next to her. We don't talk to each other as I usually do with nurses after admission interviews. After a moment, I ask her if she will leave soon, she says, tears on eyes, she is *personally* touched by Johan's interview, she does not want to leave it to another nurse but wants to document it *herself* in the records. (*Field note*)

Despite its emotional overtones, Johan's admission interview was almost a textbook example of narrative elicitation in terms of Dora's preparations for the interview and attentive and responsive listening. Johan was a good storyteller and Dora guided the storytelling with her active listening and kept it alive with her interest in the story. She also could elicit a realistic lifeworld goal out of the narrative. Yet, there was something more nuanced in this interpersonal connection, difficult to express and touch upon.

The idea of "personal click", "match", "being personally touched" is critically elaborated in care sciences (e.g. Cadge and Hammonds 2012, Williams 2001) and was also discussed during the focus group discussions, yet often very vaguely, with care taken not to sound "discriminatory" or "selective" of patients. One nurse described it as follows:

Personal chemistry for me is someone whom I get along with or someone who has the same glue. I really agree that it does not happen immediately but should feel it from every individual. (Focus group 1)

The "personal chemistry" can be seen as a diffuse, even mystifying term for sharing similar life worlds and expectations, worldviews, cultural norms, maybe even class positions. In other words, nurses arguably individualise similarities in their social imaginaries by labelling these as "chemistry". Even though it is not possible to define it clearly, as in Johan's admission interview, having the "same glue" and the ability to touch the other may lead to a credibility excess and greater openness to listen more actively to some stories.

"Multicultural" patients: Ali

The realities of admission are messy, full of questions, fear and stress. Not speaking the same language is an even more dislocating experience for patients. Some of the admission interviews appeared to be difficult because of the lack of a common language and the unavailability of interpreters at the time of the admission. There were several cases where nurses had difficulty talking to the patients because of language barriers. During focus group and informal conversations, nurses often emphasised that narrative elicitation was not always straightforward, even if not interrupted, in these cases. Unlike Johan's eloquence and comfort in his mother tongue, some patients lacked the language skills to tell their stories in the ways they would wish to do, and many needed more time and support from the admitting nurse. Yet, this involves more than language skills, it can also relate to differing degrees of "personal

chemistry". Putting narrative at the centre of the admission interview risks making intercultural dialogue even more complicated, as it was the case for Ali.

Ali was in his late 50s and hospitalised for chest pain. He was a first generation migrant and his name and complexion suggested that his country of departure was a Middle Eastern country. Helen was a young and energetic nurse and quite new on the ward at the time of the fieldwork. She did not have Dora's experience and enthusiasm for narrative and person-centred care, but she was happy to learn about the study. When the researcher came to know that she was in charge of Ali's admission, he asked her if she would agree to be observed during her admission interview. She seemed nervous as it was the first time she would be accompanied by the researcher but added a cheerful "of course!" On their arrival into Ali's room, Ali regarded the researcher with curiosity. The researcher presented himself and Ali gave his consent with a friendly smile. Helen greeted him properly and started asking the questions on the admission interview form in order. Ali had recently taken sickness-related early retirement. He was not a native Swedish speaker and was timid at first, but seemed eager to talk. He tried to open up a non-medical conversation when he said that it was boring in Sweden when it was autumn and dark. As he had recently retired, he said that he was "a bit bored" since "while working, time passed quickly". There was a moment of silence when Ali looked for approval or a response from both the timidly smiling researcher and the nurse. Helen probed abruptly and asked him about his "hobbies". This was a quick change of topic and indifferent to what he had just said. Ali did not have a "free time activity," except walks with family members that he started after retirement. He said this silently and a bit unconfidently and added that he also had family members living in his home country and he usually took longer walks when he was there. He was about to say more about this but hesitated as he did not get any reaction. Helen tried to suggest some goals (exercising) regardless of what he said about his newly acquired routines of "taking walks with family members". Ali did not look particularly interested in her suggestion and became more and more silent and detached. Helen did not have any silent moments and rushed the interview. As another non-native Swedish speaker in the room, the researcher thought about how she spoke fast, how she was almost inattentive to turning-taking and waiting for an answer, how demanding it could be for native speakers to be "patient" in a conversation, not only during narrative elicitation; this could be even harder under time pressures. The interview unsurprisingly ended with a yes and no dialogue. As Helen was expected to write down Ali's goal, towards the end, she asked once again about "exercising." Ali replied with a half-hearted "I will think about it", which Helen recorded as his goal.

Cultural competence is a framework for understanding, communicating and interacting effectively with people across cultural differences (Be-Ari and Strier 2010). The term is contested as it is often defined technically and equates culture with ethnicity, nationality or language (Kleinman and Benson 2006). Narrative elicitation from patients with migratory backgrounds, who do not speak Swedish (or not as the natives do) was also a debate in focus group discussions as many participating nurses described that they felt somehow uneasy in this type of admission interviews. Two common, almost canonical answers to this challenge was "diversity in the team" and family members as "de facto interpreters:"

We are lucky to have many colleagues who can speak other languages. We need it with *multicultural people* but it is also (about) many different cultures at the work place. Many times it is the staff who interprets but I think it is a pity for patients who don't speak because of their lacking language knowledge. I don't want to show this to the patients so that it does not become a frustration. I hope we don't do like this anyways. (Focus group 1)

Language barriers become even more insuperable in narrative elicitation. However, as Ali's admission hints, speaking the language moderately well may be sufficient to communicate

certain information but not to provide detailed narrative accounts, as Johan managed to do. This is not to say that Ali did not have a story to tell, but that he needed probably more time and support, a greater openness to listen to the so-called "multicultural" other, skills to linger in the person's "initial narratives [that] are much more likely to be hesitant, disjointed, fragmented, complicated or full of things that puzzle them" (Launer 2002: 16). Ali, as an older migrant facing an enigmatic future, with vague ideas of return migration, biographic disruption of chronic illness and changing daily activities in the absence of paid work, was apparently working out new routines and belongings. Ali clearly stated that he did not have any "hobbies", which fell on deaf ears. Helen had difficulty acknowledging his lack of "hobbies", which are widespread in common parlance. Lip servicing "exercising" as a lifeworld goal did neither helped streamlining narrative elicitation nor appealed to Ali.

Difficult patients and unrealistic goals: "I want to work"

Anna was a woman in her late forties; her dialect in Swedish suggested that she was originally from the city where the study was conducted. She was cheerful, with a friendly smile to both the researcher, and Adam, a young male nurse when they entered the room. Anna had a husky voice, aggravated by smoking. Anna looked lively and energetic, creating a huge contrast with Adam's hesitant and reserved attitude. Adam asked her if she smoked even though the room already smelled of smoke. Anna said that she "unfortunately" kept smoking but she was trying "very hard" to quit smoking, and she laughed. Adam smiled and said, "It is good that you give a try!" and asked her if she had relatives with heart failure. She could not remember. She said she had stomach ache, especially after eating, and she made a diagonal gesture to show where it hurt. Her stomach was always "terrible", that she often went to the toilet, she "never had constipation", and laughed. Adam, rather indifferent to her performance, moved to another question: "When did it (stomach ache) start?" She said: "6 months ago". Then she showed her swollen legs and Adam examined them carefully and silently.

After all these regular questions and checks, Adam's "What do you want to return to?" question came a bit suddenly, probably because of the presence of the researcher, but Anna did not find the question strange. She started by immediately saying "Work!" in a decided and confident tone, as if it were self-evident. After a heart attack last year, it was impossible for her to return to her job in elderly care, which was strenuous for her health condition, and her employers did not want to have her. It was a temporary job anyways. She was not eligible for sick leave benefits anymore as she had to find a new job suitable for her medical condition. Anna had been looking for jobs in elderly care again since she did not have other professional experience, yet employers were reluctant to employ her because of her medical history.

Anna was talkative, sitting cross-legged on the bed, recalling chronologically what she had been through since her latest hospitalisation. As she went into details, Adam did not interrupt but did not look particularly interested. He was not really looking at her in the eyes, and Anna continued to talk by addressing more often to the researcher. Apparently, Adam was not expecting such a long account with many details and a clear goal. He finally intervened as if to change the topic of "work" and asked her about her "strong sides". Anna said mockingly "My husband!" Adam smiled and repeated after her: "Your husband, ok, do you live together?" She commenced telling how her husband was loyal and caring the last year, economically supportive too, but that she now wanted to go back to work. She finished her story by underlying: "I do want to work tomorrow [short silence] but if I can't work, I would like to get a sick note". Adam started asking some other yes/no questions and Anna started to be less and less talkative. While later Adam was filling in the online document, he wrote: "Unemployed, she wants to have sick-note".

Anna was not credible as she came up with her wish to "return to work" not only because she was not well enough but also because of the strenuous character of her work. It is not uncommon that long narrative accounts from patients like Anna can end in so-called "unrealistic" goals.

This was a recurring theme in the focus group discussions. Many nurses were aware that asking open and narrative questions might lead to admission interviews longer than they could manage within the tight schedule of activities and duties. While Dora was willing to spend almost an hour with Johan since it was later in the day and "personal chemistry" had worked, many nurses felt uneasy or found it burdensome. Narrative openness and connection was considered to generate "unrealistic" goals, namely beyond the medical realm and their professional expertise. The following discussion sheds light on the contours of this negotiation, openness and translation:

N2: "What would you like to do if you were not so tired?" is a quite good question. I sometimes consider asking the same question. For example a patient arrives after a heart attack, a heart failure and I ask: what would you like to return to? It can be the case that they want to go 20 years back in time. Many do that. How did you feel before heart attack? I did this and that, I could do carpentry. But you are 85, when was the last time were you on the roof and changed roofing tiles? It is also very important to say that we cannot get you there. Do you understand what I mean? It must be realistic goals.

N1: But think also that it is good to have this communication before you throw pacemaker, a lot of medicines so that the patient believes that he will be on the roof.

N5: Lower expectations from the beginning.

N1: Exactly! [...] It can also be a conflict, now we should be realistic. We won't be able to help you with/on the roof but maybe you will do a little furniture. [...] It can also be guidance. We are not experts in this but we focus on helping you with your acute situation but I think you can take it (other problems) up with your GP. (Focus group 2)

Narrative-inducing and open questions can guide patients in expressing their wishes, emotions, and biographical ruptures that they are going through. Yet, these can also lead to "unrealistic" goals that nurses cannot help them with and endeavour to turn into realistic goals. Adam's uneasiness listening to Anna's story can be interpreted beyond the unrealistic goal which falls beyond his job description. Nurses feel more comfortable initiating admission interviews and talking about daily activities, family configurations, work experiences they are familiar with or that they can imagine. Having similar life experiences and "realistic" lifeworld goals may facilitate the start and co-creation of the narrative during the interview. Yet, some patients, once asked their stories and goals, refer to social and work-related issues which may challenge the practitioners' expectations and abilities and go unheard. Anna's wish to be able to go back to work was "unrealistic" according to Adam who, as a health professional, was familiar with this medical condition and similar patients. Anna was difficult to believe not only because she was severely ill but also because of the stereotypes around "sick-note seeking patients" (von Knorring 2008).

Discussion: Narrative elicitation as empowerment and reflexive action

Mr. G is a 72 year old *retired businessman* and *avid golfer* who had had a small myocardial infarction 15 years ago. (Italics added, Ekman *et al.* 2011: 250)

The above quote is from the initial article presenting the PCC framework in which narrative is emphasised as a significant way to attend to the person behind the patient. Mr. G is depicted in an economically advantaged position and having specific leisure activities that are recognisable in a Swedish context. We can only speculate from the short description in the article that narrative elicitation was smooth, without major difficulties for Mr. G, but it would not be farfetched to argue that Mr. G did not have any severe "credibility deficits" as it was presented as example of best practice. As we tried to nuance it with our selection of cases, every clinical

communication is unique and subject to complications and improvisations (Authors(d) 2020, Hardman and Ongaro 2020).

Our theoretical departure from epistemic injustice has shaped the ways in which we have selected and represented the cases, i.e. neither as examples of "best practice" nor as paroxysms of prejudice, stigmatisation, and exclusion. These examples were typical of others in our dataset and sought to raise attention to the realities of clinical communication that are habitually left unspoken. Similarly, our focus on the individual practitioner might seem to be asking too much from those who already face many structural constraints, but individual practice as a site of resistance can challenge impalpable inequalities and reshape the ways of using narrative in clinical communication. Three cases presented in this study illustrate subtle, differential, and often unconscious positioning and attitudes during narrative elicitation and invoke simple but important questions: Who can narrate and which stories are audible and credible in clinical communication? Who can easily and immediately benefit from such a shift in clinical communication?

The realities of narrative elicitation are messier than those presented in exemplary cases (Naldemirci *et al.* 2020). Health professionals meet patients from various backgrounds, positions, and experiences that may fail to be easily recognised and rapidly acknowledged. When narrative elicitation is endorsed and incorporated in the daily routine, this can lead to a bewildering array of stories, differing styles of narration, and a variety of issues and goals. Despite the variety of stories health professionals navigate in their daily practice, they are not exempt from hegemonic, powerful, easily recognisable tropes in a given society. A good storyteller like Johan, by referring to a world that is also more or less intelligible for the practitioner can be more privileged in expressing her own experiences and making herself listened to and believed.

The so-called "other" in narrative elicitation is the one who tells her story from a particular social, historical, biographical position that goes beyond the social imaginary of the healthcare professionals. The incipient narrative in such clinical encounters may require more support, open-mindedness (Kwong 2015), active listening (van Dulhem 2017) and awareness of different levels at work in stories (Wong and Breheny 2018). Ali as a so-called "multicultural" patient was not wordy and artful as Johan was in his storytelling. Besides his relatively poor mastery of the Swedish language, he also failed to make his everyday life, worries and wishes after retirement intelligible for the nurse. He arguably had a credibility deficit in terms of expressing his lack of hobbies and a recognisable goal to aim for. Taking walks with his family, as a more social and in a way vague leisure time activity, did not immediately appeal to the nurse, who, on the contrary, tried to encourage him to think about "exercising" as a more individual activity that is easily recognisable in the social imaginary and practical in terms of regular checks. Similarly, Anna became less credible throughout the interview despite she was a native Swedish speaker and good storyteller since the "unrealistic" goal made the nurse suspicious (von Knorring, 2008) but also helpless. Anna's co-existing problems (unemployment) haunted the narrative interview, and her initial goal was smothered.

In such an endeavour to meet the other, narrative elicitation needs to coincide a self-reflexive journey, even almost a sociological imagination. Many medical and nursing schools offer sociology courses which could be enhanced by providing prospective practitioners with reflexive tools to make sense of frictions and inequalities in a given society. There is also need for a commitment to the means of narrative empowerment. By narrative empowerment, we mean a readiness to be aware of the narrators' positioning in a given society, supportive and responsive to their possible lack of narrative resources, and resistant to easy identifications or prejudices with particular patient groups. Stigmatization, prejudices, inequalities continue to pervade clinical communications (Bradby *et al.* 2020, Hamed *et al.*, 2020) and are often elusive.

Narrative elicitation has the potential to redress them in clinical communication. However, if we take elicitation only as a "technique" and narrative as another way of "history-taking", it can privilege those who are already privileged (i.e. those who are willing and resourceful to narrate and make themselves credible vis-à-vis health professionals) and it can betray its intentions. Again narrative elicitation can be meaningful only if the interlocutor is ready "to hear" the stories she is eliciting, to position herself vis-à-vis different stories, narration styles, genres, and possibly resistances to narrate (Mishler 2005). In other words, professionals also need to be empowered in their understandings of narrative to be able to empower the others during narrative elicitation. This is not a technical skill to be included in the curriculum, but a readiness to navigate different stories, and critical awareness of potential biases and prejudices. Group-based reflective practices can be one way in which professional have 'safe' spaces to address these issues.

Fricker refers to "the virtuous hearer" as the one who "does not arrive at her credibility judgement by applying pre-set principles of any kind, for there are none precise or comprehensive enough to do the job. She 'just sees' her interlocutor in a certain light, and responds to his words accordingly" (2007: 75-76). Healthcare professionals have "pre-set principles", shortcuts, positive and negative stereotypes (Blalock and Devellis 1986) in order to streamline their daily practice in the continuous flux of admissions, consultations and discharges, but almost always at the price of missing significant nuances and complexities in the clinical dialogue. Narrative elicitation as a method behoves professionals to do more than "just see" the patients and be more "responsive to their words" while they are surrounded by diverse pre-set understandings and stereotypes. They also need to develop greater awareness of inequalities reflecting on narrative elicitation and the credibility of patients.

Epistemic injustices are often elusive. Health professionals may feel offended, or they may resist and fail to address these thorny issues. One detour could be to start by concentrating on

and parsing credibility excesses, developing "a parallel sensitivity to the epistemic saliences" (Fricker 2007: 76). The reasons why some patients are attributed more credibility in clinical communication may be rooted in "the social imaginary [that] plays a crucial role in instituting and maintaining epistemic injustices" (Medina 2011:32) and easily mystified or idealised as "personal chemistry" and sympathy with particular persons, while leaving others unheard or unbelieved. Therefore, using credibility excesses as a reflective and critical resource for thinking about those cases where they are absent, can be compelling to address often invisible inequalities, especially in person-centred care models and narrative-based approaches.

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Conflict of interests

All authors have read and approved the final version of the manuscript and there were no

conflict of interests to declare.

Ethical approval details

The study was approved by the Regional Ethical Board of Gothenburg (Nr 267-17), Sweden.

Data availability statement

The data that support the findings of this study are available from the corresponding author

upon reasonable request.

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References

Atkinson, P. (1997) Narrative turn or blind alley?, *Qualitative Health Research*, 7, 3, 325–344.

Barry, C. A., Stevenson, F. A., Britten, N., Barber, N. and Bradley, C. P. (2001) Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice, *Social Science & Medicine*, 53, 4, 487–505.

Be-Ari, A. and R. Strier. (2010) Rethinking cultural competence: What can we learn from Levinas?, *British Journal of Social Work*, 40, 7, 2155–2167.

Blalock, S. J. and Devellis, B. M. (1986). Stereotyping: The link between theory and practice, *Patient Education and Counseling*, 8, 1, 17–25.

Bradby, H., Lindenmeyer, A., Phillimore, J., Padilla, B., and Brand, T. (2020) 'If there were doctors who could understand our problems, I would be already be better': dissatisfactory health care and marginalisation in superdiverse neighbourhoods, *Sociology of Health and Illness*, 42, 4, 739–757.

Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M. and Wolf, A. (2017) Elaboration of the Gothenburg model of person-centred care. *Health Expectations*, 20, 407–418.

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H. and Wolf, A. (2020) Learning from the Gothenburg model of person centred health care, *BMJ Analysis*, 370, m2738. doi: https://doi.org/10.1136/bmj.m2738

Bruner, J. (1986) *Actual minds, possible worlds*. Cambridge, Mass.: Harvard University Press. Bruner, J. (1987) Life as narrative, *Social Research*, 54, 11–32.

Bury, M. (2001) Illness narratives: fact or fiction?, *Sociology of Health and Illness*, 23, 3, 263–285.

Cadge, W. and Hammonds, C. (2012) Reconsidering Detached Concern: The Case of Intensive-Care Nurses, *Perspectives in Biology and Medicine*, 55, 2, 262–282.

Carel, H. and Kidd, I. J. (2014) Epistemic injustice in healthcare: A philosophial analysis, *Medicine, Healthcare and Philosophy*, 17, 529–540.

Clark, J. A. and Mishler, E. G. (1992) Attending to patients' stories: reframing the clinical task, *Sociology of Health and Illness*, 14, 3, 344–372

Charon, R. (2001) Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust, *JAMA*, 286, 15, 1897–1902.

Charon, R. (2006) *Narrative Medicine: Honoring the Stories of Illness*. New York: Oxford University Press.

Charon, R. and Wyer, P. (2008) The art of medicine: Narrative evidence based medicine, *Lancet*, 371, 9609, 296–297.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., *et al.* (2011) Personcentred care – ready for prime time, *European Journal of Cardiovascular Nursing*, 10, 4, 248–51.

Ekman, I., Hedman, H., Swedberg, K. and Wallengren, C. (2015) Commentary: Swedish initiative on person-centred care, *BMJ*, 350: h160.

Frank, A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.

Frank, A. (2009) Tricksters and Truth Tellers: Narrating Illness in an Age of Authenticity and Appropriation, *Literature and Medicine*, 28, 2, 185–199.

Fricker, M. (2007) Epistemic injustice. Power and the ethics of knowing. Oxford: Oxford University Press.

Fricker, M. (2013) Epistemic injustice as a condition of political freedom?, *Synthese*, 190, 1317–1332.

Gosselin, A. (2019) 'Clinician Knows Best'? Injustices in the Medicalization of Mental Illness, Feminist Philosophy Quarterly, 5, 2, 10.5206/fpq/2019.2.7285.

Greenhalgh, T. and Hurwitz, B. (1999) Why study narrative?, *British Medical Journal*, 318, 48–50.

Gubrium, J. F. and J. A. Holstein, (2009) *Analyzing Narrative Reality*. Los Angeles: Sage.

Gunaratnam, Y. and Oliviere, D. (eds) (2009) *Narrative and Stories in Health Care: Illness, Dying, and Bereavement*. Oxford: Oxford University Press.

Hamed, S., Thapar-Björkert, S., Bradby, H. and Ahlberg, B. M. (2020) Racism in European Health Care: Structural Violence and Beyond, *Qualitative Health Research*, https://doi.org/10.1177/1049732320931430

Hardman, D. and Ongaro, G. (2020) Subjunctive medicine: A manifesto, *Social Science & Medicine*, 256, 113039.

Hydén, L.-C. and Brockmeier, J. (eds) (2008) *Health, Illness and Culture: Broken Narratives*. New York: Routledge.

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., ...Summer Meranius, M. (2018). 'Same same or different?' A review of reviews of personcentred and patient-centered care, *Patient Education and Counseling*, 102, 1, 3–11.

Kalitzkus, V. and Matthiessen, P. F. (2009) Narrative-Based Medicine: Potential, Pitfalls, and Practice, *The Permanente Journal*, 13, 1, 80–86.

Kleinman, A. (1988) *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.

Kleinman, A. and Benson, P. (2006) Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It, *PLOS Medicine*, 3, 10, e294.

Kukla, R. (2007) How do patients know?, *Hastings Center Report*, 37, 5, 27–35.

Kwong, J. M. (2015) Epistemic Injustice and Open-Mindedness, *Hypatia*, 30, 2, 337–351.

Launer, J. (2002) Narrative-based Primary Care: A Practical Guide. Oxford: Radcliffe Medical Press.

Mathers, N. J. and Gask, L. (1995) Surviving the 'heartsink' experience, *Family Practice*, 12, 2, 176–183.

Mattingly, C. (1998) *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press.

Mattingly, C. and Lawlor, M. (2000) Learning from Stories: Narrative Interviewing in Cross-cultural Research, *Scandinavian Journal of Occupational Therapy*, 7, 4–14.

McKinnon, R. (2016) Epistemic Injustice, *Philosophy Compass* 11, 8, 437–446.

Medina, J. (2011) The relevance of credibility excess in a proportional view of epistemic injustice: Differential authority and the social imaginary, *Social Epistemology*, 25, 1, 15–35.

Medina, J. (2013) *The Epistemology of Resistance: Gender and Racial Oppression, Epistemic Injustice, and the Social Imagination*. Oxford: Oxford University Press.

Mishler, E. G. (1984) *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ: Ablex.

Mishler, E. G. (2005) Patient stories, narratives of resistance and the ethics of humane care: à la recherche du temps perdu, *Health*, 9, 4, 431–451.

Naldemirci, Ö. (2013) Caring (in) Diaspora: Aging and caring experiences of older Turkish migrants in a Swedish context. Ph.D. Thesis. Gothenburg: Göteborg Studies in Sociology No 54. https://gupea.ub.gu.se/bitstream/2077/34304/1/gupea 2077 34304 1.pdf

Naldemirci, Ö., Britten, N., Lloyd, H. and Wolf, A. (2020) The potential and pitfalls of narrative elicitation in person-centred care. *Health Expectations*, 23, 238–246.

Paley, J. and Eva, G. (2005) Narrative vigilance: the analysis of stories in health care. *Nursing Philosophy*, 6, 83–97.

Sharpe, M., Mayou, R., Seagroatt, V., Surawy, C., Warwick, H., Buldstrode, C., Dawber, R. and Lane, D. (1994) Why do doctors find some patients difficult to help?, *Quarterly Journal of Medicine*, 87, 187–193.

Sinding, C., Miller, P., Hudak, P., Keller-Olaman, S. and Sussman, J. (2011) Of time and troubles: Patient involvement and the production of health care disparities, *Health*, 16, 4, 400–417.

Summer Meranius, M., Holmström, I. K., Håkansson, J., Breitholtz, A., Moniri, F., Skogevall, S., Skoglund, K. and Rasoal, D. (2020) Paradoxes of preson-centred care: A discussion paper, *Nursing Open*, 00, 1–9. https://doi.org/10.1002/nop2.520

Thórarinsdóttir, K. and Kristjánsson, K. (2014) Patients' perspectives on personcentred participation in healthcare: a framework analysis, *Nursing Ethics*, 21, 2, 129–47.

van Dulhem S. (2017) Listen: When words don't come easy, *Patient Education and Counseling*, 100, 11, 1975–1978.

von Knorring, M., Sundberg, L., Löfgren, A. and Alexanderson, K. (2008) Problems in sickness certification of patients: A qualitative study on views of 26 physicians in Sweden, *Scandinavian Journal of Primary Health Care*, 26, 1, 22–28.

Wardrope, A. (2015) Medicalization and epistemic injustice, *Medicine, Health Care and Philosophy*, 18, 341–352.

Werner, A. and Malterud, K. (2003) It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors, *Social Science & Medicine*, 57, 8, 1409–1419.

White, M. and Epston, D. (1990) Narrative Means to Therapeutic Ends. NY: Norton.

Williams, A. (2001) A literature review on the concept of intimacy in nursing, *Journal of Advanced Nursing*, 33, 5, 660–667.

Wolf, A., Moore, L., Lydahl D, Naldemirci, Ö., Elam, M. and Britten, N. (2017) The realities of partnership in person-centred care: a qualitative interview study with patients and professionals, *BMJ Open*, 7, e016491.

Wong, G. and Breheny, M. (2018) Narrative analysis in health psychology: a guide for analysis, *Health Psychology and Behavioral Medicine*, 6, 1, 245–261.