



Same *and* Different?

Perspectives on the Introduction of
Person-Centred Care as Standard Healthcare

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Abstract

This thesis examines a collection of cases and situations where efforts are being made to combine and unify the concerns of person-centred care, standardization and evidence-based medicine. Person-centred care is commonly associated with efforts to improve the quality of healthcare by catering for variation and difference while evidence-based medicine and standardized guidelines aim to assure quality by reducing difference and variation. Therefore, this thesis aims to investigate the paradoxes and tensions emerging as person-centred care is introduced as standard healthcare, and the actions taken by healthcare professionals to secure this healthcare reform in practice. The analysis builds on interviews with researchers working at a research centre where a particular standardized model of person-centred care has been developed; interviews with healthcare professionals working with and introducing this standardized model; observations of healthcare professionals applying this standardized model in practice, and related documents and written materials. The thesis builds on a practice oriented approach to person-centred care and adopts a material semiotic sensibility as a theoretical foundation. This approach enables detailed analysis of the messy, relational socio-material practices of person-centred care in action. Using the notions of tinkering and articulation work, the thesis extends the basic lessons of material semiotics by underscoring the importance of reciprocity - interrogating how inventive practices act back on and reshape tools, technologies and standards of person-centred care.

Empirically the thesis encompasses four studies. Paper I examines the mundane technologies of person-centred care, the scripts and values inscribed in these technologies and the tinkering needed to balance and bring together potentially contrasting values in practice. Paper II investigates how person-centred care and evidence-based medicine are interwoven in practice and the tensions that emerge when a randomized controlled trial is used to evaluate person-centred care. Paper III draws on the notions of articulation work and invisible work to analyse the efforts involved in sustaining a particular standardized framework of person-centred care. Paper IV identifies the tenacious assumptions embedded in a standardized model of person-centred care and the challenges emerging when this model is introduced in diverse settings.

Based on these studies I argue that while person-centred care is often advocated as the anti-thesis to standardized biomedicine this relationship is more complex. The studies in this thesis address attempts to develop a model of healthcare that is at once the *same* for all patients, yet also *different* by catering to each individual patient as a unique person. However, modelling care in this way is not without its challenges. One of the foremost challenges of making care recognizing the patient as a person into standard healthcare concerns how this person is actually

imagined and enacted. By insisting on particular routines to be followed and specific values to be recognized particular versions of person-centred care risk embedding problematic assumptions of their own. These assumptions are very similar to those it aims to move beyond in the first place. The standardized model of person-centred care, as well as the tensions and challenges it gives rise to, are negotiated and managed in a variety of ways. Caregivers are obliged to make adaptations, translations and become creative mediators in order to enable the standardized model of person-centred care to hold together. They also have to coordinate different tasks, perform complex activities for which they have little prior training, and creatively interpret incomplete instructions in order to compensate for shortfalls in information. However, the thesis concludes that things could be otherwise if person-centred care was able to learn from material semiotics. Instead of conceiving person-centred care as something that has to be implemented and safeguarded in practice, an alternative vision would be to develop person-centred care in its local organizational complexity and thereby transform it from being something ready-made, which care professionals have to adhere to, to something that is an outcome of experimental interventions.

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Paper I

Lydahl, D 'Standard tools for non-standard care – the values and scripts of a person-centred assessment protocol' unpublished manuscript.

Paper II

Lydahl, D 'Dismantling the master's house with his own tools? Engaging a randomized controlled trial of person-centred care' unpublished manuscript.

Paper III

Lydahl, D (forthcoming) 'Visible persons, invisible work. Exploring articulation work in the implementation of person-centred care on a hospital ward'. Accepted for publication in *Sociologisk Forskning*

Paper IV

Naldemirci Ö, Lydahl D, Britten N, et al. (2016) 'Tenacious assumptions of person-centred care? Exploring tensions and variations in practice'. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* (published online ahead of print 22 November)

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*I just wanna take you out and show you off
You already know that you the perfect one
~~Girl~~ when I'm with you, feel like a champion
Ever since I got with you I feel like I done won me a trophy*

Göteborg, maj 2017

1

Introduction

I think what would be valuable, would be some kind of a certification like you have with other quality standards. Because then people or wards or care centres could request to become certified and then someone else would find out if they are working according to a person-centred standard and I think that not only would this speed up the uptake of this but it would also help us doing research and applying for funding. (...) It's like a restaurant, if you have two stars in the Michelin Guide, you are inspected (...) Therefore, some kind of defined standard would be good. (Robert, Senior Professor of Medicine, the University of Gothenburg Centre for Person-Centred Care)

Person-centred care seeks to improve healthcare by recognizing the individual patient's unique experience, values and preferences, and acknowledging the patient as a responsible partner in the development and evaluation of their own care (International Alliance of Patients' Organizations, 2007; Leplege et al., 2007; Hughes et al., 2008; Moore et al., 2016). Standardization and evidence-based medicine, on the other hand, seek to improve healthcare by insuring that medical decision-making is not dependent on the subjective opinions of doctors but is instead based on scientific knowledge and research (Berg, 1997; Timmermans and Berg, 2003).

Person-centred care and standardization are consequently often posed as contrary to each other (Bensing, 2000; Mead and Bower, 2000; Berwick, 2009; Olsson et al., 2014). Patient- and person-centred care build on experiential qualitative medical knowledge rooted in clinical experience and worked out in everyday clinical practice. Standardization and evidence-based medicine are, on the other hand, associated with experimental quantitative knowledge generated for example through randomized controlled trials leading to the production of different kinds of clinical guidelines and routines for clinical practice (May et al., 2006: 1022). Difference is endorsed in patient- and person-centred care as it 'involves acquiring "true" insight into patients' questions and concerns and trying to give them the best possible care' (van Loon, 2015: 12). In contrast, evidence-based medicine and standardized guidelines aim to reduce differences and variation. Evidence-based medicine has also been criticized by some as being a potential obstacle to

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person-centeredness in seeing the illness instead of the individual and in not recognizing the patient as knowledgeable of their own illness (Cahill, 2003; Taylor, 2009).

One can find examples of these trends in healthcare policy and practice both globally (van Loon, 2015) and locally. In Sweden, evidence-based policymaking¹ has been dominant for the past decades, with the introduction of national guidelines for diagnosis, treatment, prioritization and decision-making (Masterton et al., 2015: 18). Simultaneously, there has been an increase of initiatives aiming to improve quality of care by centring on the patient and strengthening the patient position (Winblad et al., 2015). In 2011, a new public authority called the Swedish Agency for Health and Care Service Analysis was established, with the explicit task of ‘strengthening the development towards a more patient- and person-centred health and social care services’² Furthermore, in 2015 a new Patient Law was introduced in Sweden, aiming to strengthen patients’ integrity and autonomy, and to increase patients’ opportunities for being active partners in their own care and treatment (Masterton et al., 2015: 14).

Yet another example of the Swedish commitment to person-centred care is the establishment of the University of Gothenburg Centre for Person-Centred Care. This centre was founded in 2010 with the support of strategic government investment in health and care research. It has been identified as an increasingly important actor in defining person-centred care in Sweden (Masterton et al., 2015) and as an inspirational example globally (Rasmussen et al., 2014). At the Centre, a particular model for realizing person-centred care has been pioneered, based on what are called ‘a few simple routines’ (Ekman et al., 2011). Practicing these routines of *narrative elicitation*, *partnership*, and *documentation* is claimed to facilitate and safeguard a transition from existing healthcare to person-centred care. Due to its prominent profile and relative significance for Swedish healthcare reform this Centre has been the site of fieldwork for my dissertation.

While person-centred care is often framed as the antithesis of standardization and evidence-based medicine there have recently been growing discussions concerning the compatibility of these two trends and numerous efforts to actively combine them (Bauman et al., 2003; Wagner et al., 2005). Some have argued for the importance of providing evidence-based knowledge to patients to improve patient-centeredness (Hope, 2002). Others have argued for the need to strengthen the patient-centeredness of evidence-based medicine while also improving the evidence-base of patient-centred care (Bensing, 2000). In Sweden, the Swedish National Audit Office recently published a report on whether national guidelines can further patient and person-centred care. It is argued that while guidelines can act

1 Translation from the Swedish term ‘kunskapsstyrning’

2 <http://vardanalys.se/Support/In-English/About-the-Agency/> (retrieved 2017-03-31)

as valuable policy tools in this respect, many current guidelines still fail to adequately incorporate a patient perspective (Riksrevisionen 2013: 4).

This thesis deals with a collection of cases and situations where efforts are being made to combine and unify the concerns of person-centred care, standardization and evidence-based medicine. These cases and situations arise out of the everyday activities of the Gothenburg Centre for Person-Centred Care, which has been the empirical site of my research. While the Centre emphasizes person-centred care as opposed to reductionism (Ekman et al., 2011) and standardized care (Olsson et al., 2014), standardized procedures for the realization of person-centred care are still advocated as vital to ‘initiate, integrate and safeguard’ person-centred care in practice (Ekman et al., 2011: 248).

Person-centred care

Person-centred care and related notions such as patient-, family-, client-, and relationship-centred care have a long history and originated as concepts in medicine and psychotherapy already in the 1950’s (Leplege et al., 2007). The call for holistic medicine, to complement the medical viewpoint with the patient’s point of view, came in large part from general practice and was significantly furthered by Hungarian psychoanalyst Michael Balint and his colleagues (Hughes et al., 2008). Their ambition was to transform and reorient the work of general practitioners from being ‘illness-centred’ to being more ‘patient-centred’ seeing every patient as a unique human being and using psychoanalytical tools to examine the whole person in order to form a more qualified diagnosis (Balint, 1969). Balint’s ideals became embodied in the policies of the Royal College of General Practitioners in the 1960’s, which had consequences for the formation of British General Practice and the National Health Service at large (Marinker, 1998).

About the same time in psychotherapy, the American psychologist Carl Rogers (1951) developed a client-centred care approach. Contemporary versions of person-centred care are argued to largely derive from Rogers’ theories (Leplege et al., 2007: 1561). In contrast to Balint, Rogers rejected psychoanalysis. Rather than developing the role of the therapist, Rogers claimed that the therapist’s role must be limited in order to help the individual to recuperate their autonomy and to achieve self-actualization. Rogers thus had a positive view of the person, emphasizing that all persons have the strength, qualities, resources and abilities to ‘find a remedy to his/her own difficulties by him/herself’ (Leplege et al., 2007: 1561). Rogers emphasized the importance of the attitudinal disposition of the therapist, including an *unconditional positive regard*, *empathic understanding* and a *therapeutic genuineness*, over techniques (Rogers, 1957; 1975).

Different models of person-, patient-, client-, relationship-, and family-centred care gradually spread and became widely adopted around the world. In the

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late 1970's the American psychiatrist George Engel (1977; 1979; 1980) argued that biomedicine, the dominant model of disease, had played out its role and suggested a new model that attributes disease to a combination of biological, psychological and social factors. He called this the *biopsychosocial model*. In the late 1980's, patient-centred care was further developed when the Picker Institute was established and launched the Picker Commonwealth Patient-Centred Care Program (Gerteis, 1993). This program defined seven dimensions of patient-centred care, which have been subsequently widely used to evaluate healthcare (Jenkinson et al., 2002). These dimensions are: respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity.

During the 1990's, Thomas Kitwood (1992) championed the need for person-centred care in dementia care. While Kitwood drew on the humanistic ideas of Rogers, his definition of the person was less individualistic. Instead, Kitwood insisted on the relationality of personhood, which he defined as 'a standing or status that is bestowed upon one human being, in the context of relationship and social being' (Kitwood, 1997: 8). Building on Kitwood's work, Brendan McCormack (McCormack, 2004; McCormack and McCance, 2010) later developed a person-centred nursing framework. Today, different forms of '-centred care' are argued to be among the most vital and relevant topics in health policy (Harding et al., 2015: 14). Recent literature reviews indicate that while there is an abundance of person-centred care models, there is still a lack of consensus and conceptual clarity of the concept (Entwistle and Watt, 2013; Harding et al., 2015; Scholl et al., 2014). The particular realization of person-centred care studied in this thesis is therefore just an example of the many different models of person-centred care developed internationally (Entwistle and Watt, 2013). Despite the lack of consensus, several international organizations, including the American Government's Institute of Medicine; the World Health Organization; the Organization for Economic Cooperation and Development; and the International Alliance of Patient Organizations have adopted patient-centeredness as a goal for high-performing health systems. In so doing they stress the importance of recognizing person-centred care as an integral and self-evident part of quality healthcare in the 21st century (Nolte and McKee, 2008).

A one-size-does-not-fit-all standard?

Already in 2008 the Swedish government decided to make a strategic research investment in health and care research through a governmental bill (Prop. 2008/09:50). Here it was argued that while Sweden has one of the best healthcare

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systems in the world it also faces new challenges due to demographic developments with more elderly people suffering from age-related illnesses, resulting in increased demands for care. Rather than raising healthcare costs the government argued the need for more research on care.

A group of researchers at the University of Gothenburg succeeded in securing this strategic research funding. In January 2010, the University of Gothenburg Centre for Person-Centred Care was established. This centre emphasizes the importance of seeing each patient as a person, taking their subjectivity and capability into account and not reducing individuals to their disease states alone. Therefore, person-centred care is seen as implying:

A shift away from a model in which the patient is the passive target of a medical intervention to another model where a more contractual arrangement is made involving the patient as an active part in his or her care and the decision-making process (Ekman et al., 2011: 249).

To ensure the systematic practice of person-centred care the Centre has developed three ‘simple’ routines that are designed to ‘*initiate, integrate and safeguard PCC in daily clinical practice*’ (Ekman et al., 2011: 250, italics in original). According to this model, person-centred care takes its starting point in the *patient narrative*, which is ‘the sick person's personal account of his/her illness, symptoms, and their impact on her/his life’ (Ekman et al., 2011:250). Based on this narrative, together with other clinical information, a *partnership*, in the form of a mutual care plan, is to be established. The third routine concerns *documentation* of the patient narrative as well as of the partnership in the shape of a care plan (Ekman, 2014).

In the following, we meet Melanie and Nora. They both work at a hospital ward where I have carried out fieldwork. The Gothenburg model of person-centred care was being introduced here during my time in field.

It is a sunny day in August and at the ward a kick-off meeting for person-centred care is taking place. Melanie, the ward manager, starts the meeting by introducing an implementation group for person-centred care. Later, Melanie circulates handouts developed by the group. Nora, a nurse who presents the material says that it consists of an assessment protocol, a care plan, a patient diary and instructions for documentation in the medical record. I leaf through the colour-printed A4 sheets while Nora talks us through the assessment protocol. The protocol should be used in assessment interviews with newly admitted patients. By asking the questions in the protocol the nurse will be able to elicit the patient narrative, Nora explains. Based on the patient narrative the healthcare team will be able to establish a partnership with the patient, a partnership that should be documented in the care plan.

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Someone asks Nora if it is necessary to ask the patient all the questions in the protocol. Melanie takes over and explains that it is okay to skip questions that do not seem relevant, but that: 'You should always ask the questions marked in purple and use the rating scales included in the protocol. They are person-centred.'

As seen in this excerpt the introduction of person-centred care at the ward, seems to have a lot to do with protocols, scales, and documents, following certain instructions and asking certain questions. To perform a person-centred assessment interview for example you have to ask the questions and use the rating scales marked in a specific colour. In other words, a degree of standardization is discernible.

The Centre is critical of standardized models of care and evidence-based healthcare as such models 'fail to capture minority responses of individuals' and have problems to 'properly respond to individual exceptions' (Ekman et al., 2011: 249). The operationalization of person-centred care therefore apparently gives rise to an interesting tension: while opposition is expressed towards standardized models of care something like a non-standardized standard model of care delivery is proposed. Employing the routines of narrative, partnership and documentation promises to secure and consolidate person-centred care throughout daily clinical practice. However, unlike evidence-based guidelines these routines are to enable the successful delivery of care in a personal and non-standardized fashion.

In contrast to evidence-based guidelines and protocols, the routines for person-centred care are inexact and composite. They do not specify, for example, the actions needed to elicit a patient narrative. While evidence-based medicine has been shown to not only rely on scientific knowledge, but also on healthcare professionals' clinical experience, tacit knowledge and continuous tinkering (Berg, 1997), so imaginative interpretation and creative tinkering might appear even more important and indispensable for the realization of person-centred care.

Aim and research questions

Drawing on qualitative interviews, written materials, documents and observational studies, this thesis aims to investigate the paradoxes and tensions emerging as person-centred care is introduced as standard healthcare, and the actions taken by healthcare professionals to secure this healthcare reform in practice. I approach this objective through perspectives deriving from science and technology studies (STS). STS is a broad and diverse interdisciplinary research field, with a long tradition of studying the social, political and cultural shaping of science and technology and vice versa. Drawing on STS perspectives allows me to address

both the social actors and the material reality of person-centred care, while bringing into focus the work needed to introduce a standard model of person-centred care in practice.

Therefore, the aim of this thesis is also to contribute to a firmer understanding of the complex relationship between person-centred care, standardized procedures and evidence-based medicine. While a range of empirical issues are addressed in the four papers collected in this thesis, three general research questions are asked:

- What tensions and challenges emerge when attempting to make care recognizing the patient as a person into standard healthcare?
- How does a standard model of person-centred care transform clinical practice(s)?
- How do clinical practitioners in turn actively negotiate and manage the new demands made on them by a standard model of person-centred care in their everyday work?

Outline of the thesis

The following chapter reviews notable sociological contributions to research on person-centred care. It draws on a recent attempt to categorize different traditions of research on person-centred care and uses this to analyse and discuss historical sociological perspectives and critical sociological viewpoints on person-centred care. The chapter concludes by discussing what new insights a more practice-oriented approach to the study of person-centred care like my own can contribute in comparison with earlier research.

In the third chapter, I present and account for my theoretical approach in this thesis. The chapter starts by outlining my debt to material semiotics, and thereafter it presents theories and concepts that I make use of to explore the relationship between standardization and person-centred care. Next, the chapter charts the concepts of articulation work and tinkering – concepts used to unravel the work needed to make standards of person-centred care possible to introduce in practice. Lastly, the chapter elaborates on the notions of visible and invisible work, which are important to my analysis.

In the fourth chapter, the research methods I use in this thesis are described and explained. The chapter starts by outlining the data I have gathered and drawn upon: interviews with healthcare researchers, and clinical practitioners, observations of clinical practice as well as documents and written materials collected in the field. Next, I outline which sets of data I have made use of in the different papers collected in this thesis and the reasons for my data selection. Thereafter, I describe and account for my methods of data collection before discussing how I

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have coded and analysed my data. Finally, the ethical implications of my research are detailed.

In the fifth chapter, I provide a summary of each of the four papers collected in this thesis. The sixth and final chapter concludes the introduction of the thesis by summarizing and discussing the answers I am able to provide to the research questions posed above.

2

Sociological Perspectives on Person-Centred Care

The social sciences in general and sociology in particular have played an important part in the development of person-centred care. As Hughes and colleagues (2008: 456) have argued, social scientific research has offered ‘both a vehicle for an external critique and a set of tools that can be employed within medicine to reconfigure and measure clinical practice’. Furthermore, different models of patient- and person-centred care always contain an ‘implicit appeal to psychological or sociological theories of an improved interaction as psychosocial and ethical goods’ (Hughes et al., 2008: 456).

In a literature review article in *Social Science & Medicine* Liberati and colleagues (2015) distinguish two broad streams of research on person-centred care. The first, which they see as more traditional, they refer to as *dyadic* in focus. This research addresses person-centred care at the micro-level, concentrating on the relationship between individual patient and caregiver. Person-centred care is here defined as ‘an approach to clinical practices that encourages physicians to explore both the patients’ objective disease and symptoms (the doctors’ agenda) and their subjective illness experience (the patients’ agenda)’ (Liberati et al., 2015: 46). This has led to the identification of several key features of person-centred care such as the adoption of a biopsychosocial perspective, shared decision-making and responsibility, and the strengthening of caregivers’ compassion and empathy. Empirical research in this context is often concerned with identifying features of patient-centred communication, measuring outcomes of person-centred care and of finding ways to improve patient participation. The second stream of research, which includes studies that are more recent, Liberati and colleagues define as *organizational* in focus. This research aims to identify ‘organizational and system-level facilitators of and barriers to PCC’ and it therefore addresses person-centred care at a macro-level exploring how structural, cultural and procedural dimensions of a healthcare organization either advance or obstruct the achievement of person-centred care (Liberati et al., 2015: 46).

Building on this distinction, while also problematizing it, I will in the following introduce some particularly important sociological contributions to research on

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person-centred care. First, I describe two influential historical sociological perspectives on person-centred care. Second, I offer a summary of critical sociological perspectives on person-centred care. Finally, I discuss what a practice oriented approach to person-centred care has to offer.

The disappearance and reappearance of the patient-as-person

While patient- and person-centred care may appear novel innovations in medical thinking historical sociologists of medicine have argued that seeing the patient-as-person has a long history (May and Mead, 1999). Especially important contributions tracing the patient-as-person can be found in Jewson's (1976) thesis on the disappearance of the 'sick-man' from the modern medical cosmology, and in Armstrong's (1982) argument about the rediscovery of the person already in the mid-twentieth century.

With the institutionalisation of healthcare and medicine in the 19th century, Jewson argues that the dominant medical cosmology of 'bedside medicine' was replaced by 'hospital medicine'. Within this new organisation of healthcare, the 'sick-man' as a holistic person disappeared from medical discourse, and was reduced to 'a collection of synchronized organs, each with a specialized function' (Jewson, 1976: 229). The focus of medicine thus shifted away from *illness* towards *disease*.

Armstrong on the other hand demonstrates how the patient-as-person was soon re-discovered. He argues that the patient was being seen as a negotiating partner in medicine again already in the 1930's due to the increased influence of psychoanalysis and the 'unconscious'. Furthermore, he argues that 'bedside medicine' did not disappear entirely but was rather displaced into general practice. Nevertheless, because of the increasing specialization of medicine, the professional status of the general practitioner was subordinated in favour of the specialist at hospitals. Proper core tasks of medicine were carried out at hospitals whereas the general practitioners' only functions were seen as to 'screen and refer' (Armstrong, 1979: 4). However, in the 1950's, general practitioners in the UK were given an opportunity to form a collective conscience and to reconceptualise their role and status, as the Royal College of General Practitioners was formed. In Armstrong's account, the contextual constraints in medical practice enabled general practitioners to reshape medical discourse, drawing on the inherent social tension in the doctor-patient relationship. The new medical discourse – 'biographical medicine' – is argued to have reached its full theoretical development in the work of Michael Balint (1957) and the concept of patient-centred medicine (Armstrong, 1979).

Neither Jewson nor Armstrong allows for a straightforward categorization according to Liberati et al's proposal. While both situate biographical medicine at the bedside, and thus in the dyad patient-physician, they also address macro-oriented questions about organization, discourse and cosmology enabling or restraining a biographical approach. In this sense, they belong in both research streams.

A rationality of government? Critical perspectives on person-centred care

Sociologists have noted that person-centred care can be linked to an increased emphasis on user involvement in contemporary welfare regulation at large (Cribb and Gewirtz, 2012). With its focus on active participation and shared decision-making, it has similarities with examples from education and social work. In education, student-centred learning underlines the importance of learning facilitation rather than knowledge transmission and of seeing the student as an individual who should be encouraged to be active and independent in their learning (Kember, 1997). In social work, personalisation has become a dominant idea (Beresford, 2014; Juhila et al., 2017). Although there is no agreed definition of personalisation, it has been discussed in terms of service users having more choice and control over services customised to their needs, and it is also associated with the use of personal budgets.

While user involvement is often seen as empowering users to gain more control over their welfare, Cribb and Gewirtz argue that this is not necessarily the case. Increased involvement can on the contrary amount to a form of 'enforced empowerment in which individuals are given responsibility for things they sometimes may not want to be responsible for' (Cribb and Gewirtz, 2012: 510). An increased emphasis on user involvement can therefore be interpreted as part of a liberal governmentality, in which users are managed by means of freedom and self-regulation. Moreover, Cribb and Gerwartz note that only a very specific form of involvement is encouraged. Being an active patient does not mean being active in whatever way you like:

we may be required to be consumers or to participate in decisions about our medical treatment or our children's education or we might be encouraged to somehow co-produce the services we use, but other more activist forms of citizenship, for example, campaigning or holding strikes against hospital closures or the privatisation of state schooling, are typically not encouraged or are positively discouraged. (Cribb and Gewirtz, 2012: 511)

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In a similar fashion, Mayes (2009) argues that rather than liberating the patient, person-centred care introduces new forms of power relations in the clinical encounter. However, he and others have also noted that the discourses of shared-decision making, user involvement and humanism also have a tendency of obscuring power relations and conflict (Cribb and Gewirtz, 2012; Cook and Brunton, 2015). Drawing on a Foucauldian understanding of power, Mayes argues that the person-centred approach has an inadequate understanding of power as something that physicians possess and patients lack. From a Foucauldian perspective such an understanding is problematic, as this perspective rather conceives of power as a 'relational and productive force that constructs each actor to act, think and expect certain responses from themselves and others' (Mayes, 2009: 484) than as something that can be held and wielded. In other words, person-centred care does not rebalance power relations but instead introduces new ones (Cook and Brunton, 2015: 546), in which the patient is still moulded to 'think and act toward their self in a particular ways' (Mayes, 2009: 492).

Person-centred care does not only affect the patient but is also argued to have consequences for professionals. These consequences have been discussed in terms of a call for reskilling the doctor, developing new skills, which later can be audited, diagnosed and measured (May et al., 2006). In a well-cited paper on the development of a rationality of person-centered medicine, Osborne (1994) argues that such calls for a reskilling of the doctor can be traced back to the Royal College of General Practitioners in the 1960's and 70's. At this time, general practitioners in the Royal College began locating the basis of their intellectual autonomy:

less in terms of any abstract consideration of general practice as a particular type of activity than in terms of a problematisation of the general practitioner him or herself as a particular kind of ethical persona (Osborne, 1994: 520).

The emphasis on the general practitioner's persona is seen not the least in Balint's theories. According to Balint (1957), the general practitioner's counterpart to the surgeon's knife or the radiologist's X-ray is his or her own personality. However, to use themselves, as equivalent to a drug, on the patient the general practitioners must learn to control their personalities. This control is to be achieved through the friendly and non-directive pressure of colleagues in seminar groups. By taking part in these seminars, general practitioners are thought able to develop their own personalities and personal skills. This form of self-cultivation, Osborne argues, is not a pre-condition of person-centred medicine but rather it is constitutive of it (Osborne, 1994: 524). Person-centred medicine can, in other words, not exist without, or be separated from professional self-cultivation. As general practitioners were encouraged to both monitor and be reflexive about themselves and their

work in the seminar, Osborne argues that the seminars are related to principles of audit and self-assessment. Both the emphasis on audit and the tendency to ‘control at a distance’ by means of self-regulation coincides with an advanced liberal political rationality (Osborne, 1994: 532).

The perspectives described above all share a macro-orientation towards person-centred care. However, the focus on structures and political rationalities is not deployed to identify obstacles to person-centred care but resemble more closely what Hughes et al (2008) discuss as a vehicle for external critique.

Towards a practice oriented approach to person-centred care

In this chapter I have introduced several sociological perspectives on person-centred care. These perspectives either see person-centred care as an approach to the clinical encounter, or as a set of organizational features, or something to critique as opposed to a set of tools for the reconfiguration of clinical practice. While the dyadic and organizational conceptualizations have contributed to a richer understanding of person-centred care, Liberati et al. suggest that both streams have their limitations. On the one hand, the micro-orientation risks obscuring an understanding of the bigger picture with its ‘networks of practices, interactions, relationships, and structural elements that participate in PCC’. On the other, a macro-oriented approach risks providing theories which overlook the specificities of local context emphasizing structure over agency and sometimes ignoring the experience of patients and professionals (Liberati et al., 2015: 47).

As an alternative, Liberati and others have emphasized the value of a more practice-oriented approach to person-centred care, drawing on STS theories to explore how ideals of person-centred care are actually performed in clinical settings (Liberati et al., 2015: 47; Gardner and Cribb, 2016; Gardner, 2016: 3). From such a perspective person-centred care is conceived ‘as a *collective achievement that is negotiated between patients and multiple health providers, comprising of social practices and relationships that are woven together through the material and immaterial resources available in specific organizational contexts*’ (Liberati et al., 2015: 47, italics in original). Similarly, this thesis demonstrates the vitality of both mundane technologies and creative healthcare professionals in person-centred care and points to how their reciprocal relationships are integral to person-centred care seeking to deliver equal yet unique care for each individual patient. Therefore, I share the ambition to understand and make sense of both the social actors and the material reality of person-centred care.

3

Making sense of person-centred care

In this chapter, I outline and explain my theoretical approach – how I have made sense of the Gothenburg variation of person-centred care. I start by defining my theoretical foundation, which is a *material semiotic sensibility*. Here I also discuss the notion of *script* and the *reciprocal relationship* between technology and its users. However, to make sense of a particular model of person-centred care I also need to understand the puzzling relationship between standardization and person-centred care. To do so, I draw on STS theories of *standardization*, and outline previous research which has analysed the relation between standards and person-centred care. Next, I introduce the concepts of *articulation work* and *tinkering*. I use these concepts to point to the work needed to make the tools, technologies and standards of person-centred care function in practice. Finally, I introduce the notions of *visible and invisible work* and the consequences of keeping care work either invisible or visible.

Material semiotic sensibilities

My research is rooted in material semiotics, which has been described as a *sensibility* drawing attention to ‘the messy practices of relationality and materiality of the world’ (Law, 2009: 142). Semiotics teaches us that words give each other meaning. Material semiotics extends this insight and claims that ‘entities give each other being: that they enact each other’ (Law and Mol, 2008: 58). Accordingly, material semiotics is firmly anti-essentialist. Entities have no inherent attributes or qualities but acquire these in and through their relations with other entities. A second lesson from material semiotics derives from the first. As can be inferred from its name, material semiotics collapses one of the most established dualities in sociology: that between human and things (Haraway, 1991). This means that agency is not restricted to humans. Agency is not ‘aligned with human intentionality or subjectivity’, neither is it something which something or someone has (Barad, 2007: 177-178). Rather, agency is a relationship. Hence, technologies and other non-humans are seen as actors that can be attributed the agency to *do things* to practices and other entities in the networks in which they are embedded.

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Thirdly, other taken-for-granted essentialist divisions are also destabilized by material semiotics: human and animal; nature and culture (Haraway, 1991); before and after; materiality and sociality (Law, 1999). Another foundational distinction that is eroded is that between big and small - between micro and macro (Callon and Latour, 1981). This does not mean that divisions do not exist or that there are no divisions. Divisions can be made real in practice – but they are conceived as *effects* or *outcomes* not ‘given in the order of things’ (Law, 1999: 3). Concepts that are associated with macro-theories such as class or nation-states are therefore interpreted as effects rather than explanatory foundations, which means for some working with this sensibility that their primary concern is providing new forms of description rather than explanation (Law, 2009: 147).

The material semiotic approach has a long history in science and technology studies. It emerged out of *actor network theory* (ANT) in the 1980s, and can be traced back to the seminal study of how scientific knowledge is produced in the laboratory by Latour and Woolgar, which concluded that scientific facts are not something that researchers discover by ‘pulling back the curtain on the pre-given, but hitherto, concealed’ (1986: 129). Rather, facts can be conceived as constructed in networks of different actors including technicians, lab equipment, the laboratory and the samples. Important in the construction of facts is the process of inscription. In this process, *inscription devices* transform ‘pieces of matter into written documents’, which can be used as proof (Latour and Woolgar, 1986: 51). Therefore, these devices and tools, such as a biosassay, are crucial for the phenomena under study in the laboratory – as phenomena are ‘*thoroughly constituted* by the material setting of the laboratory’ (Latour and Woolgar, 1986: 61, italics in original). Latour and Woolgar’s theories later spread and have been extensively used beyond the laboratory setting (for an overview see e.g. Law and Hassard, 1999).

A material semiotic sensibility was also deployed by Mol (2002) in her well-known study on the *enactment* of atherosclerosis. Foregrounding practices, materialities and actions, Mol argues that diseases do not stand by themselves. Instead, they depend on ‘everything and everyone that is being active while it is being practiced. This disease is *being done*’ (Mol, 2002: 32, italics in original). Moreover, objects are enacted differently in different practices – atherosclerosis is one disease when enacted clinically and another when enacted pathologically. An important consequence of Mol’s theories is that enacted objects, such as atherosclerosis, are *multiple*. Atherosclerosis is ‘more than one – but less than many’ (Mol, 2002: 55). Furthermore, diseases and bodies never appear as fragmented. Rather, the body multiple is coordinated into singularity, into appearing as something that hangs together. Coordination is the task which ‘designing treatment entails. That

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the various realities of atherosclerosis are balanced, added up, subtracted. That in one way or another, they are fused into a composite whole' (Mol, 2002: 70).

Building on a material semiotic sensibility allows me to do two things. First, it allows me to escape both the individually-oriented and the organizational conceptualizations of person-centred care described in the previous chapter. A material semiotic approach does not insist on a priori definitions, but rather encourages explorations of *how* things take shape and what meaning they acquire. Second, this approach allows me to consider both the social and material actors constituting the realities of person-centred care. It therefore helps me to step away from otherwise taken for granted dichotomies, such as person-centred care and technology; person-centred care and standardization; and person-centred care and biomedicine. These dichotomies are no longer to be seen as given in the nature of things, but as contingently produced and negotiable.

Technoscientific scripts

I use the notion of *scripts* for analysing the material reality of person-centred care. The concept originated in the work of Madeleine Akrich (1992), who argues that technologies and other objects in the design process are inscribed with a particular vision of the world. In this process innovators define actors with specific 'tastes, competences, motives, aspirations' and they also assume that actions, morality, science and economy 'will evolve in particular ways' (Akrich, 1992: 208). Therefore, the script functions like a film script in that it defines both actions and actors.

Moreover, technologies are scripted with *norms* and *values*, concerning what is good and bad, what is motivated and what is important. While technologies are often scripted as cold and impersonal, a significant insight from recent research is that technologies can also be scripted as warm and credibly imagined supporting norms that are caring, social and affective (Pols and Moser, 2009; Pols, 2010a; Pols, 2010b; Pols, 2012).

I use the notion of script to analyse the technologies used in person-centred care. In paper I, I draw on this notion to analyse what an assessment protocol does in clinical practice. Moreover, I examine the values embedded in the protocol. While I demonstrate how the script of this protocol defines both actors and actions, I do not argue for technological determinism. In line with material semiotics in general, the notion of script instead underscores the *reciprocity* of the relationship between technology and user (Akrich, 1992: 206). Therefore, technologies do not turn its user 'into mindless followers of some pre-set script' (Timmermans and Berg, 1997: 288) as users constantly underwrite, adapt and negotiate the objects. Getting a tool to work, Berg (1997: 152) argues, *requires* leaving users 'leeway to digress from the tool's prescribed steps, to skip or skew input, or to sometimes just avoid the tools completely'. I will return to the importance

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of the adaption and modification of tools and technologies later, but first I will introduce a collection of technologies that ‘has penetrated every corner of contemporary medicine’: standards and standardization tools (Timmermans and Berg, 2003: 3).

Standards and standardization tools in care and medicine

Simply defined, standards are a set of agreed upon rules spanning over more than one site or community, which are used to make things work across time and space (Bowker and Star, 1999). Standards are ubiquitous in healthcare, in the form of decision-support tools, protocols, evidence-based guidelines et cetera, and the process of rendering things uniform has been argued to be ‘a fundamental prerequisite of scientific medical practice’ (Berg, 1997: 25). In healthcare, standards are used to describe, to set a minimal limit and to reduce variation in the quality of care (van Loon, 2015). This is done in different ways. Timmermans and Berg (2003) describe four ideal types of standards in healthcare: design standards, terminological standards, performance standards and procedural standards (Timmermans and Epstein, 2010). The first specifies the properties of tools and systems, regulating for example the size of hospital beds. The second concerns the uniformity of the meaning of concepts. An example of this is the International Classification of Diseases, which is a system of diagnostic codes for disease classification. The third has to do with outcome specifications. These standards do not regulate how something should be done, but instead they regulate what the outcome of a certain action should be. The last type of standard specifies how to perform different kinds of processes, regulating how something should be done. This last form of standard has been especially prominent in modern medicine in the form of clinical guidelines.

Standardization in healthcare in the form of clinical guidelines emerged in the 1980’s to reduce variation in relation to medical decision-making. While there have always been standards in healthcare, standardization in recent decades has been directed at the content of medical work and specifically at medical decision-making (Timmermans and Berg, 2003). One of the leading proponents of standardization in the form of evidence-based medicine argues that:

The plain fact is that many decisions made by physicians appear to be arbitrary – highly variable, with no obvious explanation. The very disturbing implication is that this arbitrariness represents, for at least some patients, suboptimal or even harmful care (Eddy, 1990: 287)

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Therefore, evidence-based medicine and guidelines aim to insure that medical decision-making is not dependent on the subjective opinions of doctors, but instead on scientific knowledge and research (Berg, 1997)³.

Standardization and person-centred care

Social scientists have broadly criticized standardization and evidence-based medicine. Some have argued that it will lead to a ‘McDonaldization’ of medicine, where every patient problem would be addressed in the same way (Ritzer, 1993). Others have suggested that healthcare and medicine have suffered a loss of humanism, depersonalization ‘and the replacement of holistic care with bureaucratic control’ (Timmermans and Almeling, 2009: 21). From this perspective, standardization is seen to further a ‘standard approach to healthcare problems advocated by the guidelines, in which every patient problem would be addressed generically, as one more instance of the same’ (Timmermans and Berg, 2003: 19). Thus, standardization is claimed to impede person-centred care. Conversely, patient and person-centred care have been described as a reaction to the rise of evidence-based medicine and standardization, as they oppose its alleged reductionary and exclusionary tendencies. Therefore, person-centred care has been portrayed as the direct antonym of evidence-based medicine, taking into account the combined biological, psychological and social identity of the patient, which evidence-based medicine reduces to a formal set of signs and symptoms (Mead and Bower, 2000).

However, other researchers have suggested that the relationship between standardization and holistic care, such as person-centred care is more complex. One example is van Loon and Zuiderent-Jerak’s (2012: 122) study of a quality improvement device, which ‘aimed to transform organizations in care of older people to put the wishes of clients centre stage in the care delivery’. The article addresses the relation between reflexivity and standardization, as the quality improvement device aimed to allow reflexivity to improve the quality of care while simultaneously formalizing this reflexivity. They argue that reflexivity and standardization do not need to be opposed, but can rather be intertwined. Zuiderent-Jerak (2007; 2015) has made a similar argument in his research on integrated care

3 Clinical guidelines are one of three main components of evidence-based medicine (Bohlin and Sager, 2011).

They are developed from randomized controlled trials (RCT) and meta-analysis. RCTs are experimental research for testing new treatments or interventions. The test subjects in such trials are randomly allocated to either a group receiving the intervention, or to a control group, not receiving the intervention. Often these trials are double blind, meaning that neither the test subjects nor the researchers know who is getting the intervention and who is not. RCTs are usually used to evaluate both the effects and the effectiveness or efficacy of any intervention. A meta-analysis is a statistical technique used to combine the results of several RCT studies. They are often claimed to provide more accurate estimates of the effects of an intervention than individual RCT studies.

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pathways. He argues that standards developed in practice, which take into account local organizational complexities can actually further person-centred care. This form of 'situated intervention' in care pathways includes conceptualizing pathways and other standards as an outcome of 'an experimental change process' (Zuiderent-Jerak, 2007: 319) rather than as a '*starting point* that medical practice has to adhere to' (Zuiderent-Jerak, 2007: 315, italics in original). In this way problems related to implementation can be evaded.

Standard humans

Another critique that has been raised against standards in healthcare is that they build on a biased and exclusionary approach to knowledge making. In a study of changes in biomedical policy in the U.S, sociologist Steven Epstein (2007: 13) argues that several social groups, politicians, activists and medical professionals in the 1980's joined forces in a kind of 'antistandardization resistance movement'. This movement accused biomedicine of generalizing results from a faulty and non-representative standard human: a white middle-aged man. The movement also demanded 'the inclusion of diverse groups as research subjects', and 'the measurement of outcome difference across medical subgroups' (Epstein, 2007: 278). Epstein calls this the 'inclusion and difference'-paradigm, and while the movement started off as an anti-standardization movement the inclusion- and difference paradigm is now 'powerfully undergirded by standardization of various kinds' (Epstein, 2007: 128). However, this paradigm also has its problems. One of the things Epstein cautions against is how proponents of the paradigm tend to root identity categories, such as gender and race solely in the body, rendering them essentialist and individual rather than social and relational. In so doing, there is a risk that the intersections of social categories become blind spots.

An important lesson from standardization theory, which is employed in this thesis, is that standardization has consequences. Standards tend to presume and imagine a standard human. A standard airplane seat or a standard hamburger implies a uniform user (Epstein, 2009: 36). However, not everyone fits the standard. Moser (2005) argues that while standards create order for those inside the norm they also 'make trouble for, disable or exclude others with non-standardized bodies and subjectivities' (Moser, 2005: 677). Standards will therefore render standardized bodies invisible, letting them disappear into the background, while non-standardized bodies will be performed as problematic and visible. Moser points to the fringes of the standard arguing that '[t]he normal implies the abnormal, the deviant and lacking. However, they not only build upon otherness, but also help to produce and reproduce it' (Moser, 2005: 678). Such reasoning is employed in this thesis to explore the consequences of person-centred care as a new standard

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of care. Concern is paid to those ‘who must use the standard network, but who are also non-members of the community of practice’ (Star, 1991a: 43).

Making standards and technologies work

Standardized representations of work have a tendency to depict work as a ‘smooth, unproblematic sequence of events’ (Star, 1991b: 275). In healthcare, Berg has argued that guidelines and protocols represent ‘medical work as a sequence of circumscribed, individual steps, each of which needs to be terminated before the following can be made’ (Berg, 1996: 119). However, the reality of clinical work is often more messy and ad-hoc. The material semiotic approach teaches us that simply following instructions will not make a tool, technology or standard work (Jonvallen, 2009: 44). Rather, it has been theorized that the ‘ongoing subordination and (re)articulation’ of tools and standards carried out to ‘meet the primary goals of the actors involved is a *sine qua non for the functioning*’ of a tool (Timmermans and Berg, 1997: 291, italics in original).

In what follows I describe two conceptualizations of such adaptive work employed in this thesis.

Articulation work

One way to talk about the job that is ‘performed around’ a tool or standard (Jonvallen, 2009: 349) in order to make something ‘do-able’ (Fujimura, 1987) is to use the concept of *articulation work*. This thesis draws on sociologist Anselm L. Strauss’ (1985; 1988; 1997) definition of articulation work as ‘the specifics of putting together tasks, task sequences, task clusters – even aligning larger units of work such as lines of work or subprojects – in the service of flow’ (Strauss, 1988: 164). It is seen as activities relating to the coordination and linking together of different tasks, and can hence be seen as ‘work that supports work’ (Allen, 2014: 55). I also build on Star, who sees articulation work as work happening after breakdowns or unanticipated contingencies as it is ‘work that gets things “back on track” in the face of the unexpected’ (Star, 1991b: 275; Star and Strauss, 1999: 10). I use the notion of articulation work to highlight how the coordination of different kinds of tasks and information is vital for a routinized model of person-centred care to work.

Star further emphasizes that articulation work is commonly invisible to ‘rationalized models of work’, which means that ‘representations of work and production that consider a smooth, unproblematic sequence of events as an adequate representation cannot, and will not, admit of local, unique, unexpected solutions to problems’ (Star, 1991b: 275). Similarly, I demonstrate how the complexity of the tasks carried out to follow the routinized model of person-centred care is seldom appreciated. However, if articulation work is not taken into account only

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an idealized representation of work will be provided, a representation which fails to describe actual situations (Gerson and Star, 1986: 258).

Tinkering

Another way to discuss how standards and technologies are made to work in practice is through the concept *tinkering*. One of the earliest usages of tinkering, in STS, can be found in an essay by Knorr-Cetina (1981; see also: Knorr, 1979). Drawing on French biologist François Jacob's work she defines tinkerers as opportunists who 'are aware of the material opportunities they encounter at a given place, and they exploit them to achieve their projects. At the same time, they recognize what is feasible, and adjust or develop their projects accordingly' (Knorr-Cetina, 1981: 34). Tinkering then implies a sort of "MacGyverism"⁴ – with making do with what is available to achieve ones goals. However, unlike MacGyverism it also includes being humble and adjusting goals according to the material surroundings. Like articulation work, tinkering is in this sense a concept relating to making something work in a local practice, to contextualization and contingency.

In recent years, tinkering, as an analytical concept, has regained popularity (see for example: Barba, 2015; Grommé, 2015; Law, 2010; Pols and Willems, 2011). This thesis builds on two interrelated definitions of tinkering. In the first tinkering is used to better understand the reciprocal relationship between technologies and users (Timmermans and Berg, 1997). Here tinkering relates to adapting, negotiating and underwriting a tool, a standard or an object in order for it to function in practice (Berg, 1997). It relates to 'people willing to adapt their tools to a specific situation while adapting the situation to the tools, on and on' (Mol et al., 2010: 15). This thesis illustrates this form of tinkering by emphasizing adjustments to the technoscientific scripts of assessment protocols.

The second definition of tinkering is more abstract. Here, tinkering is often likened to the process of doctoring (see: Law and Mol, 2011; Mol, 2008; Struhkamp et al., 2009; Wallenburg et al., 2013). According to Mol, doctoring involves 'being attentive, inventive, persistent and forgiving', it is something that the whole care team is involved in and importantly 'the crucial question in relation to doctoring is not who is in charge, but whether or not the various activities involved are well attuned to one another' (Mol, 2008: 64). From this perspective, tinkering is more than mere adaptation. It is a matter of 'holding together that which does not necessarily hold together' (Law, 2010: 69). This abstract conceptualization of tinkering is used to analyse how nurses bring together and tinker to combine contrasting values scripted in a protocol.

⁴ MacGyver was an action-adventure television series in the late 80's. MacGyver, the main character, is notorious for solving unsolvable problems through his scientific knowledge, Swiss army knife and imaginative use of ordinary and everyday items.

Visibility and invisibility of work

One important theme in this thesis is the visibility and invisibility of work such as articulation work and tinkering. The work carried out to coordinate contrasting information, to manage conflicting values or to adapt mundane technologies often remains invisible to official accounts of person-centred care. By attending to invisible work this thesis therefore wants to highlight the work that goes on around the ‘dominant narrative’ of this particular standardized model of person-centred care (Goodwin, 2014: 48). While work is commonly thought of as something done ‘away from home’, sociologists of work have argued that what actually counts as work varies (Star and Strauss, 1999). Work that is visible is often associated with ‘formal work that is authorised and documented’ (Allen, 2014: 4). A lot of work, related to care and home-care is however often rendered invisible. Changing a diaper or arranging that elderly parents get home care can be seen as work that ‘just gets done’ (Bowker and Star, 1999: 232), meaning that it has no voice, and that it is ‘invisible both to friends and family, and to others in the paid employment workplace’⁵ (Star and Strauss, 1999: 12; see also: Strauss, 1985).

This thesis also uses invisible work as a theoretical lens to point to work that has to be carried out, but which is not included in formal training and/or work descriptions. A similar definition is employed by Oudshoorn (2008) in a paper on invisible work in telemedicine. Analysing the work of home-care nurses she shows that nurses often have to perform many activities, which are not included in the training they receive, such as reassuring patients that they are capable of mastering a new telemedicine technology.

Star and Strauss (1999) suggest thinking of the visibility vis-à-vis invisibility of work not as two stable absolutes but rather as two endpoints along a continuum. This means that work can be more or less visible. The creation of a non-person is one point on this scale. Here, the work is visible but the person doing this work is rendered invisible. An example of this is domestic and service work where ‘[o]n the one hand, employers usually oversee the work done, sometimes to an astonishing degree of micromanagement. On the other hand, the employees are socially invisible to the employers’ (Star and Strauss, 1999: 16). The type of invisible work analysed in this thesis is located at another point on this spectrum. Here the workers are visible but the work they perform is invisible, relegated to the background. Nursing is a good example of such invisible work as it has a long history of being deeply embedded and invisible both in terms of work descriptions and in terms of record keeping. This invisibility has, of course, been a research topic in nursing studies (McWilliam and Wong, 1994; Jackson, 1997; Latimer, 2000; McQueen,

5 One important thing to notice is the gendered dimension of invisible work as the care and reproductive work of women remains unpaid and invisible (see for example: James, 1992).

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2000; Liaschenko, 2002; Allen, 2004; Liaschenko and Peter, 2004; Allen, 2014; Urban, 2014).

However, this thesis argues that making work visible is not necessarily positive or without its costs. Rather I see visibility as somewhat of a double-edged sword. While visibility can be used as ‘resources for worker’s own use in negotiations with management’, it can also increase ‘workers vulnerability to rationalizing agendas’ (Suchman, 1995: 60). And while visibility can ‘work against automation based on simplified notions of work’ it can also lead to increased rationalization (Suchman, 1995: 60). This means that visibility simultaneously can mean increased legitimacy *and* augmented surveillance and control (Bowker and Star, 1999; Star and Strauss, 1999). Therefore, making nursing work visible is not necessarily a good thing. In a chapter on classification and its consequences Star and Bowker (1999; see also: Timmermans et al., 1998) describe the efforts to build a classification system for nursing tasks and actions. While the system made a lot of previously invisible tasks visible there is also a risk of becoming too obvious and patronizing: ‘To tell veteran nurses to shake down a thermometer after taking a temperature puts them in a child-like position’ (Bowker and Star, 1999: 249). Another risk is that the classification of tasks will be linked to determining the cost of services, which can lead to constant monitoring, connecting visibility to an increased risk for surveillance and accounting. Furthermore, nurses’ space for discretionary judgement and tinkering runs the risk of being considerably circumscribed if their work is rendered visible.

For example, workers – nurses or teachers come to mind as good examples – may quietly carry work reflecting a holistic view of the student or patient, carefully kept out of range of a more bureaucratic, reductionist set of organizational values. Sometimes positive invisibility comes with discretion, and with not having to reveal your work processes to others (Star and Strauss, 1999: 23)

This thesis therefore works with a conceptualization of work as invisible for both good reasons and bad. This is in line with how ‘visibility and invisibility are not inherently good or bad’ (Allen, 2014: 4).

Discussion

This chapter has introduced a material semiotic reading of person-centred care. According to this approach person-centred care is neither exclusively situated in the patient-professional interaction nor entirely shaped by organizational facilitators and barriers. Instead, it enables an understanding of person-centred care

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through its messy, relational and material practices. Here, I would like to underscore three promises of material semiotics, which all are connected and intertwined.

First, a material semiotic perspective questions essentialist taken-for-granted divisions and dichotomies. Two such divisions, which are often re-produced in the literature on person-centred care are those between person-centred care and standardization, and between person-centred care and technology (Bensing, 2000; Mead and Bower, 2000; Stewart, 2001). Material semiotics teaches us that these are contingent rather than necessary divisions. In practice, person-centred care can be mediated by both standards and different kinds of technologies.

Second, a material semiotic approach underscores the importance of reciprocity. This is an important second step that I find lacking in the literature that highlights the importance of recognizing person-centred care from a practice perspective. While Liberati et. al (2015) conceive of person-centred care as a *collective achievement*, the empirical studies that employ this conceptualization do not talk about the work carried out to make person-centred care technologies function in practice. Gardner (2016) illustrates how person-centred care is embedded in a sociotechnical arrangement and Gardner and Cribb (2016) analyse what role person-centred care technologies have in distributing power. In this sense, they both illustrate what technologies do to practice but neither of them interrogates what the practices are in turn doing to the technologies. Using the notion of tinkering and articulation work, this thesis explores the work needed to make standardized models and technologies of person-centred care function.

Third, a material semiotic perspective asks us to think of person-centred care as an outcome rather than a starting point. In the standardized model of person-centred care, person-centeredness is conceived as something that has to be implemented and safeguarded in practice. However, thinking with Zuiderent-Jerak (2007; 2015) an alternative vision would be to develop person-centred care in its local organizational complexity and thereby transform it from something ready-made which care professionals have to adhere to, to something which is an outcome of an experimental intervention. Intervention here is understood as changing a practice in order to learn from it or as ‘manipulating the world in order to learn its secrets’ (Zuiderent-Jerak, 2015: 22).

4

Studying person-centred care: methods and materials

In this chapter, I present my empirical material and explain my methods. I start by describing my data, accounting for how I have sampled this data, and how the different types of empirical material complement each other. Secondly, I discuss what parts of my data I have used in the different papers and why. Thirdly, I account for my methods of data collection. Fourthly, I describe how I have coded and analysed my data using an abductive approach. Finally, I provide a discussion about the ethical implications of my study.

Data

To answer the research questions of this thesis I have collected and analysed four sets of data material: interviews with researchers working at the Centre for Person-Centred Care in Gothenburg; interviews with healthcare professionals working with and introducing the standardized model of person-centred care; observations of healthcare professionals applying this standardized model in practice, and related documents and written materials. The interviews with researchers, which were collected first, are part of a larger study. This study, led by Professor Nicky Britten of Exeter Medical School, aims to investigate the ways of defining and introducing person-centred care in Gothenburg in various healthcare and community settings. Out of this study grew an interest in examining healthcare professionals actually applying the model of person-centred care in practice. I therefore made contact with hospital wards adopting the model of person-centred care. While my initial aim was to conduct an observational study, I was obliged, after encountering some problems of access, to opt for carrying out interviews with professionals working on the wards in question. Learning that yet another hospital ward was about to introduce person-centred care, I again made contact, and finally succeeded in gaining permission to carry out an observational study as originally planned. The written materials I draw upon were collected continuously during interviews with researchers and professionals, and in the field.

The first set of data consists of 19 semi-structured interviews with 20 researchers, all of them trained medical care providers working in seven research projects.

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This limited sample out of the approximately 100 researchers attached to the Gothenburg Centre for Person-Centred Care working in 40 projects was purposively selected. The aim was to cover a broad spectrum of primary, secondary and tertiary healthcare contexts (hospital care, primary care, preventive care, and out-patient care) and to address different stages of development of person-centred care. The selected projects dealt with the delivery of care for acute coronary syndrome, irritable bowel syndrome, osteopathic fractures, patient participation in hypertension treatment, healthy ageing in migrant communities, neurogenic communication disorders, and psychosis. Some of these person-centred care projects had just initiated their studies, while others were already analysing their results and some had already published several papers. In each project, interviews were held with at least two persons: the project leader and a participating researcher. This sampling procedure was chosen to get a broad representation of perspectives. I draw on these interviews firstly to explore the reasoning of those developing the standardized model of person-centred care. Secondly, these interviews are highly informative concerning the efforts to evidence-base person-centred care. Thirdly, they are revealing about the challenges of introducing person-centred care across a plethora of different healthcare and community settings.

The second set of data consists of 12 interviews with healthcare professionals working at four different internal medicinal hospital wards where the standardized model of person-centred care has been introduced. Interviewing these healthcare professionals helped me to understand how healthcare professionals experienced and managed the tensions and challenges of translating person-centred care into standard healthcare on an everyday basis. I used a purposive sampling strategy again aiming at representation of several professional categories. At each ward, I therefore interviewed the ward manager, a nurse and an assistant nurse. At one of the wards I also interviewed a physician.

The third set of data is comprised of an observational study carried out at a fifth internal medicinal hospital ward where the model of person-centred care has been introduced. Again, doing an observational study has allowed me to witness person-centred care in action. I carried out 11 days of observations in total. Three of these were at meetings on the ward, where the model of person-centred care was either discussed, developed or presented. During the remaining days, I shadowed healthcare professionals in their work. Using a purposive sampling strategy aiming for representation of several professional categories I shadowed one physician, four nurses and two assistant nurses. The nurses and assistant nurses were shadowed during one shift each, which lasted for around 8 hours, and the physician was shadowed during two shifts, since I only shadowed one physician.

The last set of data consists of different types of written materials and formal documents. This data includes four research protocols produced in one of the

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research projects under study. It also includes two admission protocols, two internal education documents and one set of instructions for documentation all deriving from the ward where I carried out my observational study. Finally, I also draw on six papers published by the Gothenburg Centre for Person-Centred Care. I draw on these written materials and documents firstly because they provide an opportunity to analyse how the standardized model of person-centred care and its routines are officially represented. Secondly, the internally produced materials allow me to analyse what instructions are given to those introducing person-centred care and what actions and actors are prescribed.

Drawing on such a diverse collection of empirical materials allows me to take a multi-layered approach and see the standardized model of person-centred care from multiple perspectives. The combination of materials offers me both an overview of the person-centred care model *and* the fine-grained detail arising from witnessing the model in action. The written materials allow me to capture the official narrative of the person-centred care model in practice – they tell me about how the model ideally should work and how things in theory should be done. Both the interview studies provide me with an understanding of how the model works or fails to work in practice. Moreover, they provide me with personal accounts, reflections and justifications concerning person-centred practice and this particular person-centred care model. Finally, the observational study enables me to witness person-centred practice itself and to observe a model of person-centred care in action.

Table 1. Overview of data material

Data	Numbers	Collected	Length	Characteristics
Interviews with researchers	19 (+1) interviews	March 2013- May 2014	45- 78 minutes	Project leaders, junior researchers, senior researchers
Interviews with professionals	12 interviews	April – June 2014	29 - 60 minutes	1 physician, 4 ward managers, 3 nurses, 4 assistant nurses
Observational studies	11 days of observation	June – September 2014	Average 8 hours/ shift	1 physician, 4 nurses, 2 assistant nurses
Written materials and documents	Documents	April 2014- December 2016	1 – 20 pages	Admission protocols, research protocols, educational materials, published papers

Methods applied in the papers

Paper I, which aims to contribute to a discussion of the material reality of person-centred practice, draws on a combination of interviews with healthcare professionals, the observational study and analysis of two assessment protocols. This sampling was chosen to capture the reciprocal shaping of the standardization tool (the assessment protocol) and practice. Drawing on the observational study allowed me to examine both what the protocols did to the practices, in which they are embedded, and to observe how healthcare professionals tinkered with them. In addition, the interviews provided verbal accounts of how healthcare professionals conceptualized the relationship between person-centred care and standardization tools.

Paper II, draws on a combination of interviews with five researchers in one of the research projects and on written materials and formal documents. The paper aims to contribute to a better understanding of what tensions and challenges are emerging when the principle of evidence-based medicine is used to evaluate person-centred care, and how these tensions are understood, reflected upon and handled in practice. I chose this research project as it was the only project at the research centre that up until then had carried out a randomized controlled trial. I used a purposive sampling strategy aiming at capturing several types of researchers, ranging from professors more or less only involved in the analysis of the material, to PhD students working more hands-on in the trial. The purpose of this sampling strategy was to get a broad view of the different kinds of challenges and consequences to be managed and negotiated. To better understand the technicalities of the trial itself I draw on four research protocols produced in the trial and three articles published in the trial.

Paper III examines the layers of work going on around the dominant narrative of person-centred care, and investigates the tensions arising when standardizing a non-standard model of care. Drawing on my observational study and shadowing of healthcare professionals I am able to get a view beyond the dominant narrative and an opportunity to learn what *is* going on, rather than what *should* be going on, as resulting from formal documents and even interviews' (Czarniawska, 2007: 33). To analyse the dominant narrative and in order to consider how the work is represented I draw on educational materials and instructions internally produced on the hospital ward in question.

Paper IV aims to explore how new models of care risk compromising themselves by acting to replace the tenacious assumptions of biomedicine with similar assumptions of their own. The paper makes use of the interviews with researchers. Eight interviews with researchers from three projects were purposefully sampled to support the analysis in the article. These interviews reflect tensions and

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variation in practice in relation to the standardized model of person-centred care, especially because of the characteristics of the patients present in these projects.

Table 2. Overview of methods in each paper

Methods	Paper I	Paper II	Paper III	Paper IV
Interview with researchers		X		X
Interviews with professionals	X			
Observational study	X		X	
Document study	X	X	X	

Data collection

Interviews

As Kvale & Brinkmann (2009) and Czarniawska (2004: 50) I regard interviews as two persons seeks knowledge and understanding in a common conversational endeavour. Thus, I see interviews not as a window on social reality but as ‘a sample of that reality’ (Czarniawska, 2004: 51). Furthermore, interviews allow one to generate data that would have been difficult or impossible to obtain otherwise (Hammersley and Atkinson, 2007: 102). Interviewing researchers and healthcare professionals can therefore reveal actions categorized as person-centred and provide reflections on the model of person-centred care in practice. Moreover, they provide valuable descriptions of events and discussions that have already taken place. In interviewing managers and project leaders the justifications for introducing person-centred care could also be discussed.

Interviewing researchers

The first set of data, was collected as part of a larger research project led by Professor Nicky Britten (see: Britten et al., 2016; Moore et al., 2016). The interviews were conducted during the spring of 2013 and 2014. I conducted ten of these interviews and colleagues from the Department of Sociology and Work Science carried out nine. The interviews lasted between 45 and 78 minutes.

A semi-structured interview guide developed by the research team led by Professor Britten was used in all interviews (see appendix A). Following textbook recommendations (Kvale et al., 2009; Kvale and Brinkmann, 2009) the interview-guide opened with a general introductory question, where we asked the interviewees to describe their research project. This was followed by questions pertaining both to the definition(s) and the operationalization(s) of person-centred care. For example, the interview guide included questions such as: How would you explain

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person-centred care to someone who had never heard of it? What kinds of strategies do you use? Could you tell me about an example of effective person-centred care in your project? This was followed by prompting questions such as: Could you tell me about a routine work day with person-centred care? The interview guide also included specific questions about what facilitates and/or hinders person-centred care.

Since the interviewees were not native English speakers the interviews were conducted in their preferred language⁶. Interviews held in Swedish were transcribed verbatim and translated to English. Interviews held in English were transcribed word-by-word. One of the interviews was held over the phone while taking notes. To make sure that the interviewees felt comfortable and to fit their busy schedules we carried out the interviews in the researchers' preferred setting. Several of the interviews were therefore made at their offices, while others were held at the Department of Sociology and Work Science.

Interviewing healthcare professionals

The interviews in the second data set lasted between 29 minutes and 1 hour and took place at the hospital in offices and in conference- or consultation rooms during the spring of 2014. Again, I made use of a semi-structured interview guide (see appendix B).

The interview guide covered themes pertaining to both the practicalities and activities in person-centred practice, and to the experience and understanding of the model of person-centred care. When interviewing ward managers I also included questions about the introduction of person-centred care, whereas other staff members were asked to describe how they were introduced to the concept and if and how they had been provided with education in person-centeredness.

While the interview data has been shared with the project led by Professor Britten I was free to conduct the interviews as I wanted. I therefore prioritized asking follow up questions on topics brought up by the interviewees. For example, when interviewing the manager and staff at one of the hospital wards, self-rating scales were described as an important tool in person-centred care. To understand what role these rating scales had it was therefore important for me to ask follow-up questions. A conversation with Madeleine, one of the ward managers, exemplifies such a follow-up discussion:

I: These scales, could you tell me something about them?

⁶ In total six interviews were held in Swedish and 11 in English.

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M: The thing is that you should be able to evaluate the pain, in the sense of breathing, since it could be a state of confusion. You could for example use ADL. There are different verified scales for different symptoms and situations.

I: Is it the nurse who does the assessment, or are there any questions...?

M: Or the assistant nurse, yes.

I: Or the assistant nurse, yes.

M: We work hard to make the assistant nurses also use scales as a tool, so that they can evaluate the interventions together with the patients, and that they have this in mind.

I: But you don't ask the patients how they assess their ability of breathing?

M: That's what you're trying to do with the help from the scales. If the patient presses the bell and says: "I'm out of breath", you should note the current status and compare to earlier periods, like when the patients are doing the same thing at home. You use this scale together with the patient, so that he or she can assess their troubles using the scale. It is from this that we later can evaluate the patient's symptoms. Previously the nurse traditionally would assess from their own understanding: "Yes that looks strenuous", and things like that. And this is the way of thinking that my view as a nurse is necessary, but I should understand that the patients have their own resources.

In this excerpt you can see how I try to understand the rating scales. To begin, I ask Madeleine a probing question (if she can tell me something about the scales), which is then followed up by a specifying question about who is using the scales. I then confirm Madeleine's answer, to signify that I have understood what she is saying. This is followed by another specifying question as I have not yet understood if patients take part in this rating.

These interviews were held in Swedish, and were transcribed verbatim (without correcting grammatical mistakes) using transcription software. Some non-verbal sounds such as laughter and longer silences were noted down as well; however I have not indicated more detailed and fine-grained characteristics, as is often done in for example conversational analysis or linguistic studies. The interviews were later translated from Swedish to English, and then I meticulously cross-checked each translation against the original transcriptions (and tape-recordings when necessary).

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Observational study

For observational studies of working practices among different groups such as healthcare professionals, *shadowing* has been suggested as an advantageous technique. According to Czarniawska shadowing signifies 'following selected people in their everyday occupations for a time' (Czarniawska, 2007: 17). It thus denotes fieldwork on the move where the researcher moves with the professionals through their daily activities and tasks. Shadowing further suggests an attitude of 'outsidedness' because while observers do not know better than an actor does, they can see different things (Czarniawska, 2007: 20-21).

While all direct observations to some extent are participatory, Czarniawska notes the difference between shadowing and participant observation. Shadowing is easier compared to participant observation 'because it does not require a simultaneous action and observation, and because participation in complex, professional activities would be impossible for most researchers.' (Czarniawska, 2007: 55-56). Moreover, while participant observers risk 'going native' shadowing allows one to keep an attitude of 'outsidedness'. In the field, however it did not seem reasonable for me to be a pure observer, without any interaction. Rather, I continuously talked to and interacted with the professional I was shadowing, asking them to explain what they were doing or to reflect on something that had been happening before. As time went by I also started helping those I was shadowing with minor tasks such as carrying dinner trays, making beds and fetching bandages.

Shadowing one physician, four nurses and three assistant nurses for eight shifts in total, took me all around the ward and the hospital. My shadowing was guided by respect for both patients and professionals. When shadowing nurses I did not always shadow them when they distributed medicines and carried out medical tests and the like when the patients were negative to my presence. Similarly, when observing assistant nurses I did not always shadow them when they were changing diapers or helping a patient to the toilet as it did not feel like something important for my study to insist on observing. These exceptions aside, I shadowed the healthcare professionals in all they were doing. I shadowed the professionals when they attended meetings, when they participated in handovers and rounds, when they prepared and distributed medication, when they held admission interviews, when they made sandwiches, when they had coffee and lunch breaks and so on.

In the field, I took continuous handwritten notes. Using a pen with different colours, I tried to separate straightforward descriptions from my own analytical memos and preliminary interpretations of different situations. I took field notes in the midst of things. During handovers, I could sit down and take notes trying to write down what was being said, what kind of materials were used, and how

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and where the healthcare professionals were looking and/or pointing. During rounds, or when in patient rooms, I often stood in the background and took notes. Initially I had an idea about transcribing my field notes after each workday transforming the field notes into thick descriptions. However, this turned out to be too burdensome, as the shifts I followed were spread unevenly meaning that I sometimes did observations between 1.45 pm and 9.30 pm and then started the next morning at 6.30 am. Therefore, I transcribed the material some weeks after finalizing the observational study.

Document study

The documents and written materials were collected in different ways. I collected assessment protocols, internal education materials and instructions for documentation during my time in field. I received some of these documents in meetings with the ward manager and others I asked for. I gathered all materials concerning person-centred care provided to the healthcare professionals at the ward, where I carried out the observational study.

I collected the research protocols analysed in paper II through a regional R&D database. One of my interviewees provided me with a project number, which facilitated the database search. Finally, I identified published papers through the research centre's homepage. After identifying these papers, I downloaded them through the different journals.

Analysis

For paper IV, the data was analysed using thematic analysis comparing similarities and differences within and between seven research projects. Initially, we read all the transcripts and highlighted where we noticed tensions in interviewees' accounts regarding the operationalization of the standardized model of person-centred care. Thereafter, our analysis focused on projects where the group of patients posed difficulties for the operationalization of the person-centred care model and the vision of personhood embedded in the model. This led to a focus on three particular projects wherein researchers questioned central assumptions of the person-centred care model. Adopting this focus, we then read and coded the data. No specific theoretical framework was used to generate the codes; rather the codes were generated from the data. The central codes were: *verbal expression, patient narrative, partnership, capabilities, authenticity, goals and uniqueness*.

For the remainder of my papers, I have made use of an abductive approach. Timmermans and Tavory defines abductive analysis as a 'qualitative data analysis approach aimed at generating creative and novel theoretical insights through a dialectic of cultivated theoretical sensitivity and methodological heuristics.' (2012: 180). Abduction is therefore a form of reasoning which depends on the interplay

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between observations and the researcher's theoretical disposition. For researchers adopting an abductive approach it is therefore necessary to have an extensive familiarity with existing scholarship and theories already from the start and throughout every research step (Tavory and Timmermans, 2014: 42). However, the researcher must also have a willingness to abandon theories and think differently. One way to strengthen abductive inferences is to 'actively look for cases that may challenge both the possible hypotheses they [the researchers] came to the field with and the framework they began with' (Tavory and Timmermans, 2014: 75).

Tavory and Timmermans describe three important methodological steps in the abductive process. The first movement they label *Mnemonic*, the second *Defamiliarization*, and the third *Revisiting observations*. Mnemonics are important since field-notes and transcripts help us to remember and hinder us from saying 'whatever we wanted to say before we came to the field' (Tavory and Timmermans, 2014: 53). Another important part of guarding against biased memories is coding and memo writing.

For first cycle coding, I have used *initial coding*, which is about 'breaking down qualitative data into discrete parts, closely examining them, and comparing them for similarities and differences' (Saldaña, 2013: 100). I started with closely reading the material while taking notes. Thereafter, I read the material again and generated empirically close codes relating to different events observed or described in the interviews or the written material such as *interviewing, documenting, preparing medicine, talking with patient, evaluating symptoms, and following/ not following instructions* to name a few. Other codes related to themes more abstract. For example, I named codes such as *time, numbering, breakdowns, evidence, difficulties in routines, definition of person-centred care, feeling of insufficiency and confusion*. A second round of axial coding followed the initial coding. Here, I compared the codes looking across the material, merged codes that were similar and started to theoretically work out themes (Tavory and Timmermans, 2014: 54). This coding was performed separately for each paper and the coding was therefore made with different theories and perspectives in the back of my mind. However, as I will show these codes also came to change and develop.

Defamiliarization relates to thinking creatively about one's data material and finding surprises. I have used two primary strategies for defamiliarizing myself with my material. First, I have read my material without the coding and slowed down at the instances that have puzzled me. I then looked at my codes of these instances and tried to come up with other interpretations. An example of such a puzzle is visible in paper III. I had shadowed Amy, an assistant nurse, for almost an entire shift and was taken by her interaction with the patients. To me, her actions could be considered as highly person-centred. However, when I asked Amy about person-centred care she said that assistant nurses were not part of the

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person-centred care routines. Amy did in other words not see her work as person-centred. After reading and thinking about this puzzle, I was still not sure how to interpret it. Therefore, I made use of my second strategy of defamiliarization: letting others take part of my material and preliminary thoughts. On several occasions I have presented tentative analysis or plain field notes at seminars to test my thinking with others – looking for alternative explanations. It was at such a seminar where I got help to think further about my puzzle with Amy. I was encouraged to read about invisible and visible work. After doing so I *revisited my observations*, which is the third movement described by Tavori and Timmermans. Revisiting empirical data has to do with re-reading the material with new insights. Taken together this means that a lot of my second cycle codes and therefore my interpretations have been changed, modified and regrouped.

Generalizability

To reach generalizable analyses Tavori and Timmermans emphasize the importance of peers, or what they call ‘the community of inquiry’. Taking part in a community of inquiry can help the researcher to produce abductive insights in three ways. It can help to press questions of *fit*, of *plausibility* and of *relevance*. A theorization fits the data material ‘when it is able to account successfully for different forms of variation’ (Tavori and Timmermans, 2014: 106), and the most important way to establish fit is through transparency so that one’s peers can reconstruct claims. In trying to establish fit, I have presented my papers to different communities of inquiry. I have presented and discussed paper I at both an STS conference and at two different nursing conferences. Both junior and senior colleagues have commented upon paper II. I have submitted paper III for comments at several seminars, both STS seminars and work science seminars. Finally, paper IV has been discussed at several seminars, and at a workshop wherein researchers interviewed for the paper participated.

These different seminars have also provided important opportunities to think about the *plausibility* of my inferences and to think about alternative theoretical accounts as recommended by Tavori and Timmermans (2014: 111). An example of this can be found in relation to how I developed paper I. I presented a draft version of this paper at a large STS conference in 2015, making the argument that in practice an opposition between person-centred care and technologies no longer holds. A member of the audience suggested that my material did not only speak of technologies but also about standardization tools. After familiarizing myself with relevant literature on standardization tools, I revisited my material and made new inferences.

When it comes to *relevance*, Tavori and Timmermans make a point of not offering methodological guidelines:

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Researchers need to use their imaginations and develop the theoretical generalizations they constructed. They need to think about how their theorization will help other researchers, who are studying other cases, to see something new in their data or organize their research differently (Tavory and Timmermans, 2014: 115).

Again conversing with the community of inquiry can help determine if the generalizations are relevant or not. Here I have found it particularly important to be relevant both to sociological/STS audiences and to a healthcare/nursing audience. I have therefore actively sought to present my papers at nursing/care conferences, keeping a dialogue with those primarily affected by the results of my studies.

Ethics

In doing research on healthcare, ethics is of great importance since one often encounters sensitive medical or personal information. Therefore, ethical approval was obtained from the Regional Ethical Review Board both for the interview study with healthcare professionals and for the observational study. Furthermore, I have made use of several strategies to conform to the Swedish Research Council's ethical principles of information, consent, confidentiality and utilisation (Vetenskapsrådet, 2002).

In the two interview studies, an information sheet was sent either in advance to the ward manager or directly to the researchers. I also brought along copies of this to each interview and before starting the interview, I discussed it with the interviewee. I also made sure to gain consent for participating in a recorded interview.

For paper IV, we decided on keeping the names of each research project as the context, groups of patients and other kinds of specificities were relevant to our analysis. However, all researchers were given a pseudonym and no differentiation is made between for example a PhD student and a senior researcher. In interviews with healthcare professionals I chose another strategy. To preserve the anonymity of both professionals, and potential patients mentioned in the interviews, I decided on anonymising not only the interviewees' names but also the names of the wards. This also included leaving out information about the specialization of the wards, since their specialization would make them recognizable. In both this interview study and in the observational study the healthcare professionals have been assigned pseudonyms. Nurses have been given a pseudonym starting with N, assistant nurses starting with A, doctors with D and ward managers with M.

To secure voluntariness and informed consent in the observational study, I sent an information letter to the ward managers to distribute before commencing

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my study. This information letter was pinned to an information board in the staff lunchroom visible for all to see. When I shadowed healthcare professionals, I continually asked them for permission. At the beginning of each shift, I informed them about myself and the aim of my study, and asked for their verbal consent. I also referred them to the information letter in the lunchroom if they wished to know more about the study. As for the other healthcare professionals present during my time at the ward, I was introduced to most of them during a kick-off meeting. I informed everyone that all names would be anonymised, that participation was voluntary and that I would respect every wish not to participate in the study. However, not all staff members were present during the kick-off meeting. Therefore, I tried to introduce myself whenever I met someone new, although I did not succeed in introducing myself to everyone at the ward.

Gaining informed consent from patients present at the ward during my observations was not without its challenges and drawbacks. Usually, the nurse/assistant nurse I shadowed would introduce me to the patient when entering a patient room. Then I was often given the opportunity to say something short in the lines of 'I am observing XX today. Is it okay if I observe while she works with you?'. In some cases the consent-asking was however 'kidnapped' by the nurse or the assistant nurse, who in these cases usually asked 'You don't mind that Doris observes me do you?'. There is a risk of coercion involved in this type of consent strategy, as patients may have felt obliged to consent to my observations. Moreover, being a patient already entails being in a vulnerable position. I therefore tried to be sensitive in the field and would often leave the patient's room to let them get some privacy.

When observing admission interviews, in which both a nurse and a patient were present, I gave them an information sheet and informed them about my observation study. Verbal consent was gained in all instances. All patients have been given pseudonyms.

Outsider or insider?

Early STS research engaging in laboratory studies, such as Latour & Woolgar (1986: 41) used the concept of anthropological strangeness to 'depict the activities of the laboratory as those of a remote culture'. In so doing they positioned the researcher as an outsider and stranger visiting the lab. In an interesting paper about how STS researchers are now more commonly invited to participate in research and interventions, Elgaard Jensen (2012) reflects upon early STS research. He argues that while the researchers were often invited to the sites, the actual labs, they were 'nowhere near the crucial *discussions or decisions*. In fact, it was usually unclear whether the natural scientist and technologists would notice their work at all' (Jensen, 2012: 14, italics in original). In other words, these early studies were

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not expected or invited to intervene or to act back on the lab. The STS-field has however evolved since these early days. STS research is no longer only ‘coming from the outside’ as researchers are sometimes even invited to take part in technoscientific projects they study.

My own position in the field has been ambiguous. When conducting interviews with researchers I have been an insider, as the project led by Professor Britten was financed by the Gothenburg Centre for Person-Centred Care. My being part of this project made recruiting researchers to interview a straightforward task. On the other hand, when holding interviews with healthcare professionals and during the observation study I was an outsider without the visible support of the Gothenburg Centre behind me. To think about my position in the field I have found the notions of *ontological relationism* (Jensen and Lauritsen, 2005), *partial connections* (Strathern, 1991), and *situated knowledges* (Haraway, 1988) useful. These notions all extend the basic lesson of material semiotics – that everything gains meaning through relations – to methodology. This means that knowledge is also generated through specific relations. Therefore, connections and relations are vital if anything is to be learned (Jensen and Lauritsen, 2005: 64).

In discussions concerning the relationship between knowledge and power several feminist and postmodern social scientists have argued that the standpoint of the subjugated should be privileged in qualitative research. One could therefore suggest that I should be wary of my connections to established authority and should instead approach person-centred care from the standpoint of nurses and assistant nurses. However, Haraway argues such reasoning also has its problems:

Such preferred positioning is as hostile to various forms of relativism as the most explicitly totalizing versions of claims to scientific authority. But the alternative to relativism is not totalization and single vision, which is always finally the unmarked category whose power depends on systematic narrowing and obscuring. The alternative to relativism is partial, locatable, critical knowledges sustaining the possibility of webs of connection called solidarity in politics and shared conversation in epistemology. Relativism is a way of being nowhere while claiming to be everywhere equally. The “equality” of positioning is denial of responsibility and critical inquiry (Haraway, 1988: 584)

While being a partial insider is risky, it also means being situated in relation to a given practice. Thinking with Haraway it has therefore been important for me to acknowledge my own situatedness and the embodiment of my knowledge. This approach of *feminist objectivity* ‘is about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become answerable for what we learn how to see’ (Haraway, 1988: 583).

5

Summary of the Papers

Study I

Lydahl, D “Standard tools for non-standard care – the values and scripts of a person-centred assessment protocol” under submission to *Science & Technology Studies*

Person-centred is often regarded as implying a turn away from technology towards more humanistic values in care. Drawing on material semiotics and the notion of technoscientific script, this paper argues that technologies are integral to person-centred practice. In so doing the paper aims to contribute to a discussion of the material reality of person-centred practice. Building on semi-structured interviews with healthcare professionals working with person-centred care and a small ethnographic study at a person-centred hospital ward, the paper makes four basic points.

First, the paper demonstrates how a mundane standardization tool in the form of an assessment protocol is an important actor in person-centred care capable of transforming the practice in which it is immersed. Moreover, this standardization tool provides a way of simultaneously reducing and embracing variation in care. While it insures that the unique patient perspective is taken into account, the basic idea is also that it should provide the *same* kind of focus on each patient. The tool thus takes into account both managerial demands and the patient experience. There is therefore an ambition to provide *equal yet unique care* for each patient.

Second, the paper shows that three different core concerns can be found in the script of the assessment protocol: a valuing of the patient’s experience and perspective, a valuing of science and medicine, and finally a strong managerial imperative. For example, the protocol includes several established evidence-based assessment scales, thereby attaching significance to science and medicine. Simultaneously, the protocol also incorporates a normative orientation, which attributes significance to the experience and perception of patient. Moreover, the information collected through the protocol is supposed to lay the foundation of a care plan including an agreed date of expected discharge. This is a managerial

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strategy to make sure that patients have a realistic view of what will happen during their hospitalization and thereby making the discharge process more straightforward.

Third, it is argued that these sometimes contrasting values, and the technologies embodying them, are rendered compatible through the continuous tinkering of healthcare professionals. This tinkering takes a variety of different shapes and forms. Sometimes it comes in the form of adjustments adapting the script of the assessment protocol, allowing more space to be found for the patient's perspectives and stories. At other times, it coincides with value conflict management, in which mediation and translation between the different values is needed.

Finally, the paper demonstrates how these concerns are re-inscribed in a new version of the protocol. This re-inscription of the values points to the significant tensions between these values in person-centred care at large. These values come from somewhere as they are a part of a particular vision of the world. Therefore, while various standardization tools may differ to accommodate specific requirements, the idea of taking the patient experience seriously while simultaneously seeking to cut healthcare costs will influence the introduction of person-centred care in other contexts as well. Therefore, it is important to recognize tinkering as a means to manage the value tensions and conflicts within the practice of person-centred care.

Study II

Lydahl, D “Dismantling the master’s house with his own tools? Engaging a randomized controlled trial of person-centred care” under submission to *Valuation Studies*.

This article deals with an intriguing case, in which a programme of standardization – evidence-based medicine – is used to evaluate what has been described as the antithesis of standardization: person-centred care. More specifically the article studies the use of a randomized controlled trial to determine if the introduction of person-centred care in the management of patients with acute coronary syndrome improves self-efficacy, reduces the duration of sick leave, decreases morbidity and increases activity compared to conventional care. Drawing on a combination of document studies and semi-structured interviews, the paper examines how person-centred care and evidence-based medicine are interwoven in practice and the tensions that emerge. In doing so, the paper studies how researchers combine an ambition to prize the uniqueness of the individual with an aim to extrapolate from knowledge of a few to produce guidelines for the many.

SUMMARY OF THE PAPERS

Starting with a description of a randomized controlled trial and its intervention the paper demonstrates how the production of evidence was prioritized during the introduction of a specific model of person-centred care over the complete care chain. However, producing evidence and evaluating the results of this person-centred randomized controlled trial was not a straightforward task. Significant challenges, the paper argues, are related to questions of variation, control and effect. Because in testing person-centred care there is a problem of knowing exactly what it is that produces an effect. Although the person-centred trial was arranged like a proper randomized controlled trial with one control group and one group receiving the intervention, it turned out to be difficult to decipher which of the different, interwoven, relational and contextual components of the intervention produced an effect.

Another challenge has to do with the tension between the demands posed by evidence-based medicine in terms of who is eligible for an intervention and the concern in person-centred care to value each patient as a unique person. The paper shows that to reduce variation potentially affecting the study, strict inclusion and exclusion criteria were necessary. While these strengthened the statistical power of the study, they also called for pragmatism in relation to person-centred care's underlying principles. In other words respecting the rigorous requirements of a randomized controlled trial led to the suspension of core values and beliefs of person-centred care. Furthermore, the inclusion and exclusion criteria defined many persons as unsuitable for person-centred care.

The article concludes that although person-centred care implies a partial demedicalization of care by emphasizing the patient narrative and partnership, the person-centred randomized controlled trial risks medicalizing care anew. It does so by standardizing the person in person-centred care in order to better evidence the outcome of changes in care delivery. The paper suggests that rather than prizing the empirical generalizations of evidence-based medicine other strategies for producing evidence of the virtues of person-centred care are required. Therefore, what is needed is perhaps not further randomized controlled trial research but rather studies of how person-centred care works or fails to work in practice for particular people.

Study III

Lydahl, D “Visible persons, invisible work. Exploring articulation work in the implementation of person-centred care on a hospital ward”. *Sociologisk Forskning* (forthcoming)

Drawing on the notions of articulation work and invisible work this article investigates the efforts involved in sustaining the realization of a specific framework

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of person-centred care. Based on a small ethnographic study carried out at an internal medicinal ward where person-centred care was implemented, this paper seeks to reveal the layers of work implicated in its realization. Furthermore, the article investigates the tensions arising when formalizing a model of care that has its basis in a critique of standardization as giving rise to reductionism and objectification. I maintain that articulation work is especially important under such circumstances. Because while some formal descriptions of person-centred care are provided, getting it to work in practice depends on the inventiveness and skill of caregivers in clinical practice.

First, the article outlines the model of person-centred care introduced and implemented at the ward. Building on the notions of patient narrative, partnership and documentation, a specific operationalization of person-centred care has been developed at the ward. According to this model, nurses should use a specific assessment protocol when interviewing patients to elicit their narratives. Secondly, a partnership should be established and documented in a care plan. Thirdly, it is emphasized that entries in the medical record should be formulated in the patient's own words. This operationalization of person-centred care gives rise to an interesting tension. Because even though person-centred care in principle is opposed to standardized models of clinical practice, formalized routines and taxonomies are developed and used at the ward to introduce and sustain person-centred care. Consequently, person-centred care is transformed from an abstract model to a set of instructions to be followed. The paper argues that while this may lead to the advancement of person-centred care, it may also imply increased scrutiny of nurses' work. Furthermore, activities which are not included in the routines, both activities which could be considered highly person-centred and activities needed to make the instructions workable, are rendered invisible and unspoken.

Second, the article demonstrates that articulation work and invisible work are vital for the realization of person-centred care. Articulation work is defined as the coordination of different tasks, and as work that gets things back on track after unanticipated contingencies. Nurses need to do a lot of creative interpretations, coordination and translations in order to put person-centred care into practice. For example, nurses have to elicit the patient narrative and then document this narrative in the medical record - complicated tasks, in which they receive little prior training. Furthermore, nurses have to find ways of coordinating incongruous information and tasks.

Finally, the article concludes that while the successful implementation of person-centred care is often argued to rely on the willingness of nurses to surrender old habits, it seems rather to hinge on the skilled inventiveness of these nurses and their ability to overcome the practical difficulties they encounter. However, while it may be tempting to make invisible dimensions of person-centred care

visible by encouraging the development of even more specified routines and instructions, it may also be better if these routines are kept simple and understood as 'loose' guidelines. Arguably, what is required is an acknowledgement of the practical challenges faced when implementing person-centred care and thereby a consideration of the relationship of healthcare professionals to the system, structure and context of care.

Study IV

Naldemirci Ö, Lydahl D, Britten N, et al. (2016) "Tenacious assumptions of person-centred care? Exploring tensions and variations in practice". Published in *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*

This article analyses the tenacious assumptions embedded in a standardized model of person-centred care and the challenges emerging when this model is introduced in diverse settings. Recent decades have witnessed mounting criticism towards the 'tenacious assumptions' of biomedicine regarding the neutrality and universality of its knowledge, leading to new initiatives seeking to replace biomedicine's 'dehumanizing procedures' and 'objectivism' with more holistic healthcare models. The aim of this article is to explore how new models of care risk compromising themselves by acting to replace the tenacious assumptions of biomedicine with similar assumptions of their own.

We do so by first tracing the history of person-centred care and then discussing a specific model of person-centred care developed at the University of Gothenburg Centre for Person-Centred Care. Finally, we introduce a case study, in which we draw on semi-structured interviews with researchers in three different research projects, situated at the research centre. All these projects developed, assessed and introduced this particular model of person-centred care, but in very different settings.

Tracing the history of person-centred care, we argue that while it has complex origins, some fundamental assumptions about the person in person-centred care can be traced. These are assumptions that conceive of the person as a reasoning individual who is capable of verbal expression. We argue that similar assumptions can be found in the specific model of person-centred care developed at the University of Gothenburg Centre for Person-Centred Care. This model is operationalized through three so-called routines. The first routine involves collecting the patient narrative, which is defined as the patient's personal account of their illness and symptoms as well as an account of their beliefs, needs, capabilities, goals and experiences. The second routine concerns the establishment of a partnership between patient and caregiver, enabling the sharing of knowledge and providing a

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basis for discussion and planning of care and treatment. The third routine concerns documentation of the patient narrative and of the partnership. We argue that these routines only can serve to initiate and safeguard the model of person-centred care if the person is able to share their narrative with the professional and wishes to take part in shared decision-making. Therefore, this model of person-centred care is based on an assumption that *a person is both capable of reasoning and verbal expression and willing to provide clear and genuine narratives and cooperate with healthcare professionals.*

In the last part of the article, we introduce a purposeful choice of three research projects where the assumed person of person-centred care is challenged and adaption of the routines is called for. The projects analysed concern healthy ageing in migrant communities, neurogenic communication disorders, and psychosis. These were purposefully chosen out of a larger sample of research projects as interviews with researchers in these projects reveal tensions and variations in practice of the aforementioned routines especially because of the characteristics of the patients concerned.

We show how these three projects present various, and sometimes related, challenges to the underlying assumptions of the person-centred care model. In both the project on neurogenic communication disorder and the project on healthy ageing in migrant communities the assumption of the person's ability to verbally communicate their narrative is challenged. This means that the researchers had to find ways to grapple and tinker with the notion of narrative in order to adapt it to the realities of care they faced. In both projects this meant a broadened definition of narrative elicitation, in which a third person, either a relative or a translator is included in telling the narrative. In the communication disorder project, narrative elicitation also included carefully observing the person and providing them with tools through which they could express themselves in non-verbal ways. Consequently, the definition of what a narrative is was broadened. From being regarded as a unique individual testimony, the narrative came to be defined as something which can be jointly constructed by the patient, caregiver, and family members, and through symbolic and material aids.

The authenticity of the patient narrative was another challenge, particularly in the psychosis project. Persons with psychosis do not always have insight into their illness and are not always alert enough to tell their stories or share their goals. Therefore, professionals in this project sometimes had to flip the advised order of the person-centred care model and initiate collaboration, consultation and at times give the patient medical treatment before the patient narrative could be elicited. Furthermore, we argue that the psychosis project challenges the assumption of the continually capable person. Our analysis suggests that in the context

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of psychiatric care capabilities constantly change and are sometimes not available to be deployed.

Another important challenge discussed deals with how the tension between the person as a unique individual and the person as a representative of a particular group is managed. This challenge is particularly visible in the healthy ageing in migrant communities' project, which works with groups rather than individual persons. We argue that this project serves as a good example of a broadened definition of the person, where the person is not only defined within a dyadic relationship between patient and care provider, but also with respect to a broader social context including family members and social support groups.

We conclude that as the person-centred care model under study was developed in a specific healthcare context the routines of person-centred care build on assumptions reflecting this context. Therefore, it becomes problematic to directly transfer them to other healthcare settings with diverse patient populations. Moreover, assuming individual capabilities of reasoning and verbal expression limits the conception of personhood and risks obscuring the creative ways that professionals and patient groups find for translating the ideals of person-centred care into practice. Therefore, we identify the need for a sensitivity towards the importance of context in developing models and guidelines for practice.

The paper was co-authored by Doris Lydahl, Öncel Naldemirci, Nicky Britten, Mark Elam, Lucy Moore, and Axel Wolf, with DL and ÖN as main authors. DL and ÖN conducted half of the interviews each, and coded and analysed the material together. ÖN had main responsibility for writing the introduction, the historical overview and the section on person-centred care in healthy ageing in migrant communities. DL had main responsibility for writing the methods section and the section on person-centred care in neurogenic communication disorder. DL and ÖN then collaborated in writing about person-centred care in psychosis care, and the discussion and conclusion. Before submitting the paper NB, ME, LM and AW all substantially commented and helped edit the paper. ÖN and DL were responsible for revising the paper, and all revisions were then approved by the whole research team .

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Conclusions

While person-centred care is commonly associated with efforts to improve the quality of care by catering for variation and difference, evidence-based medicine and standardized guidelines aim to assure quality by reducing difference and variation. However, no matter how contrary these two reform movements may appear, numerous efforts are being currently made to coordinate and combine them. In this study, I have set out to contribute to an improved understanding of the complex relationship between person-centred care, standardized procedures and evidence-based medicine. I have done so by observing and carrying out qualitative interviews with healthcare researchers and professionals working with and developing one particular model of person-centred care as well as through the analysis of written materials and documents pertaining to this model.

Prior research has typically either addressed person-centred care at a micro-level, focusing on the relationship between individual patient and caregiver, or at an organizational level addressing how structural, cultural and procedural dimensions of a healthcare organization facilitate or hinder the advancement of person-centred care. Drawing on both traditions while also breaking with both, I have employed a material semiotic sensibility in this thesis. This has allowed me to attend to the messy, relational, and material *practices* of person-centred care, and to make sense of both its social actors and its material reality.

In this chapter, I will attempt to summarize answers to the research questions posed in chapter 1: What tensions and challenges emerge when attempting to make care recognizing the patient as a person into standard healthcare? How does a standard model of person-centred care transform clinical practice(s)? How do clinical practitioners in turn actively negotiate and manage the new demands made on them by a standard model of person-centred care in their everyday work? In the following, I address each of these questions in turn. Thereafter, I discuss the advantages emerging out of my research of adopting a material semiotic approach to the study of transformations in care relations and offer some directions for future research.

Tensions and challenges of person-centred care as standard healthcare

One of the major themes in this thesis has been the relationship between person-centred care and the standardization of healthcare. Person-centred care is often advocated as the anti-thesis to standardized biomedicine. Instead of a reductionist one-size-fits-all approach to healthcare it promises to see the person behind the patient and to deliver care tailored to individual needs and goals. However, my research shows that this relationship is more complex since the studies in this thesis address attempts to standardize a one-size-does-*not*-fit-all approach to healthcare. Here, we find a model of healthcare that is at once the *same* for all patients, while also being *different* in catering to each individual patient as a unique person. One of the clearest examples of this is the endeavour to subject person-centred care to randomized controlled trial. Here, in the quest for universality and to further the cause of person-centred care, assumptions about a homogenous patient are made and rarely problematized. One of the foremost challenges of making care recognizing the patient as a person into standard healthcare concerns how this person is actually imagined in this new standard model of healthcare. Because while valuing the capable person behind the patient, listening to their narrative, and establishing a partnership may seem inclusionary and empowering this also posits a very specific sort of patient possessing a given array of abilities. Similarly, in insisting on particular routines to be followed and specific values to be recognized the Gothenburg version of person-centred care risks embedding assumptions of its own. These assumptions are very similar to those it aims to move beyond in the first place.

Another major challenge in introducing person-centred care as standard healthcare has to do with ways of working. Papers I and III show how the Gothenburg model of person-centred care sometimes conflicts with the accepted ways of working, introducing different procedures and challenging the documentation infrastructures of the hospital ward. For example, nurses who work with person-centred care are supposed to combine new person-centred tasks with all their established duties, without working overtime. Yet another challenge is that nurses are supposed to perform interviews with patients according to a specific protocol, and to document this interview in an electronic medical record that does not match the protocol. Yet another tension is that several different and sometimes conflicting concerns are inscribed in such protocols.

Transformation of practice?

The standardized model of person-centred care significantly transforms clinical practice. It changes ways of working by introducing new tasks and activities. It

considerably alters assessment interviews with patients, both in terms of which questions are asked, the overall focus and the major concerns addressed. This places new demands on the healthcare professionals, as they are expected to elicit a patient narrative – a complex task, in which they receive little or no training. The standardized model of person-centred care also transforms documentation procedures as nurses and physicians are asked to document narratives, decisions and partnerships – and this in a way easily comprehensible for the patient.

Moreover, the standardized model transforms person-centred care itself, from an abstract approach to a set of routines and instructions to be obeyed and followed. While this leads to the increased visibility of person-centred care and potentially furthers its advancement, it may also imply increased scrutiny of healthcare professionals' work. Furthermore, activities, which are not encompassed by the model, are rendered invisible and unspoken both in official accounts and for the healthcare professionals performing them.

Managing tensions, working person-centred care

The standardized model of person-centred care, as well as the tensions and challenges it gives rise to, are negotiated and managed in a variety of ways. In paper I, I point to the importance of tinkering as a means to manage tensions and conflicts. I demonstrate how nurses have to balance and bring together the potential conflicts between, on the one hand, their usual working procedures and documentation practices and on the other hand, the routines and protocols of person-centred care. Further, they have to manage the tensions within the person-centred routines and protocols themselves. They are therefore obliged to make adaptations, translations and become creative mediators in order to enable the standardized model of person-centred care to hold together. Paper III similarly demonstrates the articulation work involved in the realization of the Gothenburg model of person-centred care. I show how nurses continuously coordinate different tasks, perform complex activities, for which they have little prior training, and creatively interpret incomplete instructions in order to compensate for shortfalls in information.

In Paper IV, my colleagues and I show how researchers in different research projects come up with a variety of resourceful ways of adapting or working around the routinized model of person-centred care. We demonstrate how they do so by inventively expanding the definition of what a narrative is and how it can be elicited, by reversing the order of the person-centred routines and by extending the definition of the person.

Empirical contribution – Person-centred care as outcome rather than starting point?

Introducing person-centred care as standard healthcare seems to be anything but a straightforward task. It includes many tensions and challenges that healthcare professionals need to manage and negotiate in everyday practice. This could be likened to what is often referred to as the ‘gap’ between quality as defined in clinical guidelines and actual clinical practice. Because just as in research about the implementation of clinical guidelines, research on the implementation of person-centred care often highlights low adherence, reluctance to give up old habits and healthcare professionals failing to adopt the right mind-set (Carlström and Ekman, 2012).

My research instead suggests that the success or failure to introduce person-centred care may well depend on a great deal of barely visible and poorly appreciated work and tinkering. However, things could be otherwise. I believe person-centred care can learn from material semiotics. The standardized model of person-centred care is commonly appreciated as something that has to be implemented and safeguarded in practice. However, STS scholars have suggested doing away with the distinction between development and implementation (Markussen and Olesen, 2007; Zuiderent-Jerak, 2007). In his research on integrated care pathways, Zuiderent-Jerak suggests that such pathways should be ‘developed in ways that try to make them an *outcome* of a dynamic process of standardization, rather than a *starting point* that medical practice has to adhere to’ (2007: 315). Employing a similar strategy for person-centred care could help avoid the need to inflexibly implement it in practice and would therefore circumvent several of the problems currently encountered.

Moreover, if person-centred care were understood as an outcome rather than an already established point of departure the paradoxical relationship between standards, technologies and person-centred care would change. For example, assessment-protocols or other standardization tools could still be used but only if they resulted in more person-centred care. What is important is that tools would be accepted as needing to be developed and refined *in situ* rather than already finalized prior to use with no reference to different local organizational complexities. In so doing, problems of mismatch between protocols and medical records could be avoided, as such problems would have been predicted and taken into account to begin with. Developing situated protocols would also mean that the vision and values inscribed in protocols would reflect situated visions and values. Considering complex local practices also implies recognizing the importance of tinkering as a means to manage potential value tensions and conflicts.

Similarly, person-centred care as an outcome rather than a starting point for the transformation of care would also have effects on the visibility and invisibility of care work. If the outcome is what matters, then innovative activities not included in routines or instructions could be recognized as just as valuable as activities dutifully following protocol. My empirical studies also suggest that if one requires routines for person-centred care these are best kept simple and developed as practical guidelines, rather than inflexible requirements.

Theoretical contribution

This study contributes to discussions concerning the paradoxes and tensions emerging as person-centred care is introduced as standard healthcare. In particular, I have attended to the material reality of person-centred care and shown the work needed to make a standardized model of person-centred care and its tools function in practice. Previous research employing a material semiotic perspective on person-centred care has successfully demonstrated the difference that person-centred tools and technologies make to practice (Gardner, 2016; Gardner and Cribb, 2016), but it has not taken analysis further. My empirical studies and my theoretical approach therefore contribute in underlining the importance of reciprocity – interrogating how inventive practices act back on tools, technologies and standards of person-centred care. Using the notions of inventiveness, tinkering (Berg, 1997; Law, 2010) and articulation work (Star, 1991b; Star and Strauss, 1999) I have taken material semiotics a step further, something that is currently missing in the literature that underscores the importance of recognizing person-centred care from a practice perspective.

Taking material semiotics a step further also means acknowledging the messiness of practice, of doing away with the vision of smooth transitions and paying attention to the messy and the partial (c.f. Murphy, 2015), and focusing on that which is regularly erased from view. As empirically demonstrated in this thesis the introduction of person-centred care often entails invisible and unacknowledged work, confusion, normativity and exclusion. None of these things have been sufficiently acknowledged in previous research on person-centred care.

Even though the empirical results of this thesis might not be generalizable to other cases or situations, findings from my analysis are generalizable to theories that have much wider scope than only this case. Therefore, theoretical conclusions may be valid in relation to empirical cases similar to that of person-centred care. Whether this is actually so or not, has to be explored through further research on e.g. other non-standardized standard models for quality improvement in the welfare sector.

Directions for future research

My study has been both descriptive and theoretical in that it has explored how a specific standardized model of person-centred care has been introduced in different settings. However, to make person-centred care an outcome rather than a starting point, further *experimental* research is needed. With experimental research I mean playful action-oriented research, in which the sociologist in a double movement changes a practice in order to learn from it. Such research would abolish the development/implementation divide while also continuing to explore and negotiate the relationship between person-centred care and standardization in everyday practice.

Experimental research, or as Zuiderent-Jerak (2015) terms it ‘situated interventions’, build on extensive ethnographic observations. Moreover, the sociologist is not expected to singlehandedly intervene. Rather, situated intervention is a hybrid space ‘in which many agents constantly negotiate and influence each other’ (Zuiderent-Jerak and Bruun Jensen, 2007: 231). Being situated means being connected and relational, being involved in the practices and with practitioners. Therefore, ethnographic fieldwork would serve to both observe practices and to increase situatedness. Drawing on observations and on conversations and interviews with practitioners it would be possible to develop new routines and tools of person-centred care as interactive innovations emerging out of practice more than imposed upon it from the outside. Changes would in other words be developed and negotiated within the practice in close collaboration with practitioners.

Similarly, observations could also be the starting point for evaluations of person-centred care. Instead of assessing person-centred care through the empirical generalizations of evidence-based medicine, a material semiotic approach encourages studies of the practical strengths and weaknesses of person-centred care for particular persons under specific circumstances of care.

Svensk sammanfattning

De senaste decennierna har man kunnat skönja två dominerande trender i debatten kring hur man bör förbättra hälso- och sjukvården. Å ena sidan finns det förslag på att förbättra hälso- och sjukvård genom att använda standardiserade riktlinjer och arbetssätt. Å andra sidan finns förslag på att förbättra sjukvården genom att personcentrera vården.

Personcentrerad vård innebär att man försöker förbättra hälso- och sjukvården genom att utgå från varje patients unika erfarenheter, värderingar och preferenser och genom att se patienten som en person som är mer än sin sjukdom. Det innebär också att man eftersträvar att patienten ska bli medskapare och partner i sin egen vård och dess utveckling och utvärdering. Standardiserad vård, och det som brukar kallas för evidensbaserad medicin, innebär istället att man försöker förbättra vården genom att se till att medicinskt beslutsfattande inte bygger på enskilda läkares subjektiva omdömen utan istället baseras på vetenskaplig kunskap och forskning.

Den här avhandlingen handlar om en rad exempel och situationer där man försöker kombinera personcentrerad vård, standardisering och evidensbaserad medicin och de olika värderingar de är förknippade med. För att undersöka de här kombinationerna av personcentrering och standardisering så har jag studerat Göteborgs Universitets Centrum för Personcentrerad Vård. Vid detta centrum har man tagit fram en specifik modell för personcentrerad vård. För att omsätta denna modell i praktiken förespråkar centret att man utgår från tre rutiner. Den första rutinen handlar om patientens egen berättelse. Utifrån denna berättelse ska sedan vårdgivare och patient skapa ett partnerskap, som är den andra rutinen. Den tredje rutinen handlar om dokumentation. Både berättelse och partnerskap ska kontinuerligt dokumenteras i en vårdplan. Denna operationalisering ger upphov till en intressant spänning. För trots att centret är emot standardiserad vård så föreslår de samtidigt en sorts icke-standardiserad standardmodell för hur personcentrering bör göras.

Syftet med avhandlingen är att bidra till en bättre förståelse för de paradoxer och spänningar som kan uppstå när dessa olika perspektiv kombineras. Vilka utmaningar uppstår när man standardiserar att varje patient ska ses som en person?

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Hur förändrar en standardiserad modell av personcentrerad vård den klinisk praktiken? Hur hanterar hälso- och sjukvårdspersonalen de nya kravs som ställs på dem i och med denna standardiserade modell?

För att besvara dessa frågor har jag studerat olika former av skriftligt material och dokument så som forskningsprotokoll, vetenskapliga artiklar, bedömningsprotokoll och riktlinjer. Jag har också gjort intervjuer med forskare som jobbar på centret för personcentrerad vård. Slutligen så har jag observerat och intervjuat vårdpersonal som jobbar på vårdavdelningar där man infört denna modell för personcentrerad vård.

Avhandlingen består av en engelskspråkig introducerande och sammanfattande kappa, samt av fyra artiklar. I kappan presenterar jag mina teoretiska utgångspunkter och beskriver hur jag samlat in och analyserat mitt datamaterial. I denna svenska sammanfattning ger jag en översiktlig skildring av avhandlingens artiklar och slutsatser.

Artikel 1

I avhandlingens första artikel undersöker jag personcentrerad vårds materiella verklighet. Oftast så brukar man säga att personcentrerad vård är en sorts antites till teknologi, men i denna artikel så visar jag istället att teknologier och materialitet är en väsentlig del av personcentrerad vård. Utifrån en analys av intervjuer och observationer av vårdpersonal som jobbar på vårdavdelningar där man introducerat personcentrerad vård så gör jag fyra huvudsakliga poänger.

För det första visar jag hur ett enkelt standardiseringsverktyg i form av en bedömningsblankett är en viktig aktör i personcentrerad vård som förändrar de praktiker den introduceras i. Dessutom bidrar detta verktyg till att samtidigt både öka och minska variationen i vården. Blanketten bidrar å ena sidan till att patientens unika perspektiv tas i beaktande, men å andra sidan är också tanken att alla patienter skall ges *samma* fokus – det finns alltså en tanke om jämlik och samtidigt unik vård. På så sätt ombesörjer blanketten både styrningskrav och ett fokus på patienten.

För det andra visar artikeln hur tre värden är *inskrivna* i bedömningsblanketten: ett som handlar om patientens erfarenheter och perspektiv, ett som handlar om vetenskap och medicin och slutligen ett starkt styrningsimperativ. Till exempel så innehåller bedömningsblanketten en rad etablerade och evidensbaserade självskattningsskalor vilket tyder på betydelsen av medicinsk vetenskap. Samtidigt innehåller blanketten också en sorts övergripande normativ orientering som fäster mycket vikt på patientens egen erfarenhet och upplevelse. Dessutom syftar blanketten till att ligga till grund för en vårdplan i vilken man bland annat ska komma överens om ett utskrivningsdatum för patienten. Det här är en styrningsstrategi

som man använder sig av för att underlätta och förkorta utskrivningsprocessen vilket i förlängningen är tänk att reducera vårdkostnaderna.

För det tredje visar artikeln att dessa ibland motstridiga värderingar görs kompatibla genom vårdpersonalens ständiga pysslande och pusslande, vilket tar en mängd olika former. Ibland handlar det om att anpassa blanketten genom att till exempel skriva i marginalen för att skapa mer plats till patientens perspektiv och berättelse. Vid andra tillfällen handlar det om en sorts värdekonflikthantering där vårdpersonalen måste medla och översätta mellan de olika värderingarna.

Avslutningsvis så visar artikeln hur dessa tre värden återinskrivs i en ny version av bedömningsblanketten. Denna upprepning tyder på att dessa tre värden och de spänningar som finns mellan dem är betydelsefulla för personcentrerad vård i stort. Jag argumenterar för att de här värdena kommer någonstans ifrån och att de är en del av och representerar ett större sammanhang. Även om olika standardiseringsverktyg och blanketter kan skilja sig åt så tycks det finnas inskrivet i dem en gemensam tanke om att ta patientens perspektiv i beaktande samtidigt som de också syftar till att reducera vårdens kostnader. Därför är det viktigt att i högre utsträckning uppmärksamma hur viktigt vårdpersonalens pusslande är för att hantera de spänningar och konflikter som kan uppstå i personcentrerade praktiker.

Artikel 2

Den här artikeln analyserar en forskningsstudie i vilken man använder standardiserade metoder inspirerade av evidensbaserad medicin för att utvärdera personcentrerad vård som ofta sägs vara motsatsen till standardisering. Mer specifikt analyserar artikeln en randomiserad kontrollerad studie i vilken man försöker avgöra om införandet av personcentrerad vård hos patienter som vårdas för akut kranskärslsjukdom ökar patienternas tilltro till deras egen förmåga och fysiska aktivitet samt minskar deras sjukfrånvaro och dödlighet. Artikeln syftar till att öka förståelsen kring hur personcentrerad vård och evidensbaserad medicin kan kombineras och de spänningar som eventuellt uppstår. Artikeln bygger på analys av dokument och intervjuer med forskare som var med i den randomiserade kontrollerade studien.

Artikeln visar att det inte var helt enkelt att skapa evidens för och utvärdera resultatet av personcentrerad vård. Tvärtom så uppstod flera problem och utmaningar. Ett av dessa problem handlar om att forskarna hade svårt att veta exakt vad det var i den randomiserade kontrollerade studien som gav effekt. Fastän denna studie var ihopsatt som en riktigt randomiserad studie med en kontrollgrupp och en grupp som fick interventionen (i detta fall personcentrerad vård) så visade det sig vara svårt att urskilja exakt vad det var i den personcentrerade vården som gav effekt. Man visste helt enkelt inte om man fick effekt för att man

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strukturerat vårdvägen eller om det var för att patienten känner sig sedd eller om det var för att personalen trivs med arbetssättet. I en vanlig randomiserad kontrollerad studie kan man oftast härleda eventuell effekt till att patienten tillexempel ätit ett specifikt läkemedel.

Ytterligare en utmaning handlar om den spänning som uppstår mellan de krav som evidensbaserad medicin ställer på inkludering och exkludering i randomiserade kontrollerade studier och den ambition som finns i personcentrerad vård att se den unika personen bakom varje patient. Artikeln visar hur forskarna var tvungna att ställa upp väldigt strikta inklusions- och exklusionskriterier för att kunna genomföra den randomiserade kontrollerade studien. Forskarna bestämde tillexempel att man skulle utesluta patienter över 75 år, patienter som var för svårt sjuka, patienter med kognitiva eller mentala nedsättningar och patienter med missbruksproblematik. Å ena sidan ökade dessa kriterier studiens statistiska generaliserbarhet, men å andra sidan bidrog också kriterierna till att man fick göra avkall på en del personcentrerade principer bland annat genom att många patienter bedömdes som olämpliga för personcentrerad vård.

Artikeln sluter sig till att även om personcentrerad vård i grund och botten handlar om ett fokus på vård genom patientens berättelse och partnerskap, så finns det en risk att man medikaliserar vården när man genomför en randomiserad kontrollerad studie för personcentrerad vård. Detta sker genom att man standardiserar själva personen i personcentrerad vård för att öka möjligheten att producera evidens. Som ett alternativ föreslår artikeln att andra typer av metoder för att producera evidens för personcentrerad vård vore lämpligt. Istället för att göra fler randomiserade kontrollerade studier föreslår artikeln att man kan genomföra kvalitativa observationsstudier om hur personcentrerad vård fungerar i praktiken och vilka effekter det för med sig.

Artikel 3

Genom att använda begreppen artikuleringsarbete och osynligt arbete så undersöker denna artikel införandet och förverkligandet av personcentrerad vård i sjukhusmiljö. Genom att analysera observationsstudier från en sjukhusavdelning där man infört personcentrerad vård söker denna artikel att belysa det arbete som krävs för dess realisering och de spänningar som uppstår när man standardiserar en icke-standardiserad vårdmodell.

Artikeln börjar med att beskriva hur man valt att realisera personcentrerad vård på vårdavdelningen. Med utgångspunkt i modellen för personcentrerad vård så har man på avdelningen bestämt att processen börjar med att sjuksköterskorna ska använda sig av en specifik bedömningsblankett (som beskrivs i artikel 1) när de gör ankomstintervjuer med patienter. Detta för att inhämta patientens narrativ. För det andra så ska man etablera ett partnerskap och dokumentera detta i en

specifik vårdplan. För det tredje så har man bestämt att dokumentationen av detta i patientjournalen ska formuleras med patientens egna ord. Denna operationalisering ger upphov till en spänning eftersom man skapat formaliserade rutiner och klassifikationer för att säkra införandet av personcentrerad vård. Således omvandlas personcentrerad vård från en abstrakt modell till en uppsättning instruktioner som vårdpersonalen måste följa. Även om detta bidrar till att främja personcentring så kan det också leda till att vårdpersonalens arbete granskas och kontrolleras hårdare. Dessutom riskerar aktiviteter som inte är inkluderade i rutinerna, men som skulle kunna betraktas som personcentrerade, att bli osynliggjorda.

Artikeln visar vidare att artikuleringsarbete och osynligt arbete är helt vitalt för att man ska kunna förverkliga personcentrerad vård. Med artikuleringsarbete avses koordinering av olika uppgifter samt det arbete som krävs för att få saker på banan igen när något oförutsett sker. Vårdpersonalen måste till exempel koordinera ofullständig och motstridig information. Ibland kanske läkaren säger en sak men patienten en annan vilket ger upphov till behov av koordinering när sjuksköterskan ska dokumentera i journalen. Ytterligare ett problem är att sjuksköterskorna fått väldigt lite utbildning och träning i att till exempel intervjua patienter på ett sådant sätt att deras egen berättelse kan inhämtas.

Tidigare forskning har hävdad att framgångsrik implementering av personcentrerad vård är beroende av att vårdpersonalen är villiga att ändra sina tankemönster och gamla vanor. Denna artikel menar istället att introduktionen av personcentrerad vård är avhängig en massa osynligt och kreativt arbete som vårdpersonalen gör för att lösa problem de stöter på. Även om det kan verka lockande att synliggöra sådant osynligt arbete genom att inkludera det i instruktionerna för personcentrerad vård så argumenterar denna artikel för att inte göra det. Även om man behöver erkänna de problem som kan uppstå vid införandet av personcentrerad vård så bör instruktionerna hållas så enkla som möjligt eftersom strikta rutiner inte bara synliggör utan också tenderar att bidra till ökad kontroll.

Artikel 4

Den fjärde och sista artikeln i denna avhandling har jag skrivit tillsammans med mina kollegor Öncel Naldemirci, Nicky Britten, Mark Elam, Lucy Moore och Axel Wolf. Personcentrerad vård växte fram som en sorts kritik mot biomedicin och dess anspråk på att den typ av kunskap som skapades där var neutral och universell. Med personcentrerad vård försöker man ersätta biomedicinens antihumanistiska processer med holistisk vård. Med denna artikel vill vi undersöka om det kan vara så att nya vårdmodeller, som personcentrerad vård, riskerar att ersätta de problematiska antaganden som finns inom biomedicin med liknande antaganden.

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Artikeln börjar med en historisk översikt av personcentrerad vård i vilken vi påvisar att man kan utläsa några grundläggande antaganden om vilken slags person man föreställer sig som lämplig för personcentrerad vård. Dessa antaganden handlar om personen som en resonerande individ som är kapabel att uttrycka sig verbalt. Vi visar också att dessa antaganden även går att skönja i den specifika version av personcentrerad vård som man har utvecklat vid forskningscentret i Göteborg. Vi menar att de tre rutinerna för upptagande av narrativ, etablerande av partnerskap och dokumentation förutsätter en person som *både är kapabel till att resonera och uttrycka sig verbalt, en person som både vill och kan uttrycka sig tydligt och uppriktigt samt att denna person vill och kan samarbeta med vårdpersonal.*

Vi introducerar sedan de tre forskningsprojekt som är verksamma vid forskningscentret i Göteborg och som vi har analyserat. Dessa projekt handlar om personcentrerad vård för att främja hälsan hos äldre personer födda utomlands, om personcentrerad vård för personer med kommunikationshinder och om personcentrerad vård för personer med psykos. Dessa projekt valdes för analys eftersom intervjuer med forskare i projekten visade på intressanta spänningar och utmaningar i relation till de antaganden och förutsättningar som den standardiserade modellen av personcentrerad vård innehåller. I projekten för kommunikationshinder och för hälsofrämjande sätts antagandet om personens förmåga att verbalt kommunicera sitt narrativ på spel. I dessa projekt har forskarna därför behövt anpassa och bredda dels vad man menar med narrativ och dels hur ett narrativ kan upptas. För att kunna kommunicera ett narrativ krävs i dessa projekt ofta att man använder sig av en tredje part, antingen en tolk eller närstående. Man använder sig också av noggranna observationer av patienternas kroppsspråk och bistår dem med olika former av hjälpmedel genom vilka de kan uttrycka sig på andra sätt än genom det talade ordet. På detta sätt breddas definitionen av vad ett patientnarrativ är. Från att ha setts som patientens unika vittnesmål så ser man istället narrativet som något som skapas i samspelet mellan patient, vårdgivare, anhöriga och symboliska samt materiella hjälpmedel.

Patientberättelsens trovärdighet blir i flera av dessa projekt också föremål för en rad spänningar. Framförallt i projektet om personcentrerad psykosvård är detta en angelägenhet. Personer som har en psykos är inte alltid medvetna om sin psykos och har ibland svårt att kommunicera sin berättelse. Det kan också vara svårt för vårdpersonal att avgöra om det patienten berättar är ”sant” eller om det är en vanföreställning. Vi visar hur forskare i detta projekt därför förespråkar att man ändrar ordningen på de olika rutinerna i den personcentrerade modellen och börjar med samarbete och medicinsk behandling innan man inhämtar patientens narrativ. En annan utmaning handlar om spänningen mellan personen som en unik individ och personen som en del av en större grupp. Detta är särskilt tydligt i projektet för hälsofrämjande där man jobbar med grupper. Vi visar hur man i

detta projekt breddar definitionen av vad en person är, från att definieras som del av relationen mellan patient och vårdgivare till att definieras som en del av större socialt sammanhang.

Vi konkluderar också att den standardiserade modellen för personcentrerad vård utvecklades i ett speciellt vårdsammanhang och att den därför innehåller en rad antaganden som återspeglar detta sammanhang. Därför blir det problematiskt att oreflekterat införa denna modell till andra typer av vårdsammanhang med andra typer av förutsättningar och patienter med andra former av problem. Reflektion, nyansering och lyhörddhet inför den specifika kontexten är därför av yttersta vikt när man utvecklar personcentrerade modeller och riktlinjer.

Slutsatser

Ett huvudsakligt tema för denna avhandling är relationen mellan personcentrerad vård och standardiserad vård. Den förre anses ofta vara den senares motsats då den erbjuder anpassad sjukvård som lovar att se personen bakom patienten snarare än en sorts sjukvård på löpande band där alla patienter serveras en färdigpaketerad lösning. Min forskning visar dock att relationen mellan personcentrering och standardisering är mer komplex då det fall jag studerar tycks ha ambitionen att utveckla en sorts icke-standardiserad paketlösning, en sorts färdigpaketerad modell av personcentrerad vård.

En utmaning som uppstår när man standardiserar att varje patient ska ses som en person är vilken person det egentligen är man förutsätter. Även om det vid första anblick kan ses som mycket inkluderande och sympatiskt att se personen bakom patienten, att lyssna på dess berättelse och att skapa ett partnerskap så bör man komma ihåg att detta förhållningssätt förutsätter en väldigt specifikt typ av patient som förutsätts ha en rad fördefinierade förmågor.

Den standardiserade modellen förändrar klinisk praktik på en rad olika sätt. En praktisk sak som förändras är hur sjuksköterskor genomför ankomstintervjuer med patienter då både det övergripande temat för intervjun och de frågor som ställs förändras. Detta innebär att nya krav ställs på sjuksköterskorna då de förväntas kunna få fram patientens berättelse – en svår uppgift som de får väldigt lite träning i. Modellen förändrar även sjuksköterskornas dokumentationspraktik då de förväntas dokumentera narrativet, beslut som har fattats och partnerskapet på ett sätt som är begripligt för patienten. I och med modellen så förvandlas personcentrerad vård från något abstrakt till en uppsättning instruktioner som ska följas. Detta leder å ena sidan till att personcentrerad vård synliggörs vilket kan innebära att man kan sprida det lättare, men det kan å andra sidan också innebära ökad kontroll av vårdpersonalens personcentrerade arbete. Dessutom riskerar aktiviteter och uppgifter som inte är inkluderade i instruktionerna att osynliggöras.

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För att få den standardiserade modellen att fungera och för att hantera de spänningar som uppstår, så krävs mycket arbete av vårdpersonalen. Detta arbete kan handla om att hantera konflikter mellan olika värderingar, om att göra kreativa anpassningar av modellens verktyg eller om att koordinera olika typer av information och uppgifter.

Min studie visar att personcentrerad vård är avhängigt en massa ofta osynligt och sällan uppskattat arbete. Jag menar att en bidragande orsak till detta är att den modell för personcentrerad vård jag undersökt i denna avhandling utvecklats för långt ifrån praktiken. En lösning skulle således kunna vara att utveckla arbetssätt som utgår mer från de sammanhang vari de ska tillämpas. På detta sätt skulle modellerna komma inifrån praktikerna snarare än att åläggas dem utifrån. Genom att utgå från etnografiska studier på vårdavdelningar där forskaren först undersöker och observerar verksamheten och sedan i samråd med personalen på ett lekfullt sätt kan utveckla och testa olika arbetssätt så anser jag att man skulle kunna kringgå flera av de problem som nu uppstår.

Appendix A

Interview-guide used in interviews with researchers

Thank you to participant. Any questions about study? Go through info sheet.
Gain verbal consent. Check tape-recorder

Introductory questions: ‘your project’

I am interested in your experiences with person-centred care in your project

- Would you like to give me a brief description of your project?

Person-centred care

- How would you explain what person-centred care is, to someone who had never heard of it?

Prompt: How would you describe or define PCC? Components? Some people say ‘centring on the person or personhood?’

- How do you think it is different from ‘usual care’?

Prompt: Would you tell me about a significant change in your practice since you started to focus more on person-centred care/centring on the personhood?

[As you know there are also debates around “patient-centred care”. Would you have any comments on this perspective? Do you see any continuities with or differences from PCC?]

- Would you like to tell me about your experiences?

Prompt: what PCC looks like in your project, the intervention, how it is delivered? Staff involved? Patient’s experiences? How do they [patients] affect your work/the ways you work?

- What kinds of strategies do you use?

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Prompt: Ways of working? Routines? Documentation? Any changes-adaptions?
Examples of strategies

- Could you tell me about a routine work day with PCC?

Additional questions for PCC

- What kinds of conditions do you think are required for PCC?

Prompt: what needs to be created, some say training, communication, what fits?

- Tell me about a particular example of effective PCC in your project?
- What kinds of things do you think help PCC? Would you like to give an example?
- What kinds of things make PCC difficult? Do you remember a particular situation or incidence?
- What are your thoughts on patient-centred research?

Prompt: Methods? Measuring PCC? Data collection? Patient participation? Differences from PCC? Similarities/continuities?

- Is there anything else you would like to add?

Additional Prompts for all questions as appropriate: I am interested in what you said about.....tell me more about...What do you mean by that?

Thank you to the participant...check if still happy to use interview recording

Appendix B

Interview-guide used in interviews with healthcare professionals

Thank you to participant. Any questions about study? Go through info sheet.
Gain verbal consent. Check tape-recorder

I am interested in your experiences of working with person-centred care.

- To start with, could you tell me a bit about this ward/clinic/centre?

Prompt: Size? Practical work? Team?

- How did you start working with PCC?

Prompt: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special education/training?

- How did you implement PCC in this ward/clinic/centre? What did the implementation look like?
- Could you tell me about a regular day at work with PCC?
- Would you like to tell me about your experiences? Tell me about your practice and experiences with PCC on this ward/clinic/centre?
- How would you describe PCC to someone who is coming to work with you on your ward/center?

Prompt: How would you describe or define PCC?

- How did patients react to PCC?
- Would you tell me about any changes to your practice since you started working with PCC?

Prompt: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?

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- What kind of documentation do you use when you work with PCC? Do you use any tools, diaries, notebooks, written material as part of PCC during your day? Can you describe this for me? How do you use this documentation for PCC in your work?
- What kinds of conditions do you think are required for PCC?
- What kinds of things do you think helped PCC and what kinds of things made PCC difficult in your experience?
- Is there anything else you would like to add?

Additional Prompts for all questions as appropriate: I am interested in what you said about.....tell me more about...What do you mean by that?

Thank you to the participant...check if still happy to use interview recording

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Person-centred care seeks to improve healthcare by recognizing the individual patient's unique experience, values and preferences, and acknowledging the patient as a responsible partner in the development and evaluation of their own care. Standardization and evidence-based medicine, on the other hand, seek to improve healthcare by insuring that medical decision-making is not dependent on the subjective opinions of doctors but is instead based on scientific knowledge and research. This thesis examines a collection of cases and situations where efforts are being made to combine and unify the concerns of person-centred care, standardization and evidence-based medicine. Drawing on interviews, observational studies and written materials this thesis investigates the paradoxes and tensions emerging as person-centred care is introduced as standard healthcare, and the actions taken by healthcare professionals to secure this healthcare reform in practice.

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