Development and testing of an observation-based method to assess person-centeredness in healthcare

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To Sonja and Jonas

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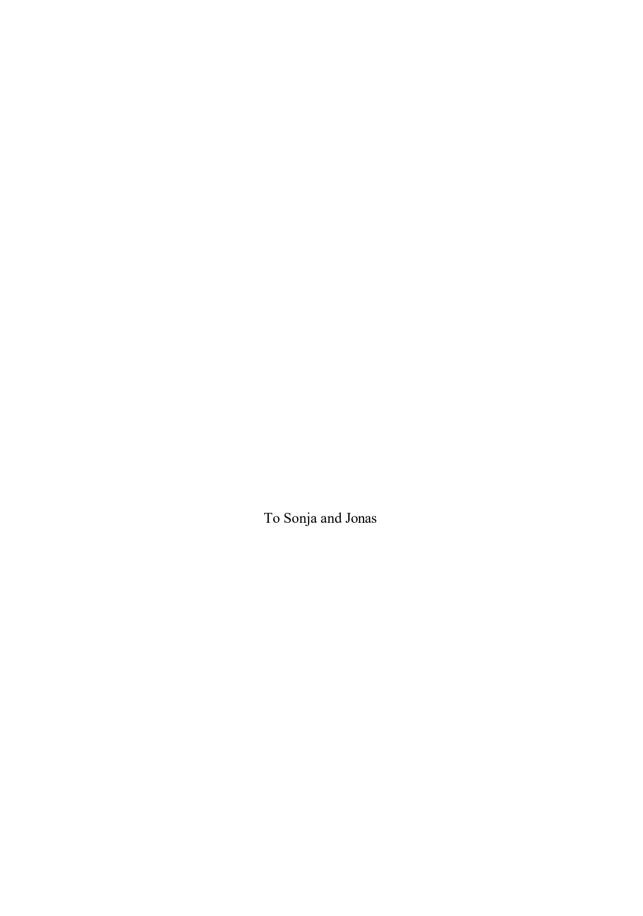
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ABSTRACT

Person-centred care (PCC) has been designated and endorsed as a core competency needed for health care professionals (HCP) to meet the evolving challenges facing health care. The aim of this thesis was to develop and test an observation-based method for assessing clinician competency in the delivery of PCC.

Study I reviewed existing PCC direct observation tools (DOT). Few of the identified 16 tools specified their conceptual base, assessed PCC holistically, were rigorously tested for reliability and validity, and none involved patients in their development.

Study II aimed to identify observable indictors of PCC through interviews with 12 patients, relatives and HCPs with experience of PCC for potential inclusion in a new DOT. Deductive content analysis was performed based on the Gothenburg Centre for Person-centred Care (GPCC) PCC framework (gPCC). Patients´ first impressions were considered to impact the content, course and outcomes of the interaction and nonverbal behaviours were seen to play a major role in shaping patients' impressions of HCPs.

Study III explored the content and usability of a preliminary DOT assessing PCC competency in four main areas, subdivided in 13 domains and each illustrated by one or more behavioral indicators. Content and usability of the tool were explored using think aloud and probing techniques in 11 patients and HCPs. In general, the participants judged the tool to be easy to use and to satisfactorily cover major PCC activities outlined in the gPCC.

Study IV evaluated the inter-rater reliability of a revised version of the DOT. Six HCPs with no training in using the DOT each rated 10 video recorded patient-HCP interactions. Intraclass correlations were fair to excellent range for 13 of the 15 domains.

In conclusion, the tool appears promising for formative use in guiding and structuring observation-based assessments and providing feedback to trainees; however, further evaluations are required to support high-stakes usage.

SAMMANFATTNING PÅ SVENSKA

Personcentrerad vård (PCV) har bedömts vara en nödvändig kärnkompetens för att möta de växande utmaningar hälso-och sjukvården står inför. Syftet med denna avhandling var att utveckla och testa en observationsbaserad metod för bedömning av personalens kompetens i att ge PCV.

I studie l genomfördes en litteraturgranskning av befintliga instrument för direkt observation av PCV. Få av de 16 identifierade instrumenten beskrev den konceptuella basen för PCV eller hade testats för tillförlitlighet och validitet och ingen hade involverat patienter i utvecklingen.

I studie ll identifierades observerbara indikatorer för PCV för potentiell inkludering i ett nytt observationsbaserat instrument, genom att intervjua 12 patienter, närstående och hälso- och sjukvårdspersonal med erfarenhet av att få eller ge PCV. Deduktiv innehållsanalys utfördes baserat på det PCV- ramverk (gPCC) Göteborgs Centrum för Personcentrerad Vård (GPCC) utvecklat. Patienternas första intryck av personalen påverkade innehåll, förlopp och resultat av interaktionen och icke-verbala beteenden ansågs här vara av avsevärd betydelse.

I studie III undersöktes innehållet och användbarheten av ett preliminärt observationsbaserat instrument för bedömning av PCV inom fyra huvudområden, uppdelade i 13 domäner vilka illustrerades av en eller flera beteendeindikatorer. Innehållet och användbarheten av verktyget undersöktes med hjälp av "think aloud" (tänk högt) med uppföljande intervjuer hos 11 patienter och personal. I allmänhet bedömde deltagarna att verktyget var lätt att använda och att det på ett tillfredsställande sätt täckte personcentrerade handlingar som beskrivs i gPCC.

I studie IV utvärderades interbedömartillförlitligheten hos en reviderad version av det observationsbaserade instrumentet. Sex hälso- och sjukvårdspersonal utan utbildning i att använda instrumentet klassificerade var och en 10 videoinspelade interaktioner mellan patient och personal. Intraklasskorrelationerna var rimliga till utmärkta för 13 av de 15 domänerna.

Sammanfattningsvis tycks verktyget vara lovande för formativ användning och för att strukturera observationsbaserade bedömningar och ge feedback till hälso- och sjukvårdspersonal även om det krävs ytterligare utvärderingar för en regelbunden och landsomfattande observationsbaserad bedömning av praktisk PCV.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I.   Ekman N, Taft C, Moons P, Mäkitalo Å, Boström E. Fors A. A state-of-the-art review of direct observation tools for assessing competency in person-centred care. *Int J Nurs Stud*.2020Sep;109:103634. doi:10.1016/j.ijnurstu.2020.103634.

II.   Ekman N, Moons P, Taft C, Boström E, Fors A. Observable indicators of person-centred care: an interview study with patients, relatives and professionals. *BMJ Open* 2022;0:e059308. doi:10.1

III.   Ekman N, Fors A, Moons P, Boström E, Taft C. A new direct observation tool for assessing person-centeredness: Evaluation of content and usability using think aloud and probing techniques *(manuscript)*.

IV.   Ekman N, Fors A, Moons P, Taft C. A new direct observation tool for assessing person-centred care: Evaluation of inter-rater reliability *(manuscript)*.

CONTENT

ABBREVIATIONS

GPCC   Gothenburg Centre for Person-Centred Care

HCP   Health Care Professional

MRC   Medical Research Council

RN   Registered nurse

Gpcc   Gothenburg Centre for Person-Centred Care framework

WHO   World Health Organisation

PCC   Person-Centred Care

1 INTRODUCTION

Healthcare systems today are organized according to the customs and procedures of healthcare professionals, rather than to meet the individual patient's needs, preferences, and values (1, 2). On the other hand, person-centred care (PCC) takes its point of departure from the perspective of the patient as a human being - a person, and not the disease or pathological process in the patient alone (3-5). Advances in medical science during the last century have led to extraordinary achievements in the cure and treatment of many diseases, which in turn have translated to increased population life expectancy (6). These successes have been accompanied by a shift in the focus of health care from caring for to curing the patient, where the patient has been relegated a role as a passive recipient of care instead of an active and responsible partner (7-9). PCC engages the patient as an active partner in care in which the person´s own experience is equally important to that of the medical professional (10).

1.1 PATIENT-CENTRED CARE

The concept of 'patient-centered medicine' was introduced into the medical literature by Michael Balint in the 1950s (7). He stressed the importance of the doctor-patient relationship and of patients´ preferences in contrast to the prevailing diagnosis-centered medicine, as a means to attend to the patient as a unique person (7). In a review of the literature on patient-centred care, Mead (11) identified 4 major areas of patient-centred care: 1) broadening the focus from the purely biological to the psychological and social levels 2) understanding the patient´s experience of illness 3) sharing power and responsibility 4) the therapeutic alliance between the patient and the caregiver. The value of relationship has however been incompletely developed in patient-centered care, which effectively centers attention on the patient (12). The implementation of the patient-centered care model has therefore not radically expanded the focus of the clinician-patient consultation from the biological basis of disease to include the patient as a person.

1.2   PERSON-CENTRED CARE

The conceptual transformation of patient- to person-centered care is based in ethics where the change of words from patient to person refocuses the attention of the clinician from the patient with a disease to the person with an illness (4, 10, 12). This change also helps to redirect clinical focus toward a respect for and inclusion of the patient's social life and relationships with others. In a synthesis of reviews of patient-centred and person-centred studies, Håkansson Eklund and co-workers argue that the goal of person-centered care is a meaningful life while the goal of patient-centered care is a functional life (13). A meaningful life means that patients´ subjectivity, strengths, future plans and rights must also be taken into account, not only their disease (4, 10).

Already in the 1950s, the psychologist Carl Rogers argued that patients should be seen and approached as persons with capacities and potential to growth and self-actualization (14, 15). He proposed that professionals should try to build relationships with their patients with such qualities that patients feel supported and free to express themselves (15). This person-centred approach in care and treatment has since then been increasingly advocated. For example, in the US the Institute of Medicine Committee on Quality of Health Care in America has identified PCC as one of five core competencies that clinicians must develop to deliver quality health care in the 21st century (1). Also in Europe, particularly in England, PCC has been strongly advocated by, for example, the Health Foundation (16). And, importantly, national and international patient organisations, such as the European Patient Forum, have for two decades argued for PCC (17-19). In Sweden, professional organisations such as the Swedish Association of Health Professionals, the Swedish Medical association and the Swedish Association of Occupational Therapists argue for more

person-centeredness in health care (2, 20, 21). Moreover, the Health and Medical Services Act (HMSA), the Social Services Act and recommendations from the Swedish Board of Health and Welfare all stress the importance of applying PCC to improve the quality of health care (22, 23). For example, the HMSA stipulates that PCC is one of five key components of good health care and underscores that *care and treatment should be conducted in collaboration with the patient* (22). Congruent with the collaborative central ingredient in PCC, Coulter, in a Cochrane review, defines PCC planning as: *an anticipatory (forward-looking), negotiated discussion or series of discussions between a patient and a health professional (perhaps with other professional or family members present) to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding* (24).

No clear consensus regarding definitions or conceptualizations of PCC exists today, but there is general agreement that care is conceived as a collaborative process between patients and health professionals. Health problems and needs are thereby defined by the clinician and patient together, who jointly make care plans with goals and implementation activities, which are followed up by both parties (25). Abundant research has shown that mutual care-planning is a central activity in PCC (25). Nonetheless, PCC is a complex and multidimensional concept which cannot be delimited to only a care plan. Wolf and co-workers interviewed patients and health professionals about how partnership was perceived in everyday PCC practice and found that patients appeared to value a process of human connectedness above and beyond formalised aspects of documenting agreed goals and care planning (26). The authors concluded however that PCC seemed to increase patients' trust in professionals as competent and able to make them feel safe and secure (26).

PCC has been of particular interest in geriatric care (3, 27-29). In care of people with dementia, the psychiatrist Tom Kitwood was the first to use the concept of PCC while McCormack and Edvardsson highlighted and developed PCC in geriatric nursing (30). During the last ten years many studies evaluating PCC have also been conducted in other settings, such as acute care, primary care and community care (31-34). In addition, several controlled studies on integrated and remote PCC have been conducted over the last five years, which is completely in line with the redesign in Swedish healthcare from hospital care to integrated PCC (35-37).

1.3 PCC FRAMEWORKS

As PCC has become more common in healthcare policy and discourse, frameworks have been developed to support operationalization into practice. McCormack & McCance highlight relationships, values, caring processes and the context of care as important concepts in PCC (10). Person-centeredness in the rehabilitation process and daily life activities is emphasized in the framework by Leplege (2007), which describes four pathways: 1) the person's specific and holistic properties 2) the person's difficulties in everyday life 3) regarding the person as an expert who should participate actively in their rehabilitation 4) respecting the person "behind" the impairment or disease (38). A framework of particular significance in PCC is *The capability approach to support person-centered care* by Vikki A Entwistle (5), inspired by, among others, Amartya Sen and Martha Nussbaum´s work (39, 40). One of the valuable contributions of Entwistle is that she clarifies how PCC can be misinterpreted by health professionals to mean that patients should make their own choices about treatment options which can make patients feel distressed (5). This might in part be linked to health professionals' wishes to respect patients' autonomy and thereby make it possible for them to decide about care and treatment. It fails to reflect the complexity of illness and how patients´ options and values are shaped by, for example, relationships and it can therefore lead to neglecting both family members' and health professionals' need to support patients´ autonomy and enable them to engage in their care. Capabilities are shaped in relationships and by interactions between people and their environments. The capability approach encourages a focus on making patients´ aware that they are free and able to be and do what they value being and doing (5).

1.3.1 THE GPCC FRAMEWORK

Endeavoring to advance and facilitate PCC implementation in healthcare, a group of multidisciplinary researchers at the University of Gothenburg Centre for Person-Centred Care (GPCC) proposed a PCC framework for implementing PCC in daily practice comprising an overall theme of partnership embodied in three core routines (i) initiating the partnership by listening to the patients' narratives, (ii) working the partnership by a mutually formulating health plans, and (iii) safeguarding the partnership by documenting the health plan and making it accessible to both parties (4). However, these important tasks will not create PCC unless the culture is thoroughly changed. Such changes should include the staffs´ prerequisites (e.g. clarity of beliefs and values)**;** the care environment (e.g. organisational systems that are supportive of sharing of power*);* person-centred processes (e.g. engagement); and outcomes **(**satisfaction with care; involvement in care**)** (41).

The framework has been evaluated in different conditions and contexts and has been shown to be associated with increased job satisfaction among health professionals (42), improved patient self-efficacy (43), cost-effectiveness compared with usual care (44) and shortened hospital stays (45). The gPCC framework has been adopted throughout Sweden in hospitals as well as primary care centres (46).

The framework has also recently been evaluated in a real-world settings with the aim to describe core practices during an implementation process of PCC in health care. The researchers found a variety of approaches to implementing PCC (47, 48). In some cases, healthcare professionals were encouraged to practice PCC without having received specific instructions or examples of how this could be achieved (47). In other settings, PCC was recommended to be

implemented by applying fixed routines and specific practices. The authors conclude that understanding and knowledge of PCC and its philosophical principles, and of influencing contextual factors and structural elements are necessary to build a common understanding of PCC (47).

1.3.2   THE BASE IN ETHICS

The gPCC framework has its point of departure in the Aristotelian ethics formulated by, in particular, the French philosopher Paul Ricoeur as *Aiming at the good life with and for others in just institutions* (49). The meaning of the good life is a "flourishing" life that is characterized by meaningfulness and harmony, which means different things for different people but can be noted or neglected, strengthened or diminished by fellow human beings. Particularly in situations characterized by asymmetric relationships, as in healthcare, awareness of the relationship between patients and professionals and how it is expressed and acted in different situations is of vital importance. But to safeguard against arbitrary care actions, Kantian morality must be included and is at once subordinate and complementary to Aristotelian ethics because the ethical goal needs to be critically assessed and passed through the examination of obligations, norms and sanctions (45, 49).

Professional knowledge implies more power and thus more responsibility, which should be balanced against the patient´s right to autonomy and integrity. When the starting point is ethics and each person is understood as unique, care actions must be tailored to each patient even if medical treatment is the same for patients with the same diagnosis. A crucial element in the gPCC framework is therefore the relationship between the patient, relatives and the professional, but also between professionals. The relationship involves a responsibility of the professional to be responsive to what patients´ communicate in words or by their actions. This relationship creates a base for a partnership that encourages the patients to actively take part in their own care and to find health strategies and solutions together with health-professionals (4, 10, 49, 50).

A person-centred approach means not only identifying health barriers but also confirming human and contextual capabilities and opportunities. People develop their capabilities in relation to other people, such as a sense of responsibility for oneself and others (5, 39, 49).

1.3.3   PARTNERSHIP

The gPCC framework defines human value as a relational concept. That is, in order to understand and trust that one has a value as a human, one must be confirmed and recognized by another human being. A partnership should therefore be about mutual respect. Health professionals need to acknowledge that patients know how their lives is affected by the illness and how it affects their present situation or everyday life (26). The concept of partnership has long been considered fundamental in nursing and in other healthcare professions (7, 15, 51). Healthcare professionals have the generic knowledge about the care and treatment of a particular condition or disease and both the patient's and the professional's thoughts and ideas should be taken equally into account. This mutual respect and partnership between experts can only happen if there exists a person-centred culture in which patients are truly listened to and health professionals are able to apply the ethics of person-centredness and work in a person-centred way (26, 52).

According to Slater and McCormick, partnership is a *practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding (53)*.

Ricoeur describes a dialectic that includes proximity and distance to human beings, which is also relevant to the relationship between the health professional and the patient but also to oneself as a person (54). In order to understand another person, in this case a patient, one must first and foremost listen to him/her. If listening works properly, the patient feels acknowledged and respected. Professionals must therefore be able to truly listen to and

understand the patient. Such an understanding approach means receiving the patient as a person, as someone who is different with specific health problems or illnesses, but also in many ways like oneself. Having such a perspective on understanding is about trying to sense, identify the vulnerability in yourself and the patient. Human vulnerability is to be capable of being strongly affected by the suffering of other people. It may sometimes be painful for health professionals when the suffering of patients is hard to relieve, it may be because of lack of time to devote for each patient as needed. It could even mean attempts to "shut down" vulnerability. But vulnerability constitutes human beings and is a human capability. Translated to care it means to be deeply touched by patients´ suffering (49, 54-57).

1.3.4　NARRATIVE

The gPCC framework uses stories and narratives to reach and influence one another (58). Narratives are the road toward telling and, therefore, knowing the self.

According to Paul Ricoeur's ethics, the person is both capable and vulnerable and our personal identities are formed in relationships between people and mediated via groups of people (institutions). Also, our narrative identity is of importance because it helps us create cohesion in our lives. Making the ethics of Ricoeur the base for PCC reinforces healthcare professionals to focus patients´ narratives and together with the patient identify what is important to her/him in daily life. In addition, by acknowledging patients and professionals as both vulnerable and capable, it signals the interrelationship and interdependency between healthcare professionals, patients, and their families. The narrative allows health care professionals to see the person beyond the patient role, to actively listen and thereby identify, together with the patient, needs, resources and capabilities (59). This results in a mutual understanding and agreement and can be manifested concretely by a personal health plan that is formulated together. It requires a lot of confidence and trust from the patients to share their narratives. It is about trust in the capable person, patient, who is both acting, responsible and suffering (57, 60). Vulnerability and suffering opens oneself to the outside world; it creates energy with others and develops the self. Vulnerability is not a weakness that makes us susceptible to the suffering of other people (54, 57, 60). Instead, vulnerability is an capability that allows us to take in other people, it creates responsibility, choices, but requires reflection (54, 60). Ricoeur believes that one understands oneself through others, that one's life and actions are intertwined with other people's

lives and actions. This can be achieved if healthcare professionals cease to see patients as an anonymous mass with the same needs as all other patients with the same diagnosis. The patient role is reversible (interchangeable) but the person is unique, and this uniqueness is made evident in the narratives (61).

Health professionals often dominate meetings with their patients. This may result from difficulties in sharing responsibility with the patient and in acknowledging that the patient is capable of taking this responsibility (39, 54, 55). Today, healthcare is organized around <u>what</u> the patient is, not <u>who</u> the patient is. The link from what to who is important and the narratives enable us to understand who we care for.

1.3.5   SAFEGUARDING THE PARTNERSHIP

In the gPCC framework safeguarding the partnership is conceived as remembering promises to fulfill professional ethical commitments to patients and to ensure that agreements with patients are respected and upheld (62). The promise to aim for health and the good life with and for patients in just institutions needs to be remembered over and over in daily care routines and practices. In order to create and maintain as just and fair organizations as possible we need routines. One way of trying to safeguard the partnership is to formulate a health plan together and document it in the patient record. This document should be available to both parties, and both should also have access to review and revise the plan throughout the entire care process (4).

1.4   EVALUATING PCC

As PCC is relational and based in an ethics that aims for the good life - health, in partnership with patients, we therefore need to evaluate if the care is respectful and based in partnership. Are the culture and practices in the setting person-centered? PCC needs to be evaluated both in clinical practice and in research to help in transforming and safeguarding a process towards PCC (63).

PCC assessment is challenged by a number of factors. Perhaps the foremost challenge is the lack of agreement in the field about what PCC in fact is and how it should be operationalized. As the literature in the area is replete with different definitions (64), conceptual frameworks (11, 50, 65, 66) and nomenclature (13) of this complex, multidimensional construct, it is little wonder assessment instruments purporting to measure PCC are often poorly correlated (67, 68).

To date, PCC has been evaluated in several controlled studies using, for example, uncertainty (69), self-efficacy (70) or health-related quality of life (71) as outcome variables. Evaluation strategies have included the use of both qualitative methods, using individual or group interviews are generally applied to gain insight into the experiences of persons receiving care (63), and quantitative methods using standardized questionnaires (69). A European standard of PCC was recently developed to describe minimal patient involvement in PCC, but it has not yet been used in evaluation projects of PCC in practical care or in research (72). Noteworthy is that all these methods appraise outcomes of PCC. However, the process of care activities in PCC, in

other words the way care is provided and to what extent the principles of PCC are applied in clinical practice are not assessed with these methods (70, 71).

Common methods for assessing competence in interpersonal interactions between health care professionals and patients are patient surveys and direct observations. Although patient surveys are less expensive and easier to administer than observation methods, they tend to yield highly skewed results and may therefore be of little help in either formative or summative applications (73). Moreover, patient surveys may be seen to assess outcomes of the interaction rather than the actual process. Although direct observation methods are more expensive and time consuming, they provide a direct window for assessing many facets of ongoing patient-clinician interactions (74).

1.5 OBSERVATION BASED METHODS

Most existing observation-based methods have mainly been developed and used to evaluate physician-patient verbal communication and often have not been designed to assess PCC holistically but rather assess specific dimensions of this multidimensional construct, for example, shared decision making (74, 75). Although guidelines exist in health professional education to help improve the quality of patient-professional interactions, they provide little guidance for preparing healthcare professionals to manage the very difficult work of cultural change (76). The use of direct observation methods has been shown to be effective and valuable for providing feedback to trainees to improve performance, which in turn may also influence the cultures and organizations in which they work and train in (76). High-quality direct observation tools could help raise the quality of the health care professionals' skills (76-78). The value of using this type of tool depends on a careful examination of the psychometric properties and their ability to produce reliable and valid measurements (79).

Observation as a method can be practiced in several different ways. One is real time observation, where an observer observes and evaluates a real or simulated patient-health professional interaction using checklists, rating scales, coding systems or overall assessments (11). This may have the advantage of seeing all angles in the room at the same time, but checklists may fail to cover some important aspects of the phenomenon of interest, for example, body language or other expressions not contained in the checklist (80).

Checklists generally consist of items describing readily observable behaviours that require little interpretation or knowledge of the construct purported to be

assessed. On the other hand, checklists may be too specific, which affect their ability to adequately cover the construct. Observer ratings are generally made using dichotomous yes/no format, with ratings indicating whether or not a targeted behaviour was performed. An example of a commonly used checklist is the CARES observational tool (81). Rating scales also consist of items, but generally require the evaluator to assess the degree to which a behaviour was performed on some form of response scale. An example of a widely used rating scale is the OPTION (82). On the other hand, coding systems are often complex and assessments often involve a high level of interpretation and hence observers require considerable training in order to use them. The modified version of RIAS (ARCS) (83) is one example of a coding system.

The second method is static, observing and evaluating a recorded material, such as video recordings of patient- health professional interactions. This version of observation can be repeated several times and thus be evaluated in a different way. Here the weak point is where the camera is fixed, meaning that it will capture only what occurs within its viewing angle (80, 84).

2 RATIONALE OF THE THESIS

PCC has been endorsed by professional and patient organisations and other stakeholders (1, 16-19, 22) as a competency needed to meet the challenges facing today's healthcare systems. Such endorsements, together with research showing positive results both concerning patient satisfaction with care and cost efficiency (43-45), have raised interest for implementing PCC in most regions in Sweden (22). Such an implementation process demands repeated evaluations to monitor progress. A commonly used strategy for assessing healthcare professionals' competence in the delivery of PCC is the use of direct observation of clinicians' behaviours as they perform patient care and clinical activities. This method has the advantage of being a window for assessing many aspects of ongoing patient–clinician interactions. However, the available direct observation tools for assessing PCC often lack a clearly defined conceptual framework.

Given the multitude and variation in existing PCC frameworks and concepts, it is important to carefully articulate the conceptual underpinnings of an instrument aimed to measure the level of observed person-centeredness in interactions between professionals and patients. Clarity and transparency are needed in describing conceptualizations in such an instrument. Patients need to be involved in the development of any assessment tool of PCC. In the absence of information about the assumptions underlying a method and theoretical and/or empirical support for those assumptions, its validity and utility as a measure for assessing PCC may be considered a matter of conjecture. First, dimensions beyond conversations, such as eye contact; body language; or indicators of shared decision-making (partnership), should be an integral part of the evaluation of PCC. Second, the methods used

should be applicable to all care and treatment provided by registered nurses, physicians, midwifes, physiotherapists, and other health professionals and ought to be evaluated in terms of PCC as well. Third, existing observation-based methods have shown face validity but are oftentimes poorly assessed and the measurements' reliability is questionable. A rigorously tested and patient-derived observation-based instrument is needed to support the education and continuous implementation of PCC in Sweden.

3 AIM

The overall aim of this thesis work is to develop and test an observation-based tool for assessing the level of person-centeredness in interactions between patients and health care professionals. The specific aims of the included studies were:

I. To review and evaluate direct observation tools developed to assess health professionals' competency in delivering PCC.

II . To identify key behavioral indicators of PCC for inclusion in this tool through interviews with patients, relatives and professionals with experience of receiving or working with PCC

III. To evaluate the content and usability of a new direct observation tool for assessing competency in delivering person-centred care (PCC) based on the Gothenburg Centre for Person-Centred Care framework (gPCC).

IV. To assess the inter-rater reliability of the 15 domains of a revised observation-based instrument for assessing health professionals' competence in delivering person-centered care.

4 METHODS

OVERALL STUDY DESIGN

An overview of the studies is shown in table 1.

Table 1, overview study design

	Design	Data collection	Participants/Material	Data analysis
I	State of the art review	Electronic literature searches in PubMed, ERIC, CINAHL Web of Science		
II	Explorative, cross-sectional	Interviews	12 participants, patients, and professionals,	Content analysis
III	Explorative, cross-sectional	Think aloud and interviews	11 participants, patients, and professionals/ Preliminary tool	Content analysis
IV	Explorative, cross-sectional	Observer ratings	6 professionals/ 10 patient-professional interactions using revised tool	Descriptive statistics; Cronbach´s alpha interclass correlation

4.1 DESIGN

Study I

State-of-the-art review was conducted to review and evaluate direct observation tools developed to assess health professionals' competency in delivering PCC.

Study II

A qualitative interview study using deductive content analysis was conducted to identify key behavioral indicators of PCC for inclusion in this tool through interviews with patients, relatives and professionals with experience of receiving or working with PCC.

 Study III

A qualitative interview study using think aloud technique with retrospective probing was conducted to evaluate the content and usability of a new direct observation tool for assessing competency in delivering person-centred care (PCC) based on the Gothenburg Centre for Person-Centred Care framework (gPCC).

Study IV

To assess the inter-rater reliability of the revised direct observation tool, a fully crossed design was used, where all raters rated all patient-health professional interactions against all items

4.2 DATA COLLECTION

Study I

Electronic searches of articles describing the development and testing of direct observation tools for assessing PCC published until March 2017 were conducted in PubMed, ERIC, CINAHL, and Web of Science for English-language. Three criteria for inclusion were: (i) direct observation tool (ii) reports and/or descriptions of any development or evaluation of an instrument that measures patient-centred care, PCC or person centredness (iii) not clinical encounters.

Study II

Twelve participants were interviewed between February and November 2018. The 3 different dimensions from the gPCC model with follow-up and probing questions guided the interviews. The interviews varied in length from 30 minutes to 1 hour and 20 minutes and were conducted either in a room in the hospital ward where the participant and interviewer could be undisturbed, by phone, or at the place of work. Eight interviews were conducted face-to-face and four interviews were conducted by phone. The interviews were made in parallel with the analyses in order to be able to include more interviews if issues and questions arose that needed further clarification and more data. The interviews were tape-recorded and transcribed verbatim.

Study III

Eleven participants were recruited from February 2022 to April 2022, all of them participated via Zoom at their homes or places of work. The tool was sent to the participants a few days prior to the scheduled session and they were asked to review and familiarize themselves with it.

The sessions comprised a think aloud phase and an interview phase. In the think aloud phase, the participants were asked to think aloud while using the tool to rate a 5-minute, video-recorded patient-physician interaction in which the patient consulted for shoulder pain in a primary care setting. The participants were instructed to talk aloud about their thoughts and actions, as well as any confusion or concerns they had. If the participants were silent for more than a few seconds, they were prompted to "please keep talking". In such cases, they were also occasionally asked to explain what they were thinking while they were silent. They were told that the think aloud phase would end when they had completed their ratings or otherwise wished to terminate the session.

Semi-structured interviews were conducted directly after the think aloud phase. Participants were first asked for their general impressions of the tool; thereafter, questions were asked, when necessary, regarding the content coverage, comprehensibility, readability, layout and response format of the tool. Questions were also asked to probe difficulties or uncertainties observed by the interviewer or verbalized by the participant during the think aloud phase. The interviews were terminated when the interviewer judged that no new information could be gleaned or at the request of the interviewee (85, 86). All sessions were digitally recorded and lasted 40 – 78 minutes (mean 58 min).

Study IV

Six participants were recruited from October 2022 to December 2022. They received an email with the instrument, 10 video-links showing interactions between healthcare professionals and patients, and instructions of how to use the instrument when they watched the video-films that were between 2-5 minutes long. The participants all individually evaluated each film, the films

were received in different order to avoid training effects. After rating the ten video-films they then e-mailed their ratings to the first author.

4.3 PARTICIPANTS/ MATERIALS

Participants with experience of receiving, working with and/or implementing PCC were recruited using purposeful sampling and selected to represent a variety of stakeholders and potential end-users. All participants were familiar with PCC concepts and had taken part in or lead seminars or training courses on the gPCC framework. The patient representatives all had chronic conditions and long experience of being cared for both in hospitals and primary care. Patients and patient representatives took part in Studies II and III.

Studies III and IV aimed to assess the content, usability and inter-rater reliability of the direct observation tool developed during this thesis work. A Swedish language version of the tool was used in both studies. In Study III, a preliminary version of the tool was evaluated. Study IV used a slightly modified version of the preliminary tool.

4.4   DATA ANALYSES

Study I

Articles were excluded that were irrelevant based on title and/or abstract and duplicates were removed. The eligibility of the records was independently assessed by three authors. All remaining articles were read in full text. To extract information about the tools a data extraction form was developed. Coverage of recognized PCC dimensions was evaluated against a standard framework and the articles were examined for any conceptual or theoretical frameworks underlying tool development. The tools psychometric performance was obtained directly from the original articles.

Study II

In this study an explorative qualitative deductive content analysis, inspired by Graneheim and Lundman, was used. The analysis was based on the gPCC framework proposed by the Gothenburg Centre for Person-centred Care (GPCC). The main categories in the analyses were the three GPCC routines: Initiating, Working and Safeguarding the partnership. The first author (NE) read through all interviews. Next, the text was condensed and coded into different meaning units and the codes were grouped into subcategories based on their similarities and differences by three authors (NE, AF, EB).

Study III

This was a qualitative interview study using think aloud technique with retrospective probing and content analysis. The method comprised three different steps (i) participants watching a video presenting a patient and doctor consultation, and think aloud and gave their comments (ii) probing after the think aloud session, and (iii) analyzing these comments deductively to obtain

knowledge on how the informants reflect on the content, comprehensiveness, and feasibility of the direct observation instrument on PCC. A Swedish language version of the tool was used. Latent content and manifest analysis were used. In the next step, three of the authors watched the videos independently and summarized their observations. Two of the authors collaborated with the first author regularly in the analysis until consensus was obtained to improve the trustworthiness.

Study IV

This study evaluated the inter-rater reliability of the tool. Sample size was estimated to 10 video-recorded patient-health professional interactions with six raters Internal consistency of multi-item domains was assessed with Cronbach's alpha. For each of the 15 domains comprising the instrument, intraclass correlations (ICC) and 95% confidence intervals (CI) were computed.

4.5 ETHICS

The studies were carried out according to research ethics guidelines and according to the Declaration of Helsinki (87). Ethical approval was received from the Swedish Ethical Review Authority for study II, III and IV (DNr 1004-17, T2021-03541 and T2022-05766-02). The participants gave their written consent, were informed that their participation was voluntary and that they had the right to withdraw. All of the informants were informed that their information would be used in research and any published quotes from the interviews would be anonymized.

5 RESULTS

Study I

Sixteen different direct observation tools for assessing PCC or specific dimensions of PCC were identified. Eleven tools were coding systems, three were rating scales and two were checklists. The conceptual/theoretical underpinnings of the tools were generally unclear and coverage of PCC domains varied markedly between the tools. Except for two tools, inter-rater reliability was reported and three tools reported intra-rater reliability. Discriminant and predictive validity were not assessed. Given the aims of PCC, patients were not involved in the development of any tool, which seems paradoxical.

Study II

The gPCC model's three routines (Initiating, Working and Safeguarding the partnership) were used as main categories. Analyses yielded nine attributes (subcategories), illustrated by example behaviours. Initiating the partnership emphasized the importance of first impressions of the health professional as crucial for engaging patients and gaining their trust and confidence both at the start throughout the encounter. Three subcategories were identified: *Welcoming, interested and courteous reception*, *Agreeing on structure and aims of the conversation* and *Eliciting patients' wishes for involvement of significant others*.

The category Working the partnership illustrated the importance of activities, attitudes and skills and open communication between patients and staff. Fundamental was to acknowledge and respect each other's knowledge and expertise when managing different situations in the care process. Especially

important aspects were that both parties' endeavor to: identify resources in the other person, find a common language, and encourage each other to actively participate in the dialogue. The category comprised four subcategories: *Attentive, empathic and encouraging manner*, *Promoting mutual understanding*, *Promoting patient engagement* and *Encouraging and friendly body language*.

The category Safeguarding the partnership emphasized the importance of reaching and formalizing agreement on and co-authoring health plans. Co-creation and documentation of the health plan was seen to ensure that it acknowledges and validates patients' concerns and perspectives, is understandable to the patient, that the patient-professional interaction is transparent, and that continuity in care is facilitated. Patient access to health plans was stressed. It consisted of two subcategories: *Collaboration and transparency in documentation* and *Verifying that patient´s and professional´s views, goals and wants are correctly documented.*

Study III

There were two predetermined main categories, Content coverage and Usability issues. The category Content coverage comprised the subcategories Comprehensiveness/ relevance and Redundancy. Participants reported that the content of the instrument was comprehensive and relevant for assessing PCC in general and gPCC in particular. Some participants pointed out the need to include a broader selection of indicators, particularly related to patients' own resources. Others remarked that the inclusion of clinician manner and skills were relevant adjuncts to the clinician activities outlined in the gPCC to more comprehensively assess PCC competency. Some participants suggested to expand the instrument to cover behaviours related to communicating medical information, particularly that the clinician should be attentive and responsive

to how the patient experiences and understands such information. Another suggestion was that since building partnerships with patients is a central goal of PCC, how well partnership was achieved should be added as an overall goal of the interaction.

In the second subcategory, Redundancy, some participants felt that the Domains "Clinician manner" and "Clinician skills" appeared to overlap. Some of the participants, when evaluating Clinician manner, interpreted the example behavioral indicators, meant to illustrate each attitude/ attribute, as a checklist of behaviours.

The category Usability issues included the subcategories Comprehension, Readability, Layout, Rating scale format, and General usability. The usability issues related mainly to item wording, layout, instructions, and response options. In the first subcategory the participants reported that the language used in the instrument was generally easy to comprehend. In the second subcategory the participants were satisfied with the font size and line spacing. To facilitate its use some participants experienced the instruments layout, in subcategory three, as too compact and suggested that the tool be spread out over more pages, with one domain per page. The fourth subcategory, rating scale, mainly concerned whether a 4 or 5-point rating scale should be used, if the scale needed verbal anchors, as well as how the "doesn't do" response option was used. In the last subcategory most of the participants thought the tool was easy to use and felt that it would be useful for assessing PCC in educational and clinical settings.

Study IV
Cronbach's alpha was acceptable (>.70) for all multi-item domains. Intraclass correlation (ICC) values indicated excellent inter-rater agreement (ICC≥.75)

for 13 of the 15 domains. However, CIs around the point estimates were generally wide and the lower bounds lay within the good range (ICC=.60-.74) for 6 domains and fair (ICC=.40-.59) for the remaining 7. ICCs for two domains, Patient perspective and Documentation, were noninformative due to their particularly wide CIs.

The development of the new direct observation tool

The tool aims to evaluate competency in the delivery of PCC. With the gPCC framework as its core, the tool was developed from a combination of the results from study II, but also from the wider PCC literature and from existing tools identified in study I. Study II served as a basis for many of the different manners and skills needed when performing PCC, that is, how to act and behave in a conversation or an interaction with a patient. A lot of other ideas were developed from study I, for example how the actual tools were built up, such as items and domains illustrating PCC. A critical element in the tool's development was the inclusion of patients from the start and to have a well-tested framework when developing a tool. The framework gPCC gave us suggestions on what domains the tool should include, and items that would illustrate concrete behaviours and performances.

The direct observation tool assess four major domains: PCC activities, Clinician manner, Clinician skills and PCC goals. The domain PCC activities covers tasks and goals to be accomplished. The tool includes eight broad sets of activities to be achieved in clinician-patient interactions. Each action is assessed against a set of defining behavioral indicators. The domain Clinician manner includes nine attitudes or attributes that the clinician should demonstrate through verbal and/or nonverbal person-centered behaviours and manners when interacting with patients. Behavioral indicators are described for each attitude. The Clinician skills domain contains sets of perceptual and

behavioral skills needed to reach PCC goals. The domain PCC Goals includes general indicators that PCC goals of patient activation, engagement and trust are achieved. All ratings are made on a bipolar, 4-point rating scale ranging from very unsatisfactory to very satisfactory, labelled --, -, +, ++. A response option called "doesn't do" is also provided for the PCC activities domain for cases where the activity is not performed. Space is provided for personal notes beside each behavioral indicator.

6 DISCUSSION

The overall aim for this thesis was to develop and test a direct observation tool for evaluating competency in the delivery of person-centeredness in interactions between patients and health care professionals.

The first step was to review and evaluate direct observation tools developed to assess health professionals' competency in delivering PCC. The conclusion was that a rigorously tested and patient-derived tool is clearly needed. The next step was therefore to identify key observable indictors of PCC by interviewing patients, relatives and professionals with experience of receiving or working with PCC. The interviews were based on the gPCC framework as proposed by GPCC. Patients´ first impressions were considered to impact the content, course and outcomes of the interaction and nonverbal behaviours were seen to play a major role in shaping patients' impressions of health professionals. The third step was to test the preliminary tool and after a minor revision the last step was to assess inter-rater reliability with healthcare professionals practicing or implementing PCC.

It was obvious from the state-of-the-art review (88) that a framework is needed when developing an instrument measuring the PCC process and particularly interactions between professionals and patients, otherwise it is hard to know if important domains of the phenomenon are included. Research in PCC has mainly focused on effects and outcomes evaluated either through individual or group interviews (63) or standardized questionnaires (69). Little attention has been directed to evaluating real-time processes and collaboration between staff and patients in PCC or the extent to which the principles of PCC are applied. We aimed for a validated theoretical framework of PCC and we decided to use the gPCC framework (4). The fact that PCC is based in applied ethics makes it

even more important with an instrument developed from a framework based in the same ethics. An interesting finding from Study II (89) was that initiating the partnership, meaning the first interaction between the patient and the professional, before the patient´s narrative, was even more important than the gPCC framework suggests. The framework emphasizes listening to the patient (4), which is important, but crucial is how this listening is initiated in terms of the professional´s attitudes and ability to develop trust. For patients to tell the professional their illness narratives they must feel safe. This is an important development of the framework since it concerns the core of PCC – partnership and relationship. Rita Charon, a well-known authority in patient narratives, emphasizes that these kinds of narratives are not restricted to written or spoken accounts of illness, but that patients' moods, silences, and bodily changes must also be included (58, 90). The professional is expected to demonstrate by her/his behaviour that the patient is first a person, a human being in the role of a patient. Human value is a relational concept - to understand and trust that one has a value as a human, a person must be confirmed and respected by another human being (54). Human vulnerability is to be capable of being strongly affected by the suffering of other people, this can be seen as an asset and be used in the clinical encounter by the professional. Because the first moment of interaction is probably when the patient is especially sensitive to the professional´s approach, the health professional must therefore be open to the patient´s suffering and her/his own vulnerability.

The applied ethics confirms the patient as a capable human being who is able to express him/herself and make decisions, which is manifested in the instrument in the items proportion of talk-time between patient and health care professional and free flow of conversation (turn taking), where patients freely and actively voice concerns, expectations, beliefs, opinions suggestions and preferences. These items are important since they are examples of the

difference between standard/good care and person-centered care. One of few instruments measuring PCC that has involved these aspects is the ARCS, a modified version of RIAS (83). In this direct observation tool, they have added four codes from the original RIAS that represent resources, coping, attribution and solution-focused techniques (83).

The gPCC framework (4) postulates that Safeguarding the partnership is a core PCC routine, in which health professionals together with patients co-document care goals and plans for accomplishing them in the patient record. We therefore included items on documentation, such as co-writing a health-plan with the patient. In Study I (88), we found this to be unique in direct observation tools. Particularly important is that the documentation is created through dialogue, whereby patients can suggest goals and care activities. This focus in PCC has been shown to promote the patient's own goals and actions in the documentation of mutually created care-plans, which can be used to tailor support and engage the patient as an active partner in their care (91). The increasing availability of electronic records may be seen to facilitate patients' access to their records, but this contributes little to the aims of PCC if the patient is not actually involved in writing the record (4). To be able to follow how documentation is performed together with patients over time is probably one of the signs of the level of practiced PCV, since research where nurses with training in the theory and practice of person-centred care, over time tended to formulate medical goals in the care-plans rather than patients´ own everyday goals (92).

There are several drawbacks to the tool we have developed. One has to do with the poor inter-rater reliability associated with the domains Documentation and Patient perspective. As we discuss in Study IV, reliability is often conceived as a characteristic inherent to an assessment tool; however, reliability estimates

may be influenced by a number of methodological factors unrelated to the observation tool per se, such as sample homogeneity, unit of analysis (93), extent of rater training (11), raters' professional background (94) and other rater characteristics/ idiosyncrasies (76). In the case of Documentation, the poor rater agreement may stem from the fact that none of the 10 video-recorded interactions used in the study showed examples of this activity (95). The inter-rater reliability of the tool needs to be assessed in larger, more diverse sample of patient-health professional interactions. On the other hand, the relatively good reliability demonstrated for most of the other domains suggests that the tool may be used with little or no rater training, which may be advantageous in many education and implementation applications where cost and time constraints prohibit the use of established tools requiring long and intensive rater training, such as the RIAS and OPTION (19,20).

Another limitation in the development of the present tool might be that we choose to use the gPCC framework. Since there is no universal definition of PCC (25) we found when we compared to other frameworks that the advantage of using gPCC was the concrete operationalization of PCC, and that it contained important aspects from other frameworks, such as the capability approach by Entwistle (5). Other aspects more rarely seen in other frameworks were, for example, safeguarding the agreement through the documentation. Even though we found the gPCC framework to be helpful in the development of the instrument, we are also aware that the construction of the tool was probably coloured our own particular definition and views of what PCC is.

Another limitation may be that no testing was made in educational settings and no students tested the instrument. On the other hand, Studies III and IV showed that the tool was easy to use despite the fact that none of the participants had any training. The fact that little training is required may be especially

advantageous as PCC implementation efforts become more widespread, as is the case in Sweden.

Methodological considerations

The base for the development of the present observation-based instrument was the state-of-the-art review of direct observation tools for assessing competency in person-centred care. It may be speculated that the eligibility criteria for selecting tools for inclusion in the review were too stringent and narrow and hence we may have missed relevant tools. On the other hand, tools not fully meeting inclusion criteria were thoroughly discussed and agreed on by co-authors.

In our Studies II and III patients represented almost half of the participants. The sample of informants in these studies was, however, rather small. Adding informants might have improved the richness of our data, but since they were largely in agreement regarding what health professionals should do and how they should be in person-centred clinical encounters the number seemed sufficient.

 The use of a video-recording of a patient-physician interaction in study III may have impacted the participants' positive appraisals of the usability of the tool. Our usability results may therefore not be generalizable to other observation formats. Due primarily to social distancing during the Covid pandemic, the sessions were conducted remotely via the videoconferencing platform Zoom rather than in person. Although such platforms offer advantages regarding flexibility, efficiency, convenience and cost- effectiveness, there is little research on their effects as a data collection method in qualitative research (96, 97). The design of Study III seems to have been appropriate since the participants were asked to think-aloud when using the

instrument for the first time and probing interviews ensured that their comments were understood correctly. In the content analyses we found several categories to be similar, which indicate that saturation may have been achieved.

7 CONCLUSION AND FUTURE PERSPECTIVES

The notion of PCC is centred on mutuality and a balance of power between staff and patients; a distinct move from the paternalistic biomedical model to a person-centred model. A direct observation-based method to assess the level of person-centeredness in real life can help focus human relationships and interactions in care, and thereby develop and enforce the implementation of PCC in Swedish health care. Exploring the alignment between healthcare services and PCC may prove beneficial in ensuring the practice of PCC in healthcare service. Today several barriers to the implementation of person-centred care exist, including traditional practices and structures; skeptical, stereotypical attitudes from professionals; and factors related to the development of person-centred interventions (98). These barriers may be overcome through training of project managers, involving patients in research and adopting adaptive strategies by researchers (98). A recent implementation study (47) on the gPCC framework suggested that PCC training and education should not be limited to healthcare professionals, but rather should include other stakeholders, such as managers and quality controllers, responsible for monitoring and securing changes of the care process (47).

Knowledge gained from measuring PCC may help in guiding and setting priorities within the healthcare system and has the potential to help to move PCC from its current rhetorical nature to a genuine commitment and priority of health professionals. Lastly, the effective use of PCC direct observation tools with accompanying feedback may be of value in healthcare education and professional training.

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APPENDIX