



Unintended ignorance: The narrative of ‘the missing patient voice’

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abstract

This paper brings attention to the production of unintended ignorance in the context of patient involvement in the re-design of healthcare services. Ignorance is usually treated as the result of human and intentional inattention. Recent calls stress that more empirical studies are needed that go beyond understanding ignorance as performed by individuals to explore ignorance as a sociomaterial practice, including all its heterogeneous elements. Actor-network-theory (ANT) assumes that power does not relate primarily to human intention, but instead to the capability of actors, human and non-human, to cause relational effect. Through the lens of ANT and translation, this ethnographic study illustrates how ignorance is produced throughout a service design process in Norwegian health care seeking to involve patients and include the patient voice. It finds that ignorance is produced as patient-centred policy translates into a label — ‘the missing patient voice’ — enrolling actors and contributing to unintentionally ignoring the real patient voices. This article brings empirical insight into ignorance as practice by giving voice to the non-human actors involved in such efforts, bringing conceptual attention to the material dimension of ignorance. Furthermore, this study affords nuance in understanding practices of patient-centred care by offering a critical perspective on how well-intended efforts of locating and including the patient voice in healthcare services can become symbolic and instead bring passive, token patients (with no voices) into being.

Introduction

Conceptualisations of ignorance usually distinguish between ignorance as a product of intentional, deliberate inattention and as something unintentional, a state of 'being ignorant' in terms of lacking knowledge about certain conditions (Roberts, 2012; Gross, 2010, Smithson, 1989). Recent research of ignorance in the organisational context has tended to focus on intentional ignorance relating it primarily to human agency tied up in the individual's ability or will to ignore. Ignorance is therefore usually explored as a resource that helps human or organisational actors, and as something actively and intentionally produced for different strategic purposes (Schaefer, 2018; Roberts, 2012; McGoey, 2012; McGoey, 2007).

In order to better grasp the phenomenon of ignorance recent calls have stressed the need for more empirical studies that go beyond understanding ignorance as performed by individuals and explore ignorance as a socially constructed and practiced phenomenon that also gives attention to all the heterogeneous elements involved (Bakken and Wiik, 2017; High et al. 2012).

Process perspectives focus on how and why things emerge and change over time (Tsoukas, 2017). One process perspective, actor-network theory (ANT), addresses how patterns or things stabilise in actor networks where human and non-human, macro- and micro-actors are empirically treated the same, with potential capabilities of causing relational effects (Latour, 1986; Callon and Latour, 1981). This study puts forward that an ANT perspective can provide insight into the practice of ignorance and bring nuanced understanding to the production of ignorance beyond human intention or the unintentional result of simply lacking knowledge. Specifically, this study critically investigates how a non-human actor, a label, contributes to the production of unintended ignorance in the context of patient-centred care.

By definition, the concept of patient-centred care implies that patients' subjective experience and voices have somehow been neglected in the organisation of health care. Hence, there is a need for care to be *patient-centred*; that patients should have a stronger voice and be more involved and empowered in the provision of health care services (Liberati et al., 2015; Tanenbaum, 2015; Mead and Bower, 2000). Traditionally, patient

involvement has been about empowering patients' voices through shared understanding and power in clinical decision making (Dent and Pahor, 2015; Dubbin et al. 2013; Greener, 2007; Mead and Bower, 2000). Recently, patient involvement has been called for in the context of public innovation and re-organisation of services. In public service strategies, innovation is encouraged (Andersen and Pors, 2017), and new methods and approaches centred on 'the user experience', such as service design, co-production, and user involvement. Such approaches are considered more suited to centre service provision and the organisation of care around the patient experience and voice (Greenhalgh et al., 2011; Bason, 2010).

Despite the intention to offer patient-centred health care services, research and policy point out that patients' voices are still easily disregarded in health and care services, and the issue continues to be on the global political agenda (Tanenbaum, 2015; El Enany et al., 2013; World Health Report, 2008; Crawford et al., 2002). Research looking into patient-centred care-related approaches, such as shared decision making or involvement in service development, point to the different and often conflicting meanings for service providers making it difficult both to conceptualize and operationalize patient-centred care (Liberati, 2015; Dubbin et al. 2013; Gillespie et al. 2004). Furthermore, patient or user involvement can also become a set-up that contributes to further marginalisation of patients (Fleming et al., 2017; Martin, 2008), sustains existing power relationships (El Enany et al., 2013), and that is unrepresentative and tokenistic in nature (El Enany et al., 2013; Crawford et al., 2003). Notions of involvement can create illusions that patients and providers are equal partners when in reality this is more symbolic than social (Kirkegaard and Andersen, 2018). Idealistic policy can result in organisational blind spots, where impossible ideals force health professionals to ignore that policy is unrealistic (Fotaki and Hyde, 2014). Increasingly, patient-centred care is approached as constructed in relational practice. Such studies look into how patient-centred care policies and care logics work out 'on the ground' and help uncover the micro power dynamics that play into patient-centred care practices (Habran and Battard, 2019; Liberati et al. 2015; Mol, 2008). In this paper, I build further on such research and ask; how may discourses of patient-centred care paradoxically end up silencing patient voices and excluding them in practice?

I explore the production of ignorance through an ethnographic study of a project in the Norwegian healthcare setting inspired by a user-centred service design methodology. The project sought to improve coordination between care providers and the service pathway to a vulnerable patient group based on foregrounding the patient experience and empowering the patient voice in service design and delivery. This study looks into how ignorance was produced despite intentions and ideals of inclusion and empowerment.

Specifically, I employ the concept of translation from ANT to illustrate how ignorance was produced as the mission of the patient-centred project translated into a label, 'the missing patient voice', enrolling actors and contributing to unintentionally ignoring the real patient voices.

This finding leads me to suggest that labels, as well as other non-human actors, can contribute to the production of ignorance. While most empirical work on ignorance in the organisation and management field has approached the production of ignorance from a human agency perspective (Schaefer, 2018; Roberts, 2012), I cast light on a performative and (socio)material dimension that can further elucidate the production of ignorance beyond understandings of ignorance as primarily the result of intended action. Instead, I argue that ignorance can be unintended, and at the same time, caused by capable actors. The contribution of this paper is thus to bring attention to the unintentional and material dimensions of ignorance as well as the role of ignorance in haltering patient empowerment in patient-centred care practices.

The paper proceeds as follows: In the next section, I present the concept of ignorance – specifically, ideas of ignorance relating to intentionality and agency. I then link this with a processual and performative perspective, namely, ANT, which considers non-human agency in social and organisational processes. The research design is then presented, followed by the narrative analysis, 'A project searching for a missing patient voice', and a concluding discussion, where I link the findings to the concept of ignorance and reflect on contributions for the practice of patient-centred care.

Theoretical and analytical framework

Ignorance as the result of intentional or unintentional unknowns

The idea that ignorance is ‘intentionally fostered and maintained’ (McGoey, 2012: 571) has been important in terms of looking at ignorance as a resource (known unknown) and something actively produced instead of just a ‘lack of knowledge’ (unknown unknown) one should seek to overcome (Roberts, 2012; McGoey, 2007; Smithson, 1989). It is about knowing what not to know and about selective ‘seeing’ (Otto et al., 2018). Scholars have drawn attention to organisational ignorance (Roberts, 2012), strategic ignorance (McGoey, 2012) and managerial wilful ignorance (Schaefer, 2018), to mention a few types. This intended production of organisational ignorance is usually understood as a result of individual (primarily human) agency. For example, in Schaefer’s (2018) empirical study of innovation practices in a technology organisation, he illustrates how tensions between myths of rationality and pressures of working efficiently resulted in managers ‘sticking to their visions’ leading them to actively and wilfully ignore relevant information. Organisational ignorance connects with an idea of agency as ‘the capacity of an individual or entity to cause an effect’, where the organisation is the source of agency (Roberts, 2012: 219), or conversely, individual managers’ willingness to ignore produces an intentional state of ignorance indicating that individuals are ‘the prime movers of organisational knowledge creation’ (Nonaka, 1994: 17 as cited in Schaefer, 2018: 3). In contrast, an unintentional form of ignorance connects with the idea of a state of ‘being ignorant’, when there is insufficient knowledge about certain conditions (Gross, 2010). Then, ignorance can appear through the revelation of a surprise that triggers awareness of one’s ignorance and lack of knowledge (Smithson, 1989).

Then again, ignorance has also been seen as something existing between the intentional and unintentional. An active form of ignoring can be the result of unconscious suppressions derived from social taboos or constraints that make it difficult to process unsettling knowledge (Roberts, 2012). The analysis of pollution and taboo in the classic work of Mary Douglas looked at how societies organised untidy experiences by making clear distinctions between the sacred, the clean and the unclean (the polluted). The sacred

must be continuously protected via ‘rituals of separation and demarcation and [...] reinforced with beliefs in the danger of crossing forbidden boundaries’ (Douglas, 1966: 197). A taboo is the social prohibition of certain forms of knowledge that are either proscribed or seen as impure – hence, knowledge to be ignored (Roberts, 2012). Douglas argues that ‘pollution can be committed intentionally, but intention is irrelevant to its effect – it is more likely to happen inadvertently’ (Douglas, 1966: 12). It is the power inherent in the structure of ideas released by human action – not the power vested in individual humans – that produces pollution; this, in turn, creates the conditions for establishing social taboos.

Fotaki and Hyde’s (2014) study of failing strategies in the British National Health System looks at the development of organisational blind spots from a socio-psychological and affective perspective. These researchers found that the split between policy formation and implementation enabled policymakers to become unrealistic and idealistic, whereas operational staff were faced with ‘impossible ideals’. They were not able to implement these unrealistic policies or to have their difficulties heard. This resulted in affective, defensive psychological mechanisms, such as splitting and blame, leading to organisational blind spots. Knudsen’s (2011) functional concept of ‘forms of inattentiveness’ explains how actively ignoring relevant information is neither intentional nor unforeseen; instead, it is a unity of a problem and a solution produced in activities. Knudsen (2011) illustrates how the use of signs of imagined knowledge, as well as inclusion and exclusion of specific actors and guidelines, is actualised as knowing of problems and solutions to such problems that inevitably produce ignorance or blind spots. Moreover, he proposes that these forms of inattentiveness have a function in under-structured decision-making processes (Knudsen, 2011).

As I have shown, several researchers point towards understanding the underlying visions, strategies and ideals that might lead to or play a role in producing ignorance. Recent calls stress the need for more empirical studies that go beyond understanding ignorance as performed by individuals and explore ignorance as socially constructed and practiced phenomena, including all its heterogeneous elements (Bakken and Wiik, 2017; High et al., 2012; Roberts, 2012; Smithson, 1989). To further such understanding, I will

elaborate on policy ideas as performative discourses, operating as performing actors that play a role in the production of ignorance. For this, I employ a processual and performative analytical lens inspired by ANT and the process of translation that I think can help bring attention to the material and performative side of production of ignorance.

Actor-network theory and translation

Performative and process perspectives focus on how and why things emerge and seek to understand instead of reducing complexity (Tsoukas, 2017). Hence, any phenomenon or social order can be approached as ongoing processes not primarily driven by intentions but resulting from associations or networks between actors (Latour, 2005; Barad, 2003). ANT assumes symmetry between all actors – with no a priori distinction between human and non-human actors (e.g., objects, texts, ideas) or micro- or macro-actors (individuals, organisations, institutions) (Hernes, 2005). The idea of following objects via a narrative is central to ANT, starting with the ‘actant’, as that which accomplishes or undergoes and act (Czarniawska, 2007). An actant can be a human; it can also be an animal, object, or concept (Czarniawska and Hernes, 2005: 8; Latour, 1994).

An idea can become an object – a linguistic artefact – when it is used repeatedly as a label (Czarniawska and Joerges, 1995: 24). This process of stabilisation is often known as ‘translation’, which explains how an actant brings on board actors, identities, patterns, and the relation between them as one collective actor – the actor network (Latour, 1999, 2005). Latour (1999: 70) stresses ‘the chain of transformation’ that enfolds one ordering into the other, enabling a tracing of reference through the network of translation to arrive at the original place of enquiry (Harris, 2005). In this process of translation or ‘circulating reference’, the original sample needs to be simplified and made less difficult to suit the context (Jensen et al., 2009). Since it associates with a range of prior knowledges now enrolled in the network, it stays the same while at the same time becoming something different. Hence, translation leads to a heterogeneity of actors and unpredictable outcomes (Latour, 1986; Callon and Latour, 1981). Discourses can travel across social levels and shift from being abstract ideas into objects, matter, or enacted practices. Thus, we can understand that

discourses or representations do not represent an external reality but rather constitute an internal reality (Latour, 1999; Foucault, 1977). Hernes (2005: 114) brings translation into the 'confined spaces of organizations' where different institutions, macro-actors, can be brought into being through the discursive enactment of individual organisational actors.

Actor networks are unstable constructions that require effort to stabilise. Hence, power is central in translation processes but not something actors possess as such (Jensen et al., 2009; Latour, 1986). Power (to change) relates not primarily to (human) intention but rather to the capability of actors (human and non-human) to cause effects to other actors within the network; in other words, it represents 'all the intrigues, calculations, actors of persuasion and violence, thanks to which an actor or force takes, or causes to be conferred on itself, authority to speak or act on behalf of another actor or force' (Callon and Latour, 1981: 279). Butler (1993, 1999) provides similar critical perspectives on how discourses work performatively. Building on Foucault and Derrida, she shifts focus from intention to citation as the underlying force of performativity: '[P]erformativity must be understood not as a singular or deliberate "act", but, rather, as the reiterative and citational practice by which discourse produces the effects that it names' (Butler, 1993: 2). Looking at this in relation to gender, Butler explores how norms work to constitute subjects and the materiality of bodies. In my analysis, I draw on the notion of 'translation' in following how a patient-centred care project process unfolds. Specifically, I show how the mission of the project translated via related policy into a label of 'the missing patient voice', and how it stabilized as an actant figuring as the 'true' representation of patients. Inspired by Butler (1993, 1999) I show how a missing voice is discursively talked into being through power struggles that paradoxically involved ignoring the real voices in the project. The label became a productive resource to bring attention to the patient voice that further stabilized as 'missing'.

Research design

This article is based on an ethnographic case study of a project inspired by service design in Norwegian health care in which the search for the missing patient voice contributed to producing ignorance.

Research context

Norwegian healthcare policy calls for patient-centred care. In 2014, the Minister of Health presented a political plan for Norwegian health care that was ‘The patient’s health service’ with the ambition to place the patient in the centre and increase quality of care (Helse- og Omsorgsdepartementet, 2014). Policy literally tell health personnel to ask patients ‘what matters to you’ (Meld. St. 26, 2014-2015: 11). The explicit focus on the patient requires a shift in practices and how care is organised, and public authorities are calling for service design as a go-to innovation method to accomplish patient-centred healthcare services (Meld. St. 11, 2015-2016: 125):

Service design is a new tool for improving and simplifying health care services. It combines process understanding with visualisation. Designers draw from today’s situation. This way a common understanding is created among the actors of what is important to change and how it can be done.

Service design is a practice and ‘a human-centred, creative and iterative approach to service innovation’ (Sangiorgi and Prendiville, 2017: 2), combining a focus on service interfaces and interactions with co-production and ‘engaging people in the design for better service experiences’(Sangiorgi and Prendiville, 2017: 2). User representation is central to all stages, from the problem formulation to the insight phase, piloting, organisational implementation, and further provision of services (Junginger and Bailey, 2017; Sanders and Stappers, 2008).

Research setting

The service design project was initiated by a university hospital to improve services and coordinate care for a particularly fragile and vulnerable patient group – elderly patients with multiple illnesses. Their medical picture is complex, and the patient voice is easily lost in the coordination between care providers. A central premise of the project was that the patients’ voices

should be involved in both the design and delivery of a new service model; hence, a service design methodology was applied. More specifically, patients were observed and interviewed in their homes to learn about their needs and expectations of services. Furthermore, a service model of ten routines was designed to convey the patient voice in coordination. The routines were checklists, scripted dialogues, and templates for documenting the patient voice and experience based on the slogan, 'what matters to you'. The project included three clinics at the hospital and the home nursing units, service offices, rehabilitation institutions, and general practitioner (GP) representatives from two related municipal districts. A project manager from the university hospital administration was engaged with a project group consisting of hospital nurses, municipal case workers, home nurses and GPs. The project manager recruited patients and saw that the routines were tested and implemented throughout the service interfaces.

Methodology

The university hospital and business school where I am a PhD researcher were partners in a publicly funded research centre on patient-centred innovation, which allowed me to access the case for fieldwork. The case was purposely selected based on the mission to find ways of involving the patients in both the design and delivery of services (Flyvbjerg, 2006). I used participant observation and qualitative interviews to gain insight into the interactions between project participants in the search and inclusion of the patient voices. Documents, such as annual reports, formal presentations, and public documents about the project, were studied to better grasp the problem formulation of the project, the framing of service design and user involvement and how the process was planned and formally executed.

I followed the project over the course of eighteen months, with regular participation in project activities. I participated in eight out of eleven project meetings, and two out of four workshops, where I took comprehensive field notes (Wolfinger, 2002) and wrote down observations almost verbatim, organised temporally (Emerson et al., 1995). For the meetings and workshops that I was unable to attend (some had taken place before I entered the field site), I studied minutes of meetings and PowerPoint presentations that were distributed to participants via email. All notes were

written up and elaborated on from memory later the same day. From my observations, I realised that the practitioners had different ways of involving patients in their work. Therefore, I proceeded to interview the ten project participants that had been most present in the project meetings – namely, two hospital nurses, two GPs, two case workers, three home nurses and one head nurse at a rehabilitation institution. All interviews were audio-recorded and later transcribed and coded with the field notes.

Together with the project manager, I interviewed eleven patients who participated in the project. We developed an interview guide covering patients' experiences of being involved in the project and in caring practices. This allowed me to explore notions of involvement from various perspectives. The interviews were audio-recorded and transcribed by the project manager. The joint affiliation with the research centre allowed the sharing of patient data.

Because some informants also engaged in ethnography-like types of knowledge seeking (searching for the patient voice), my study required multidimensional relationships with people in the field (Garsten and Nyqvist, 2013). In addition to conducting the patient interviews, I participated in nine meetings with the project manager, including planning meetings for a workshop about user involvement. Here, my role in discussions on user involvement was more participatory which would sometimes complicate my role as an observer. This required that I created strategies to address difficult situations when they happened, for example, by always being clear about my role, by avoiding questions, by playing them back, and by refraining from taking sides in discussions. I also developed sensitivity to these moments in my field notes (Guillemin and Gillam, 2004). Being included in the project manager's struggle to operationalise user involvement led us, however, to reflexively explore such topics in interviews, which revealed great insight into what was happening. Despite the efforts to avoid influencing the process, there is a possibility that my presence and affiliation with the research centre on patient-centred innovation added 'weight' to the trend-setting user-centred actant, contributed to the production of ignorance.

Data analysis

I followed a grounded theory (Glaser and Strauss, 1967) approach, working with an open-ended approach from the data on ‘the ground’. This involved systematic conceptualisation and comparison with similar and distinct research areas to reach conceptual saturation. Inspired by ANT, I started by identifying the key events (project workshops, project meetings, patient interviews), as well as the actors/actants (project manager, care workers, patients, project mandate, patient personas, project descriptions, discourses) and the connection between them, including how these connections changed along the way (Hernes, 2005). Following Latour (1999: 70), I traced ‘the chain of transformation’ back to the original place of enquiry and studied the formal project mandate and descriptions of the project, linking them with my observations and interviews to make sense of what was happening.

Analysing the project as a process of translation helped me see how the intention of finding and including the missing ‘patient voice’ seemed to persist despite being challenged by the ‘real voices’ of the patients. This led me to conceptually explore this as a case of organised ignorance. After going back and forth between actors and connections between them, a coherent story gradually emerged, and I felt it was sufficiently saturated as a narrative explaining how the process unfolded (Hernes, 2005: 118).

We can now look at what happened when the vision of patient-centred care was translated into a local project seeking to involve patients whose voices were assumed to be ‘missing’ in the provision and organisation of care.

A project searching for a missing patient voice

Identifying ignorance: ‘The missing patient voice’

I entered the project site as an observer after the project had started, but luckily there were linguistic ‘artefacts’ allowing me to follow ‘the chain of transformation’ back to the original place of enquiry (Latour, 1999: 70).

The mission of the project was to contribute to ‘The patient’s health service’ by developing a new service model. Policy ideas and evaluations were referred to in PowerPoint presentations introducing the project stating that there is ‘little user involvement’, that users experience fragmented health care services¹², and calling for the inclusion of patients’ and users’ voices in the organisation and coordination of health care services⁵. The mission translated into a task description that the project would locate and include ‘the patient voice’ and handle user involvement in both the development of and as an important part of the new solution. In order to locate and include the patient voice, which was presented as somehow neglected, the project adopted a service design methodology. The project manager explained:

in coordination, out in the home service, with the GP, everywhere we wished to grasp the patient voice. And our approach was supposed to be user centric. And it [service design] was something we thought of – it is trendy, right, it is “the whole patient first”, mastery, white papers en masse, it is written in all guiding documents – that we should have a greater focus on the user.

The patient voice referent was translated into a service design methodology. Service design did not originate specifically from healthcare policy but from information and communication technology (ICT) policy relating to public innovation and initiated to make public services more accessible and user-friendly.⁴ Service design is also mentioned in healthcare plans as a tool for innovation in healthcare services⁵ and matches the focus on user/patient

¹ Meld. St. 26 (2014-2016) Fremtidens primærhelsetjeneste stating that users experience fragmented services and little user involvement

² Forskningsrådet (2016) Evaluering av samhandlingsreformen, p. 14 stating that ‘consideration of patient/user participation is one of the areas that ought to be given particular attention

³ Meld. St. 47 (2008-2009) Samhandlingsreformen, p. 25 stating that specifically patients’ and users’ voices are important when identifying good patient pathways. Patients and users are carriers of the needs and live the lives the services target

⁴ Meld. St. 27 (2015-2016) Digital agenda for Norge, p. 43: ‘the government will stimulate for more uses of service design to contribute to more, good user-centered services’.

⁵ Helse- og Omsorgsdepartementet (2015) Omsorg 2020 Regjeringens plan for omsorgsfeltet 2015-2020., p. 49: ‘some of the municipalities’ most important

involvement spelled out in healthcare reforms and white papers.⁶ As such, it was strategically in line with guiding policy, as well as being true to the mission of involving patients in the process.

In November 2015, the insight phase was initiated to learn more about how patients experienced healthcare services. The project manager worked with a professional service designer to sketch the service journey of four patients based on interviews of the patients and the different service providers (19 interviews in total). They found that

the patient voice is unclear.... Summing up after 19 interviews, the patient voice is unclear, structures are deficient for listening, documenting, and conveying. The patient is often unable to speak their case.

The project manager further explained in an interview:

it was brought to our attention that we to a small degree make use of the patient voice and that we neglect the patient voice in the information that we share.

The patient voice was referred to in the project as ‘weak’, ‘not heard’, ‘unclear’, ‘neglected’, ‘not made use of’, and something ‘we are not good at listening to’. The problem with the patient voice also confirmed the initial assumptions of the project manager, stating in an interview that ‘it was an assumption in the steering group – well, we thought it was like that’, as well as the official discourse in health care.

This focus on ‘the patient voice’ as neglected, ignored, and somehow missing in the organization of care became a representation of the patient, and a label through which the project further developed. Since the project’s mandate was to develop a new service model that included the patient perspective, a service model of ten routines was designed and piloted. The routines were different checklists, templates for how to dialogue with patients, routines for sharing information, and arenas for the different

collaborative partners on research, innovation, and service design will be given grants and instruments to aid the health care services’.

⁶ Meld. St. 34 (2015-2016) Verdier i Pasientens Helsetjeneste – Melding om prioritering., p. 1: ‘Users and patients must be involved in the design of priorities of health services at all levels’.

service providers to meet with the patients. All routines included the requested question to patients – what matters to you? – as a tool to locate the patient voice.

‘What matters to you’ was a slogan that can be traced to a 2014 learning network concerned with elderly patient pathways. It came as a response to another, more common diagnostic question – that is, ‘what is wrong with you’ – and it was meant to redirect focus from the biomedical gaze and to patients’ resources and ability to master their own lives.

It gradually became clear that the routines to improve service provision were not so much the result of an emerging service design process that involved the patients and care workers, rather it came directly from the project mandate. Most of the routines were already existing, called for specifically from the policy level (e.g., ‘what matters to you’), and revisions of previous projects as ‘best practices’, and good organisational solutions to the established ‘patient voice’ problem:

The mandate said that we should look at coordination, holistic care in hospitals... so we established a working group to operationalise these important things in concrete routines that we were going to do. So, the routines are collected from that mandate, right. (Interview, Project manager)

They [the routines] are very similar to what the other [projects] are doing. It is similar to the coordination routines for some municipalities I have seen. It is the same; it goes [that way] again. This is also in relation to the revisions that are done of the coordination reform. There was some low-hanging fruit [existing routines], and one decided for ten [routines]. (Interview, GP 2)

This can be seen as a process of stabilization (translation), bringing on board different terms such as ‘The patient’s health service’ with focus on patients’ right to choose; the slogan – ‘what matters to you’; and service design as a method to invoke user-friendly services. Tracing these terms back to the original place of enquiry (Latour, 1999), they reflected different practices and motivations for involving patients, approaching the patient voice from different levels; the individual level in patient-practitioner relationships, and a collective level of a common user voice as an organizing principle for inclusive services. Still, they shared the ability to underpin the focus of a neglected, weak, or missing patient voice. As I will show, the label ‘the

missing patient voice' was strengthened and stabilized further throughout the project.

Dealing with ignorance in the project

The piloted service model was brought into the testing phase of the service design process, where the ten routines were tested with recruited 'project patients' throughout the service network. The care workers from each node in the service chain (home nursing units, hospital clinics, service offices, rehabilitation institutions, GP offices) met frequently throughout the process in formal project meetings organised by the project manager to share experiences and discuss how the new routines were working.

The patients were not physically present in these meetings, but they had been 'transported' via hospital records and digital touch points to PowerPoint presentations of 'patient personas'. The use of personas is a vehicle for representing 'the user experience' in service design (Stickdorn and Schneider, 2014). An example is as follows:

Patient 1 (City district 1, Orthopaedic unit)

Social woman, 76, lives on the first floor without an elevator. One son who lives [abroad]. She receives home nursing. The illness history resulting in admission was bone fracture. She then went to a rehabilitation home; two weeks later, she had a check-up with her GP and operation at the university hospital orthopaedic unit was considered.

Other illnesses: Chronic obstructive pulmonary disease, diabetes, osteoporosis

'The (missing) patient voice' was made present by the patient personas, which paradoxically seemed to focus more on 'what is wrong with you' than 'what matters to you'. This enabled the project manager, whose focus was to ensure that patients' voices were considered, to redirect focus from 'what is wrong with you' and mobilise 'what matters to you', calling upon 'the patient voice' as if it was missing.

The following field note is from Project meeting 3:

Patient 6 is presented, and they discuss possible mental stress and anxiety. The project manager says that really grasping that anxiety will also be a question regarding patient involvement.... She turns to one of the home nurses, asks if they have a procedure for this when patients get home from hospital; a conversation that is about “how are you doing now”. Home nurse (unspecified) says, “That is what we do”. The project manager responds and wonders, “What matters to you in practice?” The home nurse responds: “That is our work, yes, that is what we do”.

When I explored the problem of ‘the missing patient voice’ further, it was difficult to grasp. What was really the problem? ‘The missing patient voice’ was a label that patients and care workers did not really recognise, although this was never discussed openly in the project meetings, despite often being implied, as the vignette above illustrates. Rather, this was information that came out during the interviews, when I asked the participants to reflect on how user involvement had been handled in the project. Home nurses, GPs, service officers and hospital nurses had different practices of involving patients, but all emphasised that patient involvement was nothing new. Here, this is illustrated by statements from two different home nurses:

But it has always been like that. That the user decides and that you should listen to the patient. I have not experienced anything new with that [in the project]. (Interview, Home nurse 2, City district 2)

“What matters to you” is how the city district works.... We always collaborate with the patient. It is how we work every day. (Interview, Home nurse 3, City district 1)

The patients we interviewed seemed to generally feel involved. They talked about healthcare services as being part of their everyday life; the level of involvement always depended on what they were currently facing and what they needed. Sometimes, they would use their voice to decide on the level of assistance for daily activities, such as cooking or bathing:

In the evening, they [home nurses] come and make me dinner.... They wanted to come in the morning too, to make coffee and butter my bread, but then I said no, I don’t want to, because I like to make it myself. I can manage to butter my own toast. (Interview, Patient 7)

Other times, patients needed to be advised or told what to do, as in the following example:

But that was a completely different situation [in the hospital]. I walked in the corridor, and they told me, “Madam, you should slow down, take it easy, get some rest!” ... They told me at the hospital that I should just eat and relax and get as well as I could. I gained weight again when I was there, got back my appetite and had someone to talk to. (Interview, Patient 3)

Or, patients would use their voice to decide on treatment:

-Did they involve you?

-Yes, all the nurses helped and talked a lot...they asked questions about my symptoms prior to my operation. Two of the doctors stood together by my bed and asked me again and again if I was sure that I wanted the surgery. I decided all by myself, I want to be able to breathe better. (Interview, Patient 3)

User involvement activities were initiated throughout the project, for instance, in workshops organised specifically to locate the patient voice. When asked about these activities in interviews, few of the care workers seemed to remember them well, if at all, or be able to link them to the design of new routines:

Researcher: In what ways has the patient voice been included in the development of the solution?

GP 1: I can't say it has been all that clear, not in any other way than a little bit through the pilot that was done, picking up the user voice there, but... that is one way to get the user voice out, and it has been done through the after-interviews... asking them how was it for you, how did you experience it, but then we are sort of behind after the solution has already been developed...

The project manager was genuinely concerned about bringing the patient's voice out, and she was dedicated to the user involvement approach in the project. Still, at one point, even she questioned the idea of 'the missing patient voice' that had come to be a known truth in the project:

[T]he question, “what matters to you” – does it take us where we want to go? But I think that when it comes to the user, it says that one of the most basic principles of service design is to work user-centred [refers to the official website for municipalities]. To work user centrally means to systematically make use of the user's voice in the whole development process. And we did that, don't you think? But it is interesting because the user voice that was missing, I did not really find it again in the project... (Interview, Project manager)

The multiple versions of patient involvement showed how the patient voice was always an ‘unknown’, emerging in care practices and not some empirical representation to be ‘found’. Hence, there were hesitant voices, including that of the project manager; however, it seemed that ‘the missing patient voice’ representation persisted, legitimised by policy and the user-centred service design method now enrolled in the network (Latour, 1999, 2005). As the narrative develops, these multiple patient representations created frictions, which paradoxically enabled the label ‘the missing patient voice’ to grow stronger.

Production of ignorance in the project

On many occasions, there was frustration among the care workers because the new routines did not seem to fit their idea of what the patient needed. It was clear how the care workers had different notions of patient involvement and were ignoring each other’s perspectives. This would often lead to negotiations and acts of persuasion between the care workers themselves, and between the care workers and the project manager, as illustrated in the following observation notes:

The case workers argue that they know the patients and they know that they can function well at home. They seem to be frustrated by the hospital nurses who promise patients places in rehab centres. They want the hospital to start focusing on “selling home” to the patients. (Observation note, Project meeting 3)

Hospital nurse 1 says that she misses medical information from the home nurses. Home nurse 3 responds that ‘the thing about the home service, we don’t measure the blood pressure unless there is a specific need’. Hospital nurse 2 says the home nurses measure too seldom. Home nurse 3 responds that they don’t have a standard and that they don’t have the opportunity to measure the blood pressure for all their users (Observation note, Project meeting 8)

The practitioners sometimes suggested changes to routines that they found were not working in practice:

Home nurse 1 says, “Maybe we have to reconsider that routine?” The project manager responds, “Where is the patient’s voice in that?” (Observation note, Project meeting 4)

When discussing a routine, the project manager says, “As far as possible, we wish to complete this routine. We are in a project, and we have to test this.” Case worker 1 points out that they experience some difficulties with this routine. The project manager responds, “I have to break through [the discussion] We can discuss [it] later...” (Observation note, Project meeting 3)

In these situations, the project manager would often redirect the discussion toward the patient – *Where is the patient’s voice in that?* She would remind the project participants to consider the patient voice, thereby talking into being that it is missing. Hence, ‘the missing patient voice’ actant stood in the way of care workers using their voices to suggest possible changes to the routines that were not working and engage in co-creation. The new set of routines was treated as *the* patient-centred solution to *the* ‘found’ problem of a collective missing patient voice, whereas the patient voices that the care workers brought into the discussion were not treated as legitimate in representing the patient.

The voices of the care workers and their experience with the patients were ignored by informally enforcing a taboo – namely, that any insight that might be understood as not complying with ‘the missing patient voice’ representation is somehow polluted. In contrast, the idea of user centrality is clean, maybe even sacred (Douglas, 1966). Because of this, the project manager would not change the routines during the testing phase, arguing, ‘We are in a project’. In this way, she ignored the voices of the project participants (and implicitly the patients) by reminding the practitioners to consider the patient voice. The frictions between the various patient voices represented through the care workers gave ‘the missing patient voice’ label authority to speak or act on behalf of the patients and gave the project manager an opportunity to get the care workers to align in the name of ‘the patient voice’ (Callon and Latour, 1981: 279).

The testing phase of the project went on for a little more than a year. The patients reported that they were generally happy with the care that they received but did not seem to notice much change in the service that they had received since the project started. Despite the frictions and disagreements illustrated above, I experienced that the practitioners gradually showed more awareness of their own and each other’s perspectives and practices, and that they became more reflexively aware of the fact that they did not

know all aspects of patients' experiences. To further encourage implementation of a user-centric model, the project was absorbed into a larger project network in the municipality. Hence, the 'new' user-centred model was launched as a solution of 'best practice' to yet another set of problems concerning patient-centred care, and perhaps for new ignorance to emerge.

Discussion and conclusion

Recent calls stress that more empirical studies are needed that go beyond understanding ignorance as performed by individuals to explore ignorance as encompassing socially constructed and practiced phenomena, including all its heterogeneous elements (Bakken and Wiik, 2017; High et al., 2012; Roberts, 2012; Smithson, 1989: 6). Several researchers point towards understanding the underlying visions, strategies and ideals that might lead to or play a role in producing ignorance (Fotaki and Hyde, 2014; Knudsen, 2011). Hence, I want to elaborate further on ideas and discourses as actants with the agency to perform and play a role in the production of ignorance.

Ignorance is usually treated as the result of intentional or deliberate inattention, something that helps human actors or organisations obtain resources or deny liability (McGoey, 2007) or considered as strategically necessary, for example, to uphold 'the vision' (Schaefer, 2018). ANT assumes that power does not relate primarily to human intention, but instead, it relates to the capability of actors, human and non-human, to cause relational effect (Jensen et al., 2009; Latour, 1986). I have looked at the production of ignorance through the lens of ANT and translation, which enabled me to illustrate how non-human actors, specifically a label, can contribute to the production of ignorance. I analysed how a patient-centred care project translated into the label of 'the missing patient voice' that gradually enrolled other actors which paradoxically ended up ignoring the patient voices in the project.

A common and often true assumption accompanying discourses of patient-centred care is that the patient voice is insufficiently involved in healthcare services (Tanenbaum, 2015). It was acknowledged that there was ignorance

(i.e., lacking knowledge) about the patient experience in the coordination and provision of healthcare services for the elderly patient group. The project was set up to overcome ignorance by employing a user-centred service design methodology. The discourse of patient-centred care matches the premise of service design theory and method – that expert bias can be avoided by starting and evolving design in ‘the user experience’. I found that the insight that the patient voice was neglected was already a premise and trendsetting actant in the project, a label that grew stronger as it enrolled other actors and enacted the project into further being by becoming embedded into the routines and the project manager’s discursive practices. She would call upon the patient voice while ignoring the voices of care workers and patients in the project.

As such, service design became enrolled as an actor and was denied a process of emergent, iterative and user co-created design. Instead, the different service-design-inspired activities set up to test and iterate the service design (workshops, project meetings, patient interviews) became like separate and symbolic user involvement events, working to underpin the label of missing voice. The label had become ‘sacred’; treated as a collective empirical finding instead of an inclusive method to bring on both individual voices as they emerged from experience. The care workers’ notions of patient involvement were ignored, handled as ‘polluted’ (Douglas, 1966).

Hence, the label of ‘missing patient voice’, stabilized as an actor, was capable of contributing to the production of ignorance. This finding leads me now to critically reflect on understandings of ignorance that privilege the human intentionality perspective and that sees ignorance as either intentional or unintentional.

As the narrative analysis shows, the insight that the patient voice was missing was not really to be found in the project. Care workers and patients reported that patients were involved to the extent they were able and wanted to be involved. The missing ‘missing patient voice’ was also revealed as a surprise to the project manager, who became aware of a state of ignorance (Gross, 2010). Nevertheless, ‘the missing patient voice’ as a concept continued to be actively maintained throughout the project. How can we make sense of this?

I argue that this form of active ignoring of the patient and care workers' voices was not the result of deliberate inattention nor a complete state of 'being ignorant' in relation to the patient voice. The project manager's intention was to really see and listen to the patient. She would continuously bring focus to 'the patient voice', asking 'where is the patient voice in that?' Still, this recalling of 'the missing patient voice' became a way of iterating the expectation of the ignored patient, citing it, and thereby talking it into being (Butler, 1993). Interestingly, what was ignored was how caring always includes managing ignorance. Allowing patients to be vulnerable and unknowing was central to caregiving. It meant that home nurses needed to find out with Patient 7, when she needed help with her food, and when she could manage to butter her toast. It meant that Patient 3 felt involved, when the nurses and doctors asked questions, but she decided on surgery independently because she wanted to breathe better. She also felt involved when she was told to relax and rest and had someone to talk to. What was 'unseen' (Otto et al., 2018) in the problematisation was that involving patients was always ambiguous and emerging in caring practices; it was always an unknown. The insight that patient involvement was multiple was not treated as something to learn from, but rather as ignorance to be reduced (Gross, 2010). Hence, the label, underpinned by policy and the service design method, gained authority to speak and act on behalf of patients in the project. Despite the best intentions, patients were prevented from using their voice by the very operation of patient involvement, which paradoxically led to 'the missing patient voice' being performed into being.

An actor-network perspective opens up the black box and explains how processes end up with unpredictable and heterogeneous outcomes. We cannot know in advance what associations come about or who will cause effects (Latour, 1986). Butler (1993) argues that it is not intention and deliberate acts but citation that is the underlying force of performative discourses. Ignorance can be the result of discourse producing the effect that it names. Hence, I argue that we can understand this as an example of unintended ignorance. Conceptualisations of ignorance tend to differ between actively intended ignorance on the one hand and unintended ignorance as a state of 'being ignorant' on the other (Roberts, 2012; Smithson, 1989). I argue that there can be active, but still unintended,

ignoring coming from the best intentions. Inclusive and empathic visions and policy, such as patient-centred care, are easily agreed on. Similarly, care workers are motivated by empathy for patients and practice care by building relationships with patients over time (Habran and Battard, 2019). In the middle, we can find highly motivated, idealistic middle managers employed to operationalise the visions. As I have learned, they are left dealing with the tensions between idealistic visions and relational care practices, and they are vulnerable if they question either. Therefore, I argue that we should not underestimate the power of visions to hijack development projects, separating them from relational practices of care.

A contribution of this paper is that it furthers the understanding of organised ignorance as a socially constructed and practiced phenomenon (Bakken and Wiik, 2017; High et al., 2012; Roberts, 2012). The findings illustrate how non-human actors can mobilise and enrol organisational actors, contributing to producing and maintaining ignorance performatively. This brings attention to the material dimension of the production of ignorance and challenges the human agency perspective often associated with active forms of ignorance.

Another contribution is to add perspectives to the understanding of the organisation and practice of patient-centred care (Habran and Battard, 2019; Liberati et al., 2015). The empirical findings bring attention to what happens when strategies and policies that are meant to accomplish patient-centred care produce the opposite, namely, practices of ignoring the patients. Hence, I argue that the performative dimension of patient involvement discourses and practices needs closer attention and reflection in patient-centred care practices. On that note, since discourses of patient-centred care are increasingly matched with innovation strategies, such as service design, this study also contributes to a growing debate in service design dealing with the struggle of being reduced to project-specific activities. It suggests that the path towards long-lasting change for service design also requires reflective practice of the hidden norms, rules and beliefs that guide actors in service design (Vink et al., 2021).

In the context of user involvement, co-production, and service design in health care, recognising the missing user voice is important in terms of

bringing focus to the potential marginalisation of patients in healthcare services. Agreeing that the focus on user involvement in the design and practice of care should be celebrated, I wish to argue that it should not be taken for granted as a solution to the problem of ignorance. It is important to stress that rather than arguing that there is no problem of patients' missing voices, the intention is to bring focus to how a defined knowledge problem of missing voices can amplify already troubling asymmetries by creating impossible ideals (Fotaki and Hyde, 2014). The label 'the missing user voice' can organise care work and end up being more about keeping up appearances and respecting conventions and ideals (Douglas, 1966) than including the patient voices. Furthermore, it seems that the patient's voice is always unknown – something always to be sought in everyday care work. This may be why it needs to be continuously on the agenda, not as a missing user voice problem of knowledge but as a missing user voice condition of ignorance that needs to be embraced as open, ongoing reflection in relational care work.

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