Exploring person-centered care in acute psychosis care settings

Findings from the Person-Centered Psychosis Care project

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ABSTRACT

Many persons with psychotic disorders are in need of inpatient care at some point in time. The inpatient setting is suggested to need reform to better deliver recovery-oriented care and align with legislation emphasizing patient participation and autonomy. Person-centered care holds potential to contribute to needed change but has not been sufficiently explored in acute psychosis care settings.

The aim of this thesis was to explore outcomes and experiences of the Person-Centered Psychosis Care project (PCPC), an educational intervention for inpatient staff launched at the Psychosis Clinic in Gothenburg. PCPC aimed at creating a sustainable increase of person-centeredness at the psychosis care wards. Patient reported outcomes (empowerment and consumer satisfaction, **Paper I**) and registry data (care consumption, **Paper II**) were compared in pre- and post-intervention samples. Focus groups were used to capture staff experiences of PCPC (**Paper III**). Post-intervention care experiences of patients and next-of-kin were explored with individual and focus group interviews (**Paper IV**).

The findings show that PCPC could not be associated with improved empowerment but with improved satisfaction with care. Length of hospital stay, and length of involuntary stay were longer after the intervention. Staff experiences reflect both a theoretical understanding of person-centered care and a translation into practice, with positive changes such as improved work environment. However, organizational and practical features obstructed implementation. Service user and next-of-kin data reflected mixed experiences of inpatient care, suggesting that person-centeredness does not yet permeate the care process, even though some positive experiences of a more person-centered care emerged.

Taken together, findings from the four studies suggest that PCPC was successful in enhancing person-centered thinking and actions in staff, but not all were committed to the project and organizational or practical features obstructed implementation. The findings in **Study I, II** and **IV** might be explained by such insufficient implementation. Results must be regarded as tentative due to study limitations.

Keywords: Person-centered care, Psychosis, Schizophrenia, Inpatient care, Empowerment, Satisfaction, Length of stay, Length of involuntary stay, Staff, Next-of-kin

SAMMANFATTNING PÅ SVENSKA

Psykossjukdomar som schizofreni, vanföreställningssyndrom eller schizoaffektiv sjukdom drabbar ca en av 100 personer, och i Sverige lever runt 35 000 personer med schizofreni. Dessa sjukdomar innefattar typiska psykossymptom så som hallucinationer och vanföreställningar men kognitiva funktionsnedsättningar är också vanliga. Att tidigt få behandling och stöd är viktigt för att kunna återhämta sig och skapa förutsättningar för det liv man vill leva. Riktlinjer för psykosvård betonar vikten av att anpassa vårdinsatser så att varje patient får det stöd just hen behöver. Traditionellt har sådana riktlinjer fokuserat på att minska symptom och öka funktion. Detta är fortfarande grundläggande och viktigt i all behandling, men är ett smalt sätt att se på hälsa som dessutom bidragit till att ge patienter en passiv roll inom vården. Idag influeras både riktlinjer och vårdpolicys av idén om patienten som en aktiv partner i vårdprocessen. Person-centrerad vård syftar till detta och har sin utgångspunkt i att se patienten som en person. Det betyder att varje patient ses som kapabel och en aktiv partner i sin vård utifrån att hen är expert på sig själv, med resurser, behov och förväntningar som är avgörande för vårdprocessen. Patientens berättelse om sin situation och sig själv är central, och en lyckad vårdprocess bygger på att patient och vårdgivare bildar ett partnerskap där man utbyter information, tar vara på båda parters expertis och tillsammans kommer överens om en plan för återhämtning och ökad hälsa.

I psykosöppenvård finns vårdmodeller som bygger på dessa principer. I slutenvården, dvs dygnet-runt-vård på sjukhus, visar dock rapporter och forskning att patienter och närstående upplever att de inte får tillräckligt stöd för återhämtning, att miljön kan vara direkt ohälsosam och att de i liten utsträckning har möjlighet att påverka vården eller delta i beslut. En faktor som späder på dessa intryck är tillämpningen av tvångsvård. Tvångsvård regleras av lag och innebär att under vissa kriterier kan en person mot sin vilja läggas in och hållas kvar på sjukhus samt tvingas ta emot behandling. Att öka person-centreringen inom psykosslutenvården skulle kunna bidra till en bättre vårdupplevelse och en bättre återhämtning för personer med akut psykos. Dock är person-centrering i psykosslutenvård för lite undersökt och därför ämnar denna avhandling utforska hur person-centrerad vård kan användas och vad det kan leda till i psykosslutenvård.

Avhandlingens delstudier utvärderar en intervention som syftade till att öka person-centreringen på fyra slutenvårdsavdelningar inom psykosvården i Göteborg. Projektet kallas Person-Centrerad Psykosvård (Person-Centered Psychosis Care, PCPC) och innefattade en utbildningsintervention för slutenvårdspersonal. Deltagarna fick både teoretiskt och praktiskt fördjupa sina kunskaper om person-centrering och hur det kunde användas i deras kliniska arbete. De fick sedan själva skapa mindre förändringsprojekt som de testade att implementera på sina arbetsplatser för att öka person-centrering. Exempel på projekt var att skapa en rutin för att kontaktpersoner och läkare skulle kunna ha regelbundna samtal med patienter, att skriva vårdplan tillsammans med patienten och öka involvering av närstående genom att bjuda in till samtal.

Avhandlingen innefattar fyra delstudier med olika perspektiv på PCPC. I **delstudie I** undersöktes patienters empowerment (översätts ibland med egenmakt och handlar om i vilken mån man har makt över situationer och faktorer som påverkar ens liv) och nöjdhet med vården med skattningsformulär. Patienter som vårdades på slutenvården rekryterades för att delta strax innan utskrivning. 50 patienter innan och 50 patienter efter interventionen deltog. Empowerment var oförändrad men patienterna som vårdats efter PCPC var nöjdare med sin vård.

I **delstudie II** jämfördes vårdtider för samtliga patienter som vårdats på psykosavdelningarna under året innan PCPC mot alla vårdade under ett år efter. Både vårdtider och tvångsvårdstider var längre efter interventionen medan andelen tvångsvård och återinläggningar var liknande mellan grupperna.

Delstudie III undersökte personals erfarenheter av hela projektet genom fokusgruppintervjuer. Resultatet visade att deltagarna tagit till sig personcentreringsprinciperna och att dessa användes i praktiken på olika sätt. Personalen beskrev hur de tyckte att det blivit en bättre vårdmiljö för både personal och patienter men att det fanns hinder för att arbeta person-centrerat som hade med vårdorganisationen och det praktiska arbetet att göra. De gav också exempel på saker som gynnade omställningen till person-centrering vilket till stor del hade med personalens egenskaper att göra.

I **delstudie IV** undersöktes hur patienter och närstående upplevde slutenvården efter att PCPC implementerats genom intervjuer. De beskrev både vårdmiljön och vårdkvaliteten med exempel som gav en bild av att person-centrering existerade i vissa möten och situationer men inte genomsyrade slutenvården. Personalens bemötande beskrevs över lag som gott, men många patienter och närstående upplevde sig inte bli involverade i vården och vårdmiljön beskrevs som fortsatt problematisk.

Slutsatsen från studierna är att PCPC tycks ha framgångsrikt påverkat personal att både tänka och agera mer person-centrerat på sina arbetsplatser, men all personal engagerade sig inte i projektet och organisatoriska faktorer så som personalomsättning, otillräckliga resurser för att driva förändring och hierarkier påverkade implementeringen negativt. Resultaten av delstudie I, II och IV kan förklaras av en ofullständig implementering. Svagheter i studiedesignen gör att resultaten ska ses som preliminära.

LIST OF PAPERS

Paper I. Allerby, K., Goulding, A., Ali, L., Waern, M. (2020). Striving for a more person-centered psychosis care: Results of a hospital-based multi-professional educational intervention. *BMC Psychiatry 20:523.*

Paper II. Allerby, K., Gremyr, A., Ali, L., Waern, M., Goulding, A. Increasing person-centeredness in psychosis inpatient care: care consumption before and after a person-centered care intervention. *Submitted.*

Paper III. Allerby, K., Ali, L., Goulding, A., Waern, M. (2022). Increasing person-centeredness in psychosis inpatient care: staff experiences from the Person-Centered Psychosis Care project (PCPC). *BMC Health Services Research 22:596.*

Paper IV. Goulding, A., Wiktorsson, S., Allerby, K., Ali, L., Waern, M. Emerging person-centredness: Service user and next-of-kin experiences of psychosis inpatient care after a person-centred care intervention. *Submitted.*

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ABBREVIATIONS

ANCOVA – Analysis of Covariance

EQ-5D – EuroQoL-5 dimensions

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, Fifth Ed.

GAF – Global Assessment of Functioning

GPCC – Gothenburg center for Person-Centered Care

ICD-10 – International Statistical Classification of Diseases and Related Health Problems – 10th Revision

LoS – Length of hospital Stay

LoIS – Length of Involuntary hospital Stay

PANSS – Positive and Negative Syndrome Scale

PCC – Person-Centered Care

PCPC – Person-Centered Psychosis Care

RSS – Remission sub-scale of the Positive and Negative Symptoms Scale

SDM – Shared Decision-Making

QoL – Quality of Life

UKU-ConSat – UKU-Consumer Satisfaction Rating Scale

VAS – Visual Analogue Scale

INTRODUCTION

With this introduction I will set the stage for the exploration of person-centered care (PCC) in psychosis inpatient settings by shortly introducing psychotic disorders, current thoughts of its treatment and the role of acute hospital care (mainly referred to as inpatient care) including current problems. Thereafter person-centered care is introduced with a short summary of previous research. Finally, I describe the Person-Centered Psychosis Care project, which is the basis for the studies in this thesis.

SCHIZOPHRENIA & PSYCHOTIC DISORDERS

Psychotic disorders are characterized by the presence of psychotic symptoms such as hallucinations, delusions or thought disorders, and cognitive dysfunction is a common and important trait. Major diagnoses are schizophrenia, schizoaffective syndrome and delusional disorder, specified in the diagnostic criteria of DSM-5 or ICD-10 (American Psychiatric Association, 2013; World Health Organization, 1992). Schizophrenia usually presents in young adulthood involving hallucinations and delusions along with different degrees of cognitive symptoms, such as executive dysfunction or working memory deficits, and so-called negative symptoms for example anhedonia or motivational deficits. Life-time prevalence is traditionally reported at 1%, with ranges from 0.5% - 1.6%, suggesting approximately one out of 100 persons will experience schizophrenia during their lifetime (Perälä et al., 2007; Rössler, Salize, van Os, & Riecher-Rossler, 2005; World Health Organization, 2001). Schizoaffective disorder features similar symptoms but involves manic or depressive episodes and is reported at the less frequent prevalence of 0.3% (Perälä et al., 2007). Delusional disorder presents with non-schizophrenic delusions (meaning non-bizarre) as the main symptom; hallucinations or cognitive symptoms are marginal. The debut is usually later in life, at middle age, and the lifetime prevalence has been reported at 0.2% (Perälä et al., 2007).

Whilst there are similar core symptoms of these disorders, the prognosis in terms of persevering symptoms and disability varies somewhat among diagnostic groups and largely at the individual level (Rössler et al., 2005). The impact of schizophrenia is substantial from a societal perspective, as patients with schizophrenia are reported to account for more than 1% of the world's total Disability-Adjusted Life Years (DALY)[1], and nearly 3% of all Years Lived with Disability (Rössler et al., 2005). Schizophrenia and similar psychoses impact on the ability to independently carry out daily activities and work/studies. This causes low employment rates (5-23%), with many depending on social benefits or the family to provide for them (Thornicroft et al., 2004). Medication and unhealthy lifestyle contribute to physical health problems; diabetes and cardiovascular diseases are common complications (von Hausswolff-Juhlin, Bjartveit, Lindstrom, & Jones, 2009). This, in combination with suicide, helps to explain why life expectancy is reduced by as much as two decades in persons with schizophrenia and similar psychoses (Tiihonen et al., 2009). Social exclusion and stigmatization further adds to the burden (Sibitz et al., 2011), and these phenomena are sometimes extended to informal caregivers such as family or friends (Kadri, Manoudi, Berrada, & Moussaoui, 2004; Phelan, Bromet, & Link, 1998; Struening et al., 2001). Although these figures present a dire picture, research also shows that ~50% may reach a seemingly stable remission (Lambert, Karow, Leucht, Schimmelmann, & Naber, 2010).

PSYCHOSIS TREATMENT STRATEGIES AND RECOVERY

The complexity and complications of the psychotic disorders make comprehensive care needed (Mohr et al., 2018). Evidence-based recommendations for practice are provided by national guidelines, such as the guidelines from British National Institute for Health and Care Excellence (NICE) and the Swedish National Board of Health and Welfare (National

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[1] Disability-Adjusted life year (DALY) is a way to quantify the burden of different diseases where one DALY represents one year lost of "healthy" life. It combines mortality, which is years lost due to premature death, with disability, which is years lived with disability.

Institute for Health and Care Excellence, 2014; Swedish Board of Health and Welfare, 2018). Early detection and intervention are stressed. Pharmacological, psychological, social, occupational and educational interventions are suggested to reduce symptoms, foster coping strategies and improve abilities to function in different aspects of life. Further, programs to enhance a healthy lifestyle are suggested and there should be regular check-ups of physical health. Alongside assessing patients' needs, next-of-kins' needs should also be assessed to provide fitted support and information on psychosis management, with a positive message about recovery (National Institute for Health and Care Excellence, 2014; Swedish Board of Health and Welfare, 2018).

Parallel to the recommendations of the content of care, there is a great emphasis on the conduct and attitude of professional carers (hereby referred to as staff). A personal and empathic approach focusing on building therapeutical relationships in a hopeful atmosphere is put forward. This is in line with what patients express wanting from staff and part of an overall transformation of the care organization in which the patients' experiences and satisfaction are important outcomes (National Collaborating Centre for Mental Health, 2012). Strengthening the patients' role is emphasized as staff are guided to foster autonomy, promote active participation in decision-making and support self-management.

The above described components resonate from the evolvement of treatment goals. While traditional medical recovery implies symptomatic remission and improvement of dysfunction, personal recovery (hereby referred to as just recovery) emphasizes the patients' personal growth and life goals, with or without symptoms. In a seminal work on recovery, the CHIME framework was created from the body of existing recovery research. According to the CHIME framework recovery-oriented practices should support the processes of connectedness, hope and optimism, identity, meaning in life and empowerment (Leamy, Bird, Boutillier, Williams, & Slade, 2011)[2]. This means

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[2] Recovery is the goal of recovery-oriented practice which is rooted in the recovery movement. It claims the right for persons with mental health problems to thrive,

in practice that we should adopt and convey a more positive view of prognosis, allow and assist patients in pursuing own goals, and function as facilitators in their process towards a meaningful life situation. This shift from a mainly medical paradigm to the ambitious goal of recovery has major implications as the role of health care services moves towards that of facilitator for personal health.

INPATIENT PSYCHOSIS CARE

Although todays' organization of psychosis care outlines outpatient services as the main provider, inpatient services remain a vital part of the care spectrum. As many as 50% of patients with first-episode psychoses are reported to need hospital care during the first seven years from onset (Ajnakina et al., 2020), and about the same proportion is suggested to need rehospitalization during the first years (Cougnard et al., 2006). The share of patients that needs inpatient care has remained stable over time, but the number of days spent in hospital (LoS) has drastically decreased over the last decades (Ajnakina et al., 2020). In a psychiatric context, patients with psychotic disorders take a large part of the inpatient resources, mainly by overrepresentation in long stays (Golay, Morandi, Conus, & Bonsack, 2019; Han et al., 2021). Long inpatient stays have been related to interrupted social integration (Smith et al., 2020), which suggests a need to avoid long-term hospitalization. From an economic perspective inpatient care is expensive and a takes up a major part of the cost of schizophrenia care, most pronounced in treatment-resistant patients (Kennedy, Altar, Taylor, Degtiar, & Hornberger, 2014).

Although being an important part of the care for persons with psychosis, criticism of both the content and the manner of how inpatient care is delivered has been put forward (Schizophrenia Commission, 2012). While quantitative

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to pursue own life goals, and to choose own paths, on equal terms as the rest of the adult population (Davidson, 2016). Influenced by civil and human rights movements it aims at assuring mental health users have access to society, with its privileges and responsibilities, or put in other words: to ensure full citizenship.

studies of patient satisfaction with psychiatric inpatient care suggest high levels of satisfaction, having schizophrenia is related to lower levels of satisfaction (Krupchanka et al., 2017). A special, and problematic, characteristic of psychiatric inpatient care is the use of coercion. Involuntary hospitalization implies a violation of a person's autonomy and integrity and is thus restrictively used according to thorough legislation. Patients presenting with psychosis are at increased risk of being involuntarily admitted (Walker et al., 2019), and account for 30-50% of all involuntary admissions in European countries (Salize & Dressing, 2004). The proportion of involuntary admissions reported for admitted persons with schizophrenia was 43% (world-wide) in a recent meta-analysis (Yang et al., 2020). A slightly lower proportion, 30.5%, was found in the European subsample. Although the experience of involuntary admissions does not necessarily hamper future treatment engagement, patients with such experiences show greater sensitivity to future coercion, both perceived and formal (Jaeger et al., 2013). Some patients recognize the need for coercion and acknowledge the benefits of received treatment, but many question the need to be involuntarily admitted or confined for a longer period of time (Katsakou et al., 2012). Detrimental effects of involuntary admission have been vividly captured in qualitative research. The opposite of recovery-orientation emerges as patients describe the care as disempowering and damaging to their wellbeing (alongside some benefits of needed treatment) (Mueser, Lu, Rosenberg, & Wolfe, 2009; Murphy et al., 2017; Sugiura, Pertega, & Holmberg, 2020). Qualitative studies further elucidate how both voluntarily and involuntarily admitted patients with psychosis describe the inpatient setting as chaotic and unsafe (Fenton et al., 2014; Lilja & Hellzén, 2008), lacking in information (Perry, Taylor, & Shaw, 2007; Sugiura et al., 2020), providing insufficient or disempowering interaction with staff, (Murphy et al., 2017; Sugiura et al., 2020), and leaving patients with experiences of not being respected or seen as human beings (Lilja & Hellzén, 2008).

Similar views are reported from next-of-kin; the care system as a whole emerged as unsupportive and confusing, failing to work proactively, while inpatient services are perceived as providing care in a degrading manner for patients and failing to include next-of-kin in planning and information (Sugiura et al., 2020). Staff in both general psychiatric and psychosis inpatient settings describe a difficult working situation where they try to deliver good care but are limited by high workload which prevents quality time with patients, and an unpredictive or chaotic milieu which leads to reactive rather than proactive actions (Molin, Graneheim, Ringnér, & Lindgren, 2016; Thompson et al., 2019). Detaching from patients or going into self-survival mode have been described as responses to these suboptimal work situations (Molin et al., 2016).

Although there are positive reports of inpatient care as well, often related to good relations with staff (Fenton et al., 2014; Murphy et al., 2017), findings suggest a need to transform inpatient services to better fit the need of patients and next-of-kin, and align with recovery-oriented care (Andreasson & Skärsäter, 2012; Mohr et al., 2018; Murphy et al., 2017). A recent review of patients' experiences identified four areas for improving inpatient care to better promote recovery: high-quality relationships, reducing negative experiences of coercion, health-promoting environment and person-centered encounters (Staniszewska et al., 2019).

PERSON-CENTERED CARE

Person-centered care (PCC) is widely recognized as a modern approach to care, associated with high quality of care, and aligning with guidelines and legislation that emphasize patient participation and autonomy (Swedish Code of Statitutes (2017:30), 2017; Swedish Council on Health Technology Assessment (SBU), 2012). PCC has been described as a counterpart to the traditional care organization with patriarchal attitudes and hierarchical structures that give the patient a subordinate position (Ekman et al., 2014). While widely used, the concept has no uniform definition. Several reviews and concept analyses[3] have described PCC in different settings with some reoccurring principles; *empathy*; understanding and supporting the patient, *respect*; when approaching patients and for patients values and choices, *engagement*; committing with time and effort, *relationship*; therapeutically and

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[3] A concept analysis is a method for examining the semantic structure of a concept, to clarify what it is, by determining its defining attributes (Walker & Avant, 2005). Examples of frequently cited concept analyses on PCC are those of Morgan and Yoder (2012), and Slater (2006).

trusting partnerships, *communication*; dialogue and information, *shared decision-making*; active patient participation and empowerment, *holistic focus*; a psycho-social context-dependent whole-life perspective, *individualized focus*; attending to the unique person, and *coordinated care*; coordination between professions, care contexts, and being persistent over time (Håkansson Eklund et al., 2019). The goal of PCC has further been aimed at a meaningful life, which differs profoundly from traditional treatment goals like symptomatic remission or patient-centered goals like a functional life (Håkansson Eklund et al., 2019).

Starting with the person

The basic assumption of PCC is that health care must recognize the *person* being a patient. The rationale is found in the philosophical view of what a person is. Carl Roger's work with client-centered therapy is often considered the starting point for PCC. In his practice, the philosophical view of personhood became paramount for the professional (counselor in his case), and was based on assumptions of each person's worth, ability to self-direction and capacity. Rogers' approach built on the view of individual persons as self-fulfilling and constructive by nature (Rogers, 2012). In the personalism described by Christian Smith, the human person encompasses an inherent agency and capacity aimed at developing and thriving, as a person. These qualities are present in all human persons, and are not dependent on outer sources to exist, but highly dependent on the outer world, e.g. social relations, to come in to meaning and to thrive (Smith, 2015). Further, striving towards something good and the capacity to strive, implied by both Rogers and Smith, have been described in depth by Paul Ricœur (2011). He attributes the human person linguistic, acting, narrating and ethical capacity, which all exist in a dialogical manner. Everything formulated in speech, done or narrated is directed toward or in response to oneself or another, emphasizing the interrelational nature of human beings. The attribute of ethical capacity, or responsibility, is detrimental for the understanding of the human endeavor. Ricoeur (2011) suggests that all human persons strive towards the good life, but this is intertwined with others as the endeavor includes pursuing a good life both with and for others. Ricoeur thus suggests that a good life cannot be achieved by oneself and not for oneself alone but must be sought with and for the other as well. Smith (2010) presents similar ideas by connecting personal flourishing with the promotion of others' happiness and linking it to the "human goods" that work as motivators for the process of thriving. In Ricoeur's thinking the interrelational aspects involve also "institutions". Institutions refer to society or non-personal relations with which we are in constant dialogue. These institutions must be "just", i.e. providing the prerequisites for striving towards the good life for all, where each human person is responsible for keeping the institutions just (Kristensson Uggla, 2020; Ricœur, 2011).

These ideas, that personhood comprises fundamental capacities for acting and taking one's life forward towards a good goal or a flourishing state, constitute, in my opinion, the motives for PCC to acknowledge patients as competent partners in the care process. I further trace the importance of building therapeutical relations with patients and next-of-kin, put forward in PCC, to the important role that dialogical social relations possess in cultivating the capacity to thrive.

The ideas described above say something fundamental about all humans. The other perspective represented in PCC is the uniqueness of each human person, the identity. Ricoeur addresses this perspective by using the concepts of idem and ipse. Idem represents the identity of some*thing,* summarized by *what* that something is, qualities or attributes that can be shared with others. Ipse represents the identity of some*one*, *who* someone is; the core of self that distinguishes one from all else. Ipse shows itself and evolves itself through the dialogical interaction with others (and with the self), building the identity from memories and present experiences, but also from the stories or definitions others attribute to it. So, while a long list of characteristics, or idem, can contribute to the understanding of a person's identity, listening to the stories from and about that person opens up the possibility to understand something about who that person is (Kristensson Uggla, 2020). In PCC this is important as measurements and medical history can describe a patient (addressing idem), but to connect to the person, and understand what that person needs and wants (beyond a plaster on a wounded knee) the patient's story is needed (Ekman, 2022).

A framework for person-centered care

The philosophical underpinnings described above guided the development of a framework to facilitate PCC in practice by the Gothenburg Centre for Person-Centred Care (GPCC)[4] (Britten et al., 2020; Ekman et al., 2011). Emphasizing the partnership as a cornerstone, three routines are described:

1. Initiating the partnership through the patient's narrative; by listening to the patient the professional can begin to understand something about who this person is, in the conversation between patient and professional a joint understanding of the illness can emerge, and this guides the following work.
2. Working the partnership; by using the understanding and information emerging from the narrative (wishes, resources, needs), a care plan can be co-created where the patient's life situation is guiding. The patient is encouraged to become an active part in both planning and enacting the plan. Sharing information and decision-making are important activities.
3. Safeguarding the partnership with documentation; writing and updating the health plan in a, for the patient, accessible manner and transferring that plan to other caregivers as the patient moves through the care system.

PCC outcomes

There is a growing body of studies exploring outcomes of PCC. In somatic care, PCC interventions have provided desirable patient outcomes such as improved satisfaction and self-efficacy, as well as reduced care consumption in terms of decreased length of hospital stay (Olsson, Jakobsson Ung,

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[4] GPCC is a national interdisciplinary center for PCC research and implementation, organized at the University of Gothenburg. The center was established in 2010 with funds from the Swedish Government for strategic investments in research. More than 100 affiliated researchers (national and international), in several research groups, explore and evaluate different aspects of PCC and its organization and implementation. More information is found at the centers web page: https://www.gu.se/en/gpcc

Swedberg, & Ekman, 2013). However, studies are not consistent in their findings so the evidence of the effectiveness of PCC remains inconclusive. In dementia care, PCC models have been associated with reduced agitation and increased quality of life for residents (Ballard et al., 2018; Chenoweth et al., 2014; Livingston et al., 2014; Yasuda & Sakakibara, 2017). There are several reports showing positive outcomes for care staff working in nursing home settings, including increased wellbeing and satisfaction (Brownie & Nancarrow, 2013; Edvardsson, Fetherstonhaugh, McAuliffe, Nay, & Chenco, 2011; Edvardsson et al., 2015; Lehuluante, Nilsson, & Edvardsson, 2012; Willemse et al., 2015). Within mental health services there are few outcome studies on the implementation of PCC. Outpatient interventions suggests enhanced service engagement, improved adherence, increased satisfaction with care and better social functioning in patients (Malm, Ivarsson, Allebeck, & Falloon, 2003; Stanhope, Ingoglia, Schmelter, & Marcus, 2013). In psychiatric inpatient settings, studies focus on concept analyses or the testing of specific features which might add to increased PCC (Gabrielsson, Sävenstedt, & Zingmark, 2015). Existing evidence suggests that interventions increasing or building on PCC features might decrease use of restraints (Barton, Johnson, & Price, 2009; Wale, Belkin, & Moon, 2011), decrease depression, symptoms of withdrawal and agitation (Doran et al., 2010) and increase satisfaction in staff (Berger, 2006).

Important concepts and their relation to PCC

In the psychiatric context there are some major concepts which are frequently referred to in both literature and practice which are tightly related to PCC. I will shortly introduce them, their relation to each other and to PCC.

Shared Decision-Making

Shared decision-making (SDM) is the activity and process through which patients impact directly on treatment- and care-decisions. Its definition has expanded from describing an act of sharing information and agreeing on a choice of treatment, to involving the elicitation of patients' preferences, goal setting, engagement in care planning and communication training (Zisman-Ilani, Barnett, Harik, Pavlo, & O'Connell, 2017). Its role in the partnership between patients and staff, contributing with the practical aspect, establishes SDM at the center of person-centered practice. SDM has been widely researched in psychiatry and proved both feasible and wanted by persons with psychotic disorder, also in inpatient settings (Beitinger, Kissling, & Hamann, 2014; Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Hamann et al., 2020). In a meta-analysis, small positive effects on treatment-related empowerment (using proxy measures such as perceived involvement in decision-making and self-efficacy) have been found for SDM-interventions for patients with psychosis (Stovell, Morrison, Panayiotou, & Hutton, 2016). Neither relation to clinician nor decision-making ability were improved by SDM interventions. SDM as a separate or one-occasion feature tended to be less effective than when incorporated into a treatment program and related to long-term decisions (Joosten et al., 2008). Psychiatric patients' experiences of SDM suggests that personal support and dialogue is needed to promote participation in decision-making, as is attaining knowledge and understanding responsibilities (Dahlqvist Jönsson, Schön, Rosenberg, Sandlund, & Svedberg, 2015).

Recovery-oriented practice

I have already introduced recovery-oriented practice, but I will elaborate further on its intertwined relation to PCC and SDM. Recovery is about pursuing a wanted life and thriving in the community, and *all* life domains are involved. In psychiatric services we have traditionally been involved in one part of the health domain: psychiatric illness. As the focus of health has expanded, so has the target for health care interventions; from a narrower focus on psychiatric symptoms, to a wider focus on overall health with or without psychiatric symptoms. This has implications also for shared decision-making. In a comprehensive paper on the role of SDM in recovery Davidson, Tondora, Pavlo, and Stanhope (2017) make two important points (among others); 1). Patients with years of contact with psychiatric services are used to being told what to do (more or less explicitly); they are affected by the until recently dominating view of psychiatric illness as severely limiting the prospects of life. Bearing this in mind, it is not an easy task for patients to both trust the willingness of the professionals to release some of their decision-making power, and to trust themselves as capable of making life choices. 2).

The scope of SDM has changed for health care staff, from being focused on symptom control and making treatment decisions, to involving a commitment to understand the patient in order to assist an insecure or sometimes incapable person to pursue a meaningful life (for the patient, not as defined by the health care professional). The crucial tasks of seeing the patient as a person, and exploring the person's narrative, suggest PCC to be a salient component in successful recovery-orientation.

Empowerment

Empowerment has been defined both as a goal, in terms of having *control over determinants of qualities of life*, and as a process, entailing *interpersonal processes that contribute to increasing a person's control over those determinants* (Tengland, 2008). This involves power which is further clarified by the articulated aim for empowerment, expressed by Cattaneo and Chapman (2010) as "change in a person's social influence". They suggested a model of empowerment (understood as a process), based on six core components; goals (personally meaningful and power-related), self-efficacy (a belief in own ability to accomplish)[5], knowledge (on how to accomplish), competence (skills needed to accomplish), action (taking the decided measures to accomplish) and impact (accomplishment/failure and feedback). These core components are described as interacting to either enhance or obstruct the empowerment process and are all mediated by social context (Cattaneo & Chapman, 2010). Working in ways that are empowering for the patient thus needs to involve the elicitation of personally meaningful goals, creating opportunity and environment for patients to attain knowledge and develop skills, and encouraging patients to engage (acting towards the goals, e.g. making decisions) (Cattaneo & Chapman, 2010). For staff, this is also suggested to entail limiting one's own power over both the patient and the change process (Tengland, 2008). Self-

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[5] Self-efficacy, or trust in one's own ability to accomplish a specific goal, is a key feature in personal change and agency (Bandura, 1986). Bandura (1977) describes four main ways which promote self-efficacy; performance accomplishments which entail own experience of accomplishment, vicarious experience which refers to accomplishments by peers, verbal persuasion which means encouragement, and physiological (or psychological) states which refers to the physical (or psychological) response of a behavior.

efficacy is suggested as an important driver of the process (Cattaneo & Chapman, 2010). In turn, self-efficacy is sensitive to the impact (accomplishment or failure), which gives an example of the interactive relation. The described process highlights the importance of staffs' approaches to patient participation and decision-making.

Improved empowerment can be the result of successful SDM, as SDM involves increasing patients' control over decisions impacting on health and wellbeing (Duncan, Best, & Hagen, 2008). It could also be considered a prerequisite for SDM, as one will likely not engage in such a process without some level of empowerment (Dahlqvist Jönsson et al., 2015; Davidson et al., 2017). The two concepts are intertwined as they share several components and interact but differ in aims. The connection with SDM makes empowerment central in PCC, and further aligns with the PCC focus on capacity and building on patients' own resources (Entwistle & Watt, 2013). As described previously empowerment is also a characteristic of the recovery process (Leamy et al., 2011). That process starts for many people in utter insecurity over one's ability and future, it is therefore crucial to help patients "master" their situation, but to assist in personal recovery this help must be made in a manner that is empowering. Health care staff must therefore encourage patients to find own ways, instill hope of what is possible and assist with tasks that the patient is presently incapable of. This is the way that patients can grow, and take control of their own life situation and thus have the courage to start to envision life goals, and starting to pursue them (Davidson, Rowe, Tondora, O'Connell, & Lawless, 2008). In this sense, working to enhance empowerment in patients is of importance not only to regain mental health, but in the longer run to facilitate true recovery (Leendertse et al., 2021).

Recovery-oriented practice is the organization and delivery of care that aims to promote patients' personal recovery and thriving life in the community. Person-centered care, through its appraisal of personhood and proposed framework for care practice provides a clinical guidance to realize recovery-orientation with empowerment working as an important mediator for patients to take action and pursue recovery. SDM is a prominent feature in realizing PCC and a practical starting point highly interrelated with empowerment.

THE PERSON-CENTERED PSYCHOSIS CARE INTERVENTION

To align care with recovery-oriented practice, meet patient- and next-of-kin demands, and better adhere to clinical guidelines, the Person-Centered Psychosis Care project, PCPC, was initiated (Goulding, Allerby, Ali, Gremyr, & Waern, 2018). PCPC's overall aim was to increase person-centeredness at the inpatient care wards of the Psychosis Clinic in Gothenburg, a Swedish major city. The project was a collaboration between the Psychosis Clinic and the University of Gothenburg. Based on previous interventions organized by GPCC (Britten et al., 2020; Lindström & Hök, 2020), an educational intervention influenced by participatory design[6] (Spinuzzi, 2005) and Kotter's change theory[7] (Kotter, 2012) was launched. Staff were involved as co-creators in order to make use of their collective knowledge and achieve sustainable change. The intervention aimed to advance staff thinking and reform the practical work. This was to be achieved by mixing educational days of theoretical work with practical testing of PCC features in the everyday work at the wards. Change theory was included to equip staff with skills to create and test change projects on the wards, e.g. setting specific and measurable goals that are accepted and realistic with explicit time frames.

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[6] Participatory design is rooted in the democratization of knowledge-making and stresses the inclusion of participants (could be workers or members of an organization or community etc.) in the process of invention or development. The tacit knowledge participants hold should be explored and used, which can be done by allowing participants to work from their position, empowering them to evolve practices. This way, new practices, systems, or routines align with the tacit knowledge, rather than implementing a new system which disrupts participants' ability to use their skills optimally.

[7] Drawing on own experiences of changing organizations John Kotter describes eight steps to achieve sustainable change: 1) engage participants to see the urgency of change, 2) find influential persons to lead the change, 3) develop vision and strategy for participants to relate to and 4) comprehensively communicating it, 5) empower all affected to participate in a positive manner, 6) create short-term wins to credit and show participants change is happening, 7) use the short-term wins to create a momentum for the change process (following-through on the vision), and 8) ensure that the change is anchored in the organizations culture.

The educational intervention consisted of six conference days, spread over six months. During these days participants were introduced to the philosophy underpinning PCC and the GPCC framework in lectures. Workshops and reflective sessions in different formats such as Open Space[8] (Owen, 2008) and World Café[9] (Brown & Isaacs, 2005) were used to allow participants to process new information and experiences, and find collective targets for change and ways to act. Between educational days participants planned and carried out tasks to practically try out person-centered features. Examples of such tasks were listening to a patients narrative, co-creating a care plan with the patient and documenting that plan. Experiences from these "field testings" were then reflected upon during the following educational day, thus creating new knowledge and ways of thinking by mixing theoretical and practical experiences. To further broaden the understanding, patients and colleagues from the Psychosis Clinic's outpatient units contributed with their respective perspectives on care, the latter as they are working according to a person-centered care model (Malm, Ivarsson, & Allebeck, 2014). External educators from GPCC assisted with their broad knowledge of PCC and contributed with a second perspective; implementation know-how (including organizational psychology, and how to create feasible, evaluable projects).

One third of all inpatient care staff (10 from each ward), with all professions and roles represented, participated in the educational days, thereby being given the role of "change agents", the drivers of change in practice. Staff members

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[8] Open Space Technology is a method, or a meeting strategy, in which an unlimited number of participants share their perspectives and focus on developing solutions to complex problems. The participants are given only a preset theme, after which they themselves set the agenda for the Open Space meeting, which serves as a community-building activity that promotes engagement from all participating.

[9] World Café Methodology aims to share knowledge among participants and make use of their collective intelligence to find new ways to act or new desirable goals. A large number of participants are divided into smaller groups that are seated around "coffee shop tables" where they discuss pre-set questions in a solution-oriented way. After a pre-set time, participants shift table to continue discussions with a new group, thus "cross-pollinating" ideas and bringing the essence of the former conversation to the next rounds of conversation. At the end, key-insight or topics are visualized or summarized.

who did not take part were involved in the project through knowledge translation activities with course participants, to exchange experiences, ideas, and reflections.

The educational intervention set out to change both staff attitudes and everyday ward tasks. As a mean to that end, participants used their new knowledge and experience to create minor improvement projects to practice person centeredness and incorporate this into everyday practice. For example, staff created new routines that allowed enough time to listen to patients' narratives, a structure for writing care plans together with patients, improved the written information given to patients, and altered round routines to include the patients. The outcomes of the improvement projects were then reflected upon and revised during the ensuing educational days. After the last educational day, the project phased over to an implementation phase. Equipped with knowledge on PCC and how to work with change projects, staff were encouraged to continue the change projects as part of the everyday work, continuously changing practice to improve and refine the care process, also making a plan for the near future to continue the process. Some of the initiated projects proved not to be valuable and "died", while some transformed into new routines or new projects. During the implementation phase, booster PCC sessions were delivered to refresh the knowledge of experienced staff and to include new staff. Supervision sessions were also available for all staff in different forums delivered by professionals with PCC expertise from within the clinic. A steering group, consisting of ward managers, PCC facilitators, researchers and the clinic head had continuous meetings throughout the entire project to follow-up on progress and problems, adding support when needed, such as booster-sessions of PCC or audit of care plans to monitor progress.

The project started with the educational intervention in December 2014 and switched over to an implementation phase in May 2015. There was no real end of the implementation phase as the work to enhance and improve the PCC practice was supposed to continue. For research purposes the implementation phase was considered ended in May 2017, to provide a point of "post-intervention" measuring.

THESIS RATIONALE

Inpatient services play an important role in the care process for persons affected by psychotic disorders. Traditional roles for patients and professionals have been determined by a patriarchal hierarchy, informed by the biomedical perspective where professionals have the roles of experts and actors while patients have a more passive role (Ekman et al., 2014). The impact of the recovery movement in psychiatry and the strong push for patient involvement and autonomy by legislation and guidelines are changing the traditional care paradigm (Davidson, 2016; Swedish Code of Statitutes (2017:30), 2017; Swedish Council on Health Technology Assessment (SBU), 2012). Person-centered care aligns with that reorientation as it aims at changing the traditional care organization by putting the person being a patient at the center, elevating his/her role to equal partner in the care process, and focusing on individual visions of health (Ekman et al., 2011). PCC thereby holds promise to reduce the negative consequences of traditional approaches to inpatient care (Staniszewska et al., 2019). The suggested potential for several improvements to the care situation is supported by studies throughout different inpatient settings (Brownie & Nancarrow, 2013; Olsson et al., 2013). Within the psychiatric sub-specialty of psychosis care PCC has primarily been evaluated in outpatient settings (Malm et al., 2014; Stanhope, Tondora, Davidson, Choy-Brown, & Marcus, 2015) and the acute inpatient setting remains insufficiently explored as to how PCC could be incorporated and what it might achieve. The educational intervention and implementation project PCPC, for psychosis inpatient staff, aimed at increasing person-centered care by targeting staff attitudes and practical work. PCPC used a participatory design to engage staff as co-creators of a more person-centered inpatient service. In this thesis PCPC is evaluated to contribute with findings to address the overall research questions of how PCC can be incorporated in inpatient psychosis care and what outcomes it might achieve.

AIMS

The overall aim of this thesis is to explore outcomes and experiences of the Person-Centered Psychosis Care (PCPC) project, from the perspectives of patients, staff and next-of-kin. Specific aims are:

I. To test whether PCPC can be related to increased patient empowerment and improved service user satisfaction.
II. To test whether PCPC can be related to reduced duration of voluntary and involuntary inpatient stay.
III. To explore staff understanding of PCC, and their work to increase person-centeredness.
IV. To explore patients' and next-of-kins' experiences of care delivered after the PCPC intervention.

METHODS

In this chapter I will describe the different methods, sampling strategies, participants, data collection and analytical procedures that were used through the four studies included in this thesis.

DESIGN

Different methods were used across the studies to match the specific aims and to gain a wider picture of the achievements of PCPC in terms of both quantitative and qualitative input (Table 1). An uncontrolled before-and-after design was used to compare patient-reported outcomes in empowerment and satisfaction with care (**Study I**), and hospital data for length of voluntary and involuntary care (**Study II**). In **Study III** focus group interviews explored staff experiences of PCPC, while mixed interview types were used with patients and next-of-kin in **Study IV**. The timeline presented in Figure 1 shows time points for the data collection for each study.

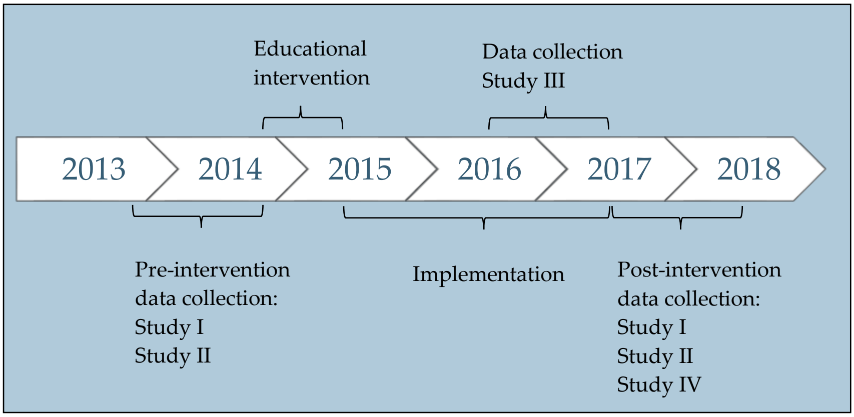

Figure 1. Timeline over data collection for Studies I-IV in relation to PCPC intervention and implementation.

Table 1. *Overview of design, data collection, samples and analysis in Study I-IV*

	Design	**Data**	**Participants/Sample**	**Analysis**
Study I	Quantitative pre-post comparison	Patient-reported empowerment and satisfaction with care	Inpatients with psychosis, recruited at discharge, *n* = 50+50	Statistical between-group comparison
Study II	Quantitative pre-post comparison	Length of voluntary and involuntary stay, using hospital administrative registry	Hospitalization episodes for patients with psychosis, *n* = 366+385	Statistical between-group comparison
Study III	Descriptive qualitative	Staff experiences of PCPC using focus group interviews	Purposefully sampled staff, *n* = 23	Thematic analysis
Study IV	Descriptive qualitative	Experiences of inpatient care, using focus group and individual interviews	Sub-sample of patients from Study I, *n* =5 Next-of-kin to Study I participants, *n* =11	Thematic analysis

SETTING

The PCPC project was carried out at the four inpatient wards of the Psychosis Clinic in Gothenburg, Sweden. The clinic is the main provider of psychosis care for the city's population of approximately 650 000 inhabitants. The wards provide acute care as complement to the outpatient services[10] which are the primary caregiver for persons diagnosed with a psychosis diagnosis (F20-F29). Patients are admitted primarily via the city's psychiatric emergency room. The wards have 11-13 beds per ward and are staffed primarily by nurses and assistant nurses who attend to the everyday care. A senior consultant psychiatrist is responsible for all treatments delivered and is assisted in the everyday management by resident and undergraduate physicians. Peer support, physiotherapists, occupational therapists, psychologists and social service counselors are available. Care and treatment decisions are primarily taken at rounds where the psychiatrist has a leading team role, but decisions are in varying extent discussed with the patient at doctor-patient consultations. The outpatient services are involved in discharge planning and some outpatient units/staff have a more active approach of visiting and taking part of the care process throughout the hospital stay.

SAMPLING & PARTICIPANTS

In **Study I** patients were recruited from the psychosis wards shortly before discharge to include patients with experience of the acute inpatient care who have recovered from the most acute state of the psychotic exacerbation. Patient records were monitored by a researcher and patients about to be discharged were approached by one of the researchers if the planned discharge was confirmed by the ward psychiatrist. To attain measures representing a large part of the patients using the psychosis inpatient services inclusion criteria were wide and exclusion criteria were kept to a minimum. Patients with a psychosis diagnosis, F20-F29 in accordance with the International Classification of Diseases (World Health Organization, 1992), who were over 18 years old were eligible. The two exclusion criteria were cognitive deficits in such severity that understanding study information or giving consent was

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[10] Swedish mental health care is organized with primary health care centers as the first line caregiver (for mental illness as well as all other non-acute conditions), serving patients with mild to moderate illnesses. Patients developing severe or complicated conditions are referred to the specialized psychiatric care clinics which provide outpatient care, with access to inpatient care for the management of the most acute phases.

impeded (as assessed by the patient's psychiatrist), and not being able to understand Swedish in such extent that study information and assessments could be understood (as assessed by staff). The latter exclusion criterion was chosen as using interpreters would introduce difficulty when assessing the responses of the Swedish questionnaires, not knowing how translators would interpret all items. Sampling continued until each group (pre- and post-intervention) reached 50 participants to assure large enough sample as advised by power calculations, with each sampling period lasting approximately eight months. A total of 185 eligible patients were approached by researchers with study information, and 102 of these signed consent forms to participate. Two were excluded as they did not answer the questionnaires.

There were no differences between participants and non-participants regarding age, gender, or admission status (voluntary/involuntary), but a diagnosis of Schizophrenia (F20) was more common among non-participants while non-organic psychosis (F29) was more common among participants (Fisher's exact test=8.52, two-tailed *p*=.035) pre-intervention. Characteristics for participants and non-participants for pre- and post-samples are presented in Table 2.

In **Study II** care consumption before and after PCPC was investigated by including all hospitalization episodes exceeding one day in length for all patients with a diagnosis of F20-F29 registered during two year-long measuring periods, one before and one after the intervention and implementation. This yielded a pre-intervention sample of 366 hospitalization episodes, pertaining to 275 unique patients, and a post-intervention sample of 385 episodes (299 patients). As some patients had hospitalization episodes in both the pre- and post-intervention samples, the total number of unique patients consuming the 751 episodes across both samples was 527. Distribution of diagnoses reported for each episode is shown in Table 3. The proportion of hospitalization episodes with care under the Compulsory Care Act was ~68% for both samples, yielding a subsample for LoIS analysis of 247 hospitalization episodes pre-intervention and 265 episodes post-intervention.

Table 2. *Characteristics of Study I participants and non-participants*

	Pre-implementation		**Post-implementation**	
	Participants (n=50)	Non-participants (n=48)	Participants (n=50)	Non-participants (n=35)
Mean age (SD)	48.0 (14.7)	49.9 (13.9)	46.9 (15.4)	46.4 (14.1)
Age range	20-78	27-77	19-84	21-88
	n (%)	n (%)	n (%)	n (%)
Women	23 (46)	24 (50)	20 (40)	15 (43)
Involuntary care	35 (70)	39 (81)	31 (62)	25 (71)
Schizophrenia	16 (32)	26 (54)	15 (30)	13 (37)
Schizoaffective disorder	11 (22)	13 (27)	10 (20)	7 (20)
Delusional disorder	6 (12)	2 (4)	10 (20)	3 (9)
Unspecified nonorganic psychosis	17 (34)	7 (15)	15 (30)	12 (34)

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Table 3. *Distribution of diagnoses registered in pre- and post-intervention cohorts for all included hospitalization episodes and the involuntary care episodes (LoIS-subsample)*

	Pre-intervention		**Post-intervention**	
	All episodes, n=366	Involuntary episodes, n= 247	All episodes, n=385	Involuntary episodes, n=265
F20 Schizophrenia, n (%)	155 (42.3)	108 (43.7)	133 (34.5)	89 (33.6)
F21 Schizotypal disorder, n (%)	1 (.3)	-	3 (.8)	2 (.8)
F22 Delusional disorders, n (%)	46 (12.6)	38 (15.4)	42 (10.9)	28 (10.6)
F23 Brief psychotic disorder, n (%)	22 (6.0)	14 (5.7)	24 (6.2)	21 (7.9)
F25 Schizo-affective disorder, n (%)	91 (24.9)	54 (21.9)	73 (19.0)	51 (19.2)
F29 Unspecified psychosis, n (%)	51 (13.9)	33 (13.4)	110 (28.6)	74 (27.9)

For **Study III** recruitment aimed at providing a heterogenous sample of staff to cover experiences of different professions, roles, and ward affiliation. Staff both with and without involvement in the PCPC educational days were included. Open invitations to participate were posted at ward offices, and invitations were emailed to all inpatient staff. The open invitation was followed by purposeful sampling in collaboration with ward managers to achieve representation of diverse staff characteristics. Participant characteristics including professions are presented in Table 4.

Table 4. *Characteristics of staff participating in Study III.*

		Mean (min-max)
Age*		41.8 (22–63)
Years employed in psychiatric services		9.2 (1–41)
Years employed at clinic		4.4 (.25–17)
		Nr (%)
Gender	Female	13 (56.5)
Profession	Registered nurse	7 (30.4)
	Nurse assistant	13 (56.5)
	Social worker	1 (4.3)
	Psychiatrist	2 (8.7)
Manager position		2 (8.7)
Participated in PCPC educational intervention		11 (47.8)
Experience of any type of PCC training prior to intervention		6 (26.1)
Previous experience of working with PCC		3 (13)

*Data missing for seven participants, calculations based on all others. Table reprinted from the original publication (Allerby, Goulding, Ali, & Waern, 2022) under the Creative Commons Attribution License 4.0.

Patients and next-of-kin were recruited for **Study IV** from participants in **Study I**. All patients recruited post-intervention for **Study I** were asked if they would: 1) accept to be contacted at a later stage with a proposal of an in-depth interview, and 2) provide a name for a next-of-kin that could be approached with the same proposition. In all, 25 patients gave consent to be approached of which five were reachable, accepted participation and showed up for the interview. Two were women, and ages ranged between 25 and 61 years with an average age of 45.6. All 25 next-of-kin named were approached by telephone, with an inclusion rate of ~44%. Non-participation was due to next-of-kin not being reached, not being able to participate because of time or travel restrictions, or not considering themselves involved in the care enough to have anything to contribute. A total of 11 next-of-kin agreed to participate of which nine were women. Ages ranged from 26 to 79 years old, with an average of 56.0. A majority were parents, although siblings, children and friends were represented.

MEASURES

The measures in **Study I** & **II** were chosen to reflect different aspects of PCC consequences, representing important outcomes from a patient perspective and from a clinical perspective. The centrality of empowerment as a process in both PCC (Morgan & Yoder, 2012) and personal recovery (Leamy et al., 2011) were reasons for choosing it as primary outcome for **Study I.** Satisfaction of care, was chosen as the secondary outcome as it has been presented as a consequence of PCC (Morgan & Yoder, 2012) and provides a measure of patient approval of the care. As severity of illness, level of function and overall health might affect both sense of empowerment and satisfaction, questionnaires to measure these variables were included.

Empowerment scale

The Empowerment scale was developed in co-operation with, and to assert empowerment in persons with mental illness, based on their definition of empowerment (Rogers, Chamberlin, Ellison, & Crean, 1997). The 28 items consist of statements reflecting five factors of empowerment; 1) Self-esteem - Self-efficacy (e.g. I generally accomplish what I set out to do), 2) Power -

Powerlessness (e.g. I feel powerless most of the time), Community activism - Autonomy (e.g. People have a right to make their own decisions, even if they are bad ones), Optimism - Control over the future (e.g. I can pretty much determine what will happen in my life), and Righteous anger (e.g. Getting angry about something never helps). Items are rated on a Likert type scale ranging from 1 (totally agree) to 4 (totally disagree) and summarized to an item mean total of maximum 4 (some items are reversed in the scoring process). The scale has been validated in samples of persons with serious mental illness (e.g., schizophrenia, major depression) showing excellent to satisfactory reliability and validity (Rogers, Ralph, & Salzer, 2010), also for the Swedish version (Hansson & Björkman, 2005).

Consumer satisfaction

The secondary outcome in **Study I** was rated using the UKU-ConSat rating scale, first developed for staff to assess patient satisfaction with care (Ahlfors et al., 2000), and later transformed into a self-assessment version for patients (Ivarsson & Malm, 2007). The self-assessment version showed acceptable consistency and satisfactory correlation to the primary scale (Ivarsson & Malm, 2007). The 11-item instrument reflects levels of satisfaction with different aspects of the care such as the possibilities to receive care as needed, the atmosphere of the ward, attitude of staff, possibilities to receive information and to participate in decision-making, as well as satisfaction with prescribed medication. Items are rated on a seven-point scale, ranging from -3 (very bad/negative/little) to +3 (very good/positive/much). Items are summarized into a total score, the higher the score, the higher the satisfaction.

Covariates

Severity of psychotic symptoms was rated using the Remission sub-scale (RSS) of the Positive and Negative Symptoms Scale (PANSS) (Kay, Fiszbein, & Opler, 1987; Opler, Yang, Caleo, & Alberti, 2007). Based on a structured interview with the patient, the assessor rates eight core symptoms for schizophrenia from 1 (missing) to 7 (extreme) according to a manual, yielding a total score between 8 and 56. We used the rating as a continuous variable.

The Global Assessment of Functioning scale (GAF) was used to assess patients' level of functioning (Endicott, Spitzer, Fleiss, & Cohen, 1976). Based on knowledge of the patient's activity and everyday functioning a score is made on a 100-point scale, with higher points indicating higher functioning.

Overall health was measured using the EQ-5D scale (EuroQol Group, 1990), a self-rating scale developed to capture health through five items reflecting mobility, self-care, usual activities, pain/discomfort and anxiety/depression, along with a Visual Analogue Scale (VAS) of perceived health. The ratings are calculated to an index ranging from -.594 to 1, the latter reflecting optimal health. The scale is used generically and has shown reasonable validity when tested specifically within a psychosis sample (König, Roick, & Angermeyer, 2006).

Care consumption

The primary outcomes in **Study II** were length of hospital stay (LoS) and length of involuntary stay (LoIS). LoS was measured as the number of days from admission to discharge (both voluntary and involuntary days included). LoIS represents only the involuntary days, that is the number of days with treatment under the Compulsory Care Act (Swedish Code of Statitutes (1991:1128), 1991). Both outcomes were calculated per hospitalization episode, not per patient, meaning that an individual patient could be represented several times if readmitted during the measurement period.

The secondary measure in **Study II** was rapid readmission defined as readmission to a psychiatric clinic within 14 days of discharge. This was chosen to reflect patients' stability at the time of discharge, or whether sufficient support was planned and engaged when discharged. This measure was included to check whether results in the primary outcomes might have consequences in terms of readmission.

DATA COLLECTION & PROCEDURE

Data collection for **Study I** started with the signing of a consent form after the patient had been given study information verbally and in writing. One of the researchers sat down with the patient, most often in a room at the ward, where questionnaires and assessment interviews were conducted. The researcher assisted patients with filling out the questionnaires or reading items if needed. Data collection took approximately 45-60 minutes per patient. Information needed to complete covariate-assessments were gathered from staff; GAF rating was conducted by a staff member who knew the patient well, who also assisted in the RSS rating. Background data were collected from medical journals.

Data for **Study II** was retrieved from the administrative register of the Psychosis Clinic, by administrative staff at the clinic.

In **Study III** and **IV** focus group interviews were conducted to collect data. A focus group is basically a *group* of individuals gathered to discuss a specific phenomenon or shared experience, in a *focused* discussion. This is an alternative to individual interviews that capitalizes on the gains of social interaction to provide a rich data set with aspects that might not emerge in single interviews (Guest, Namey, Taylor, Eley, & McKenna, 2017; Kitzinger, 2007). The discussion is facilitated by a researcher who has a more downplayed role than in individual interviews, facilitating all participants' contributions to the discussion and assuring that the discussion retains its focus on the topic (Klingberg & Hallberg, 2021).

Recruited participants for **Study III** were invited to one of six focus group interviews, each participant participating once. We chose localities close to the wards for easy access from the participants' workplace. Focus groups started with the reading of study information and signing of consent forms along with gathering of background data. Two researchers attended each interview, one leading the interview, and one assisting and monitoring. Researchers presented themselves and their role in the PCPC project. The format for the interview was introduced, emphasizing the importance of a friendly atmosphere and the requirement that interview content not be spread to others. A semi-structured interview guide, created by the researchers, and guided by Kvale & Brinkmann (2014) was employed. The guide covered the research question of how staff had engaged with PCPC in terms of understanding PCC and practicing it, with questions such as “What is person-centered care to you?”, or “Describe downsides or problems in working person-centered”. The researcher leading the interview used follow-up questions and engaged less talkative participants to attain a depth and range in the interview material. Each interview was concluded by asking if there were something participants felt they wanted to discuss further or add that had not been approached.

A similar approach was adopted for the focus groups with next-of-kin in **Study IV**. These focus groups were held at a research facility near the city center for easy access. Due to the inability, or preference, to join at the time set for focus groups, some interviews were instead individual and conducted either at the research facility or in the home of the participant. Patients participating were all individually interviewed after discharge, and all chose to do the interview in the hospital facilities (not at the wards). All interviews (focus group and individual) started as described above with collection of consent, background data and a presentation of the study, with the addition of “social rules” for the focus group participants. Semi-structured interview guides were used that covered the research question “how do patients/next-of-kin perceive the inpatient care following a PCC intervention?”. The drafting of the next-of-kin guide was guided by Krueger’s structure for focus group interviews (Krueger, 2014). Questions covered the perception of todays’ inpatient care in general, personal experiences and perceived changes. The patient guide was constructed with the same reference and procedure as described for **Study III**. Questions for patients included “What was it like to arrive at the ward?”, “What did you do on an average day at the ward?”, “What are your thoughts of the care and treatment you received?”

DATA ANALYSES

Statistical analyses

All quantitative data was analyzed using IBM SPSS Statistics, version 28. Descriptive statistics were used to present variables with means and standard deviations for normally distributed variables, and medians for skewed data. Group differences were tested using Student’s t-test, Mann Whitney U-test or ANCOVA for continuous variables, while Chi^2 goodness of fit, risk differences with confidence intervals, and Fisher's exact test were used for categorical variables. Significance was assumed for p-values lower than .05, following the golden standard for significance cut-off (Björk, 2011).

Qualitative analyses

We chose a thematic analysis for **Studies III** and **IV** as it suited our purposes of finding themes, in staff, service user and next-of-kin descriptions of their experiences. The six steps described by Braun and Clarke (2006) guided the analysis although adding sub-themes. The analyses were conducted at a semantic level, keeping interpretation close to the explicit expressions in the data. In a first step the data was made familiar by re-listening to all recordings and proofing the transcripts (as they were transcribed by a professional transcription service), and all transcripts were read in whole. In a second step initial coding was initiated as meaning-bearing pieces of text were marked with codes throughout all transcripts. In a third step the search for themes began as codes were compared, and different groupings tried out to capture main- and sub-themes. Preliminary themes were then checked against all meaning-bearing units and the whole transcript, adapting and moving codes to tighten main- and sub-themes in the fourth step. The themes were further adjusted until all codes had been included and all themes could be defined and named in the fifth step. The sixth step consisted of report writing, where a final overview of the thematization was done and some final adjustments were made. In **Study III**, the first interview was double coded and compared between two researchers, and differences discussed until reaching consensus. The remaining coding was done by one researcher. The thematization process involved a continuous discussion leading to the setting of the final themes. The coding and analysis software program NVivo12 was used to manage all steps following the initial coding. None of NVivos automation tools were used.

Study IV involved two separate analyses, one for data from patients and one for next-of-kin data. Both analyses followed the procedure described above. The thematic structures for both analyses were compared and a large overlap was observed so results were integrated. All analyses were made manually for **Study IV**.

Epistemological assumption and trustworthiness

I have taken a realist perspective when considering the qualitative data, meaning an assumption that it is possible to reach a fair understanding of "the real world" from the participants' descriptions and experiences, without conducting a more comprehensive study of the cultural context or social structures (Braun & Clarke, 2006). However, I also adhere to a hermeneutic view of how to understand that reality. The hermeneutic view suggests that we, as humans, interpret and understand everything around us through our preconceptions, which means there is no way to be completely objective. New understandings can however emerge through a process of moving between the past and the present, between the parts and the whole (Dahlberg, 2008). As our history and experiences will guide how we chose to ask questions, what aspects of a phenomena pop out and what meaning we attribute an event, it will impact on the outcome of research. To report authors' preconceptions or measures of reflexiveness is encouraged when publishing qualitative research, (O'Brien, Harris, Beckman, Reed, & Cook, 2014; Tong, Sainsbury, & Craig, 2007) as this gives the reader a chance to assess what has influenced the analysis, thus increasing the credibility of the study (Dodgson, 2019). Although impossible to supply a full picture of the preconditions affecting the data collection and analysis in **Studies III and IV**, I will shortly describe some characteristics of the research team. My own preunderstanding is much affected by the many years of work with persons with psychotic disorders. Although working mainly in the outpatient settings, there have been many visits to and some work in the inpatient settings leaving both positive and negative impressions. I have further experiences as a next-of-kin to a person with serious mental illness, where I felt much left out. My previous research has involved patients with psychosis and caregiver burden (Allerby et al., 2015; Brain et al., 2014). In PCPC I was not engaged in the educational intervention and had no previous relation to any of the participants in **Study IV** but was briefly known by some in **Study III**. All members of the PCPC research team had professional experiences of psychiatric care (involving both positive and negative impressions), and research areas (outside PCPC) such as suicidology, e-health support for mentally ill and psychotic conditions. Multiple researchers participated in the different stages of the studies which reduces the influence of personal bias. The fact that several researchers were involved enhanced reflexiveness since interpretations of data were questioned and discussed, forcing a reflection on what may guide certain interpretations (Graneheim & Lundman, 2004).

ETHICS

All studies were approved by the Regional Ethics Board in Gothenburg, registration number 773-13. The studies adhere to the principles of the Helsinki Declaration (World Medical Association, 2001) in putting the good of each patient first, protecting their rights, integrity, and privacy. All participants in **Study I, III & IV** received study information (verbally and in writing), including statements on voluntary participation, the possibility to withdraw without consequences, that decisions regarding study participation would not affect the care, and that data would be anonymized. All signed a consent form before participation. **Study II** involved hospital administrative data where no consent was required. To avoid the risk of enrolling patients in **Study I** unable to properly understand study information (due to cognitive dysfunction) patients potentially unfit, as assessed by psychiatrist, were not approached. In **Study III** & **IV** quotes used in the publication to visualize the content of the themes were cited using code names only, leaving out any participant characteristics to avoid risk of recognition by fellow colleagues and readers. All data, electronic and material, have been kept in password protected and locked spaces to protect against sensitive material coming into wrong hands or being destroyed by accident.

The Helsinki Declaration further stipulates that potential risks must be assessed and reduced, and weighted against benefits (World Medical Association, 2001). In **Study I** we took into account the vulnerable state of patients recovering from severe psychosis by limiting the number of questionnaires. We did not anticipate that our study questions would cause discomfort, but ward staff were available to provide support should this occur. There were however no reports of patients needing such support. In **Study**

IV participants were instructed to get in touch if they needed support following the interview. As person-centered care is scarcely studied in the psychosis inpatient setting, and holds potential for much needed changes, we deemed that the risk of discomfort that study participation might evoke did not outweigh the benefits of the study.

The PCPC studies were registered while data collection was ongoing at ClinicalTrials.gov, identifier: NCT03182283.

RESULTS

In this chapter I summarize the results for each study.

PATIENT REPORTED OUTCOMES

In **Study I** descriptive statistics showed no differences between the pre- and post-intervention sample on age, gender, diagnosis, severity of psychosis or involuntary care status. Two of the included covariates, GAF and EQ-5D showed higher levels of functioning and overall health in the pre-intervention sample. We found a significant correlation between these variables (Pearson $r = .31$, $p = .002$) and as this could represent an overlap in what was measured, we chose to include only EQ-5D as a covariate in the main analysis, as this measure was patient-reported. After adjusting for the covariate, estimated marginal mean for the empowerment score was higher in the post intervention sample, 2.99 (*SE* = .047) as compared to pre-intervention sample 2.87 (*SE* .048), but the result was not statistically significant, F (1, 96) = 2.2, $p = .142$, $eta^2 = .02$. Our primary hypothesis was thus not supported. Using the same covariate, the ANCOVA for patient satisfaction with care showed a significant difference between the samples with higher satisfaction in the post-intervention sample; 11.71 (*SE* = 2.15), vs the pre-intervention sample; 4.46 (*SE* = 2.15), F (1, 96) = 4.29, $p = .041$, giving support for our second hypothesis. The effect size was low, $eta^2 = .04$.

CARE CONSUMPTION

In **Study II** the length of hospital stay (LoS) had a mean duration of 40.8 (CI = 34.9-46.6) days in the pre-intervention sample, and 45.9 (CI = 41.7-50.0) days in the post-intervention sample. Corresponding means for length of involuntary stay (LoIS) was 32.3 (CI = 26.5-38.1) pre-intervention and 35.9 (CI = 31.7-40.1) post-intervention. These variables were heavily skewed in distribution which led us to use a non-parametric test. The Mann-Whitney U-Test showed a significant difference between samples, with longer LoS in the post-implementation sample (*Md* = 34.2, *n* = 385) as compared to pre-intervention sample (*Md* = 25.2, *n* = 366), *U* = 81409.5, *z* = 3.68, *p* < .0005, *r* = .13. The Mann Whitney U-test was again used to compare LoIS, finding a difference between samples with longer LoIS in the post-intervention sample (*Md* = 39.0, n = 265) as compared to the pre-intervention sample (*Md* = 28.0, *n* = 247), *U* = 37585.5, *z* = 2.91, *p* = .004, *r* = .13. To control the influence of hospitalization episodes pertaining to patients represented in both pre- and post-intervention samples, these episodes were excluded in a post-hoc analysis. The results of these Mann Withey U-tests were similar but more pronounced for both LoS and LoIS. In an explorative analysis the proportions of inpatient days spent under the Compulsory Care Act out of all inpatient days were calculated and compared in a cross tabulation, calculating risk ratios. We could not assume a difference between samples from the risk difference of .003 (90.6% vs 90.3%), *CI* = -.006; .012.

The proportion of hospitalization episodes followed by rapid readmission, our secondary outcome, was 7.7% in the pre-intervention sample as compared to 5.2% in the post-intervention sample. A chi-square goodness-of-fit test showed that this was not a significant difference, χ^2 (1, *n*=385) =3.4, *p*=.065. A post hoc analysis excluding patients represented in both samples showed similar results.

STAFF EXPERIENCES

The result from the thematic analysis in **Study III** provided us with three main themes with a total of ten sub-themes, all shown in Table 5.

These themes reflected different aspects of the PCPC intervention and implementation. *From theory to practice* showed how participants understood PCC, what expectations they held for PCC and further how they enacted person-centeredness in the everyday care at the wards. PCC was thought of primarily as an approach, rather than a method, in which the person being a patient became the focus of interest. Patients being resourceful and active in the care process emerged as a core feature of PCC. This view also enacted in practice as staff worked to facilitate patient participation and utilized patient resources to encourage them to be active. The patient-staff conversation emerged as the starting point for person-centered encounters where staff consciously engaged in an individualized manner.

Table 5. *Themes and sub-themes in Study III; Staff experiences of PCPC*

From theory to practice				
The theoretical understanding of person-centered care	Expectations on increasing person-centeredness	Person-centeredness put into practice		
Experiences of change				
Improved relations	Patient engagement	Professional growth	A better care environment	Lack of change
Barriers and facilitators for person-centered care				
Barriers	Facilitators			

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In *Experiences of change* improved relations with patients was described as a result of the person-centered approach, also leading to more active patients. Some staff experienced a positive evolvement of their professional role. The overall care environment was regarded as improved. The ward climate became more open and calmer; threatening situations and coercion could be averted, and staff found smoother ways to work. A few participants however addressed the lack of change on either the personal or ward level.

Within the theme *Barriers and facilitators for person-centered care* the fuzziness of the concept PCC and the absence of explicit routines (relating to the choice of participatory design) were described as difficulties. The implementation process was slowed down by everyday tasks which had to be prioritized over the staff-initiated intervention activities to promote change. Diverse opinions and lack of commitment on the part of some care professionals (in particular psychiatrists) were other barriers described during the interviews. Difficulties relating to patient interactions were primarily related to the situations that warranted the use of interpreters. Informal enthusiasts and formally designated PCC resource-persons were perceived as facilitating, as was the across-ward focus on a care planning routine. Facilitators were also described in terms of staff qualities. Adopting a person-centered communication style (among staff) was such a quality; continuous discussions resolved disagreements and helped staff advance a joint understanding. Having diversity among staff and being solution-orientated was also put forward as facilitating.

PATIENT AND NEXT-OF-KIN EXPERIENCES

In **Study IV** two main themes were found which described different aspects of the care experience: the *Care environment*, and the *Care quality*, both containing three sub-themes each.

Participant experiences of the care environment clustered around the *physical environment*, the *psychosocial environment*, and the *organization of staff*. The physical milieu was described mostly in negative terms and was found to be cramped or crowded, with few private, safe spaces or rooms for conversation. Positive statements stemmed from experiences of single rooms that could be personalized. The psychosocial environment was described in diverse statements, with some reflecting a tough or aggressive milieu, and others saying they experienced the ward as calm and nice. Staff approach affected the psychosocial environment and was often considered good, described with terms such as empathic, kind and welcoming. There were however also experiences of staff being distant or unavailable, or failing to meet the patients or next-of-kin in their emotional state. The third sub-theme concerning organization of staff was described by next-of-kin only. Again, perceptions differed with some finding the level of staffing to be robust and others relating a constant lack of staff. Similarly, some noted the disruption of relations with staff in connection with vacations and other situations in which contact persons changed[11]. Others emphasized the continuity of relations as the patient met the same staff during previous admissions. Other staff-related negative aspects from the perspective of the next-of-kin included a general lack of knowledge about the care of persons with psychotic disorders, as well as a power hierarchy with the psychiatrist at the top.

The quality of care was reflected through the *care content*, *communication* with staff, and *involvement* in the care process. Both involuntary care and medication were described by several participants, and this was mainly in negative terms. Involuntary treatment was perceived like a punishment. Care consisting primarily of medication was one criticism, and others reflected that decisions regarding medication were taken without the patient's approval or preferences in mind. There were however some statements showing that both involuntary care and medication were sometimes retrospectively perceived as necessary and contributing to positive outcomes. One content of care that was considered supportive was the contact person. However, problems emerged in terms of the organization of staff which resulted in the contact person not being on the ward for several days. Others did not connect with their appointed contact person or were unaware that they had one. Communication was described in many ways and participants were content when communication existed, was informative and was working to include patients or next-of-kin. Such communication could facilitate recovery. Discontent arose when information from staff was lacking, information to next-of-kin disregarded, and when communication was used by staff in an oppressive manner. Patients further described difficulties in receiving information and engaging in communicative processes during an acute psychotic episode. Participants depicted both experiences of wanting to participate in care but being blocked in different ways, and experiences of being pressured to participate although not wanting or being able to. Some participants related positive experiences, reflecting on how they felt an important part of the care

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[11] A contact person is a staff member specifically assign to a patient as the primary contact. S/he is responsible for managing requests from the patient and keeping contact with next-of-kin and care partners. All patients are assigned contact persons.

team, and that staff worked to include all patients, even those who were involuntarily committed, in the care process as much as possible.

DISCUSSION

In this chapter I discuss the findings from **Study I-IV** to achieve a comprehensive understanding of the experiences and the outcomes of the PCPC project and their contribution to the overall research question regarding PCC in inpatient psychosis care. However, I start with addressing the methodological considerations as they include some important limitations to how the findings can be interpreted and used, and as such are important to keep in mind when considering the discussion of study findings.

METHODOLOGICAL CONSIDERATONS

This thesis adopted a multi-method design to pursue different kinds of findings to answer the overall aim. These methods however come with different limitations, and I will go through our considerations regarding them.

Degree of implementation

A first major limitation, affecting all four studies, is the uncertainty of "how much" PCC was implemented. Measuring the level of PCC is quite a complex enterprise. Several aspects need to be considered. Firstly, to what extent have the thinking and attitude of staff changed to become more person-centered? Secondly, to what extent has this become visual in the practical work; what "dose" of PCC was administered to the patients, and how systematically was this done? A third aspects is the extent to which patients benefited or were affected by the changes; were the changes relevant to increase PCC from a patient point of view? There are today many scales that measure different components of person-centered care, depending on which definition of PCC is used (De Silva, 2014), with some taking a somewhat "overall" stance, aiming to capture person-centered attitudes and climate (Edvardsson, Koch, & Nay, 2010; Edvardsson, Sandman, & Rasmussen, 2008; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2012). Capturing the level of PCC more thoroughly is a larger and complicated task that would entail observation of every meeting between patients and staff. Combining different kinds of tools and targeting different aspects of PCC is today the most sound way to capture PCC (De Silva, 2014). This study however lacks any measurement of these aspects of implementation which leaves us without quantitative knowledge on the success of the intervention. One reason for this was the lack of measurements validated for psychiatric inpatient settings. Another reason was the tough prioritizing of what questionnaires to distribute to patients. We tried to narrow this as much as possible as many patients in our settings are cognitively affected and still in symptomatic recovery. As an example of this, a measurement of person-centered climate (Edvardsson et al., 2008) was added in the set of questionnaires to post-interventions patients (in an effort to validate this instrument for future use in inpatient psychiatry), it however turned out that a large part of these ratings were left unanswered as many patients simply could not manage to concentrate after doing the primary ratings. Recruiting staff for a similar rating would provide some estimates but this was not included in the ethical approval. Future studies should consider ways to incorporate some measure of PCC.

Design of Study I & II

A second major limitation concerns **Study I & II** and the uncontrolled before/after design. This choice of design prevents us from drawing firm conclusions regarding intervention outcomes. The golden standard for testing effects, a randomized controlled trial (Craig et al., 2013), was however not possible. Randomizing individual patients to PCC or a control group was not feasible as the intervention sets out to change staff's mindset, something that cannot be turned on or off for different patients within a ward. Randomizing wards, using one or two of the four psychosis wards as controls, would have undermined the power, and risked contamination and erroneous effect sizes, as patients and sometimes staff move between the wards. Further, an RCT study would have required a considerably prolonged recruitment period. A cluster randomized controlled trial would have surpassed these problems but requires a much larger trial at the regional or even national level and comes with difficulties such as difference between clusters in measures difficult to control for, such as readiness for change, evolvement of intervention and the impact of the local organization on implementation). As discussed by Craig et al. (2013), reflecting on how to evaluate complex interventions, there is not always the possibility of adopting a rigorous experimental approach when implementing a complex intervention, but evaluating is important and strategies, such as using multiple methods with different weaknesses, could contribute to enhanced design. We decided to go ahead with the weaker design in **Study I & II** as the tentative results from these studies could be discussed further in the light of the findings of the qualitative **Studies III & IV**, contributing with triangulated insights to the scarce literature on PCC in the psychosis setting. Considering the complexity of PCC and its implementation in a complex setting like ours, alignment with the Medical Research Councils (MRC) guidance on development and implementation of complex interventions (Craig et al., 2013; Skivington, Matthews, Craig, Simpson, & Moore, 2018) is desirable, as this outlines measures to entangle complexity and more precisely use different methods to strengthen findings, e.g. the use of process evaluation.

Lack of control of confounders

Study II is to be interpreted with great caution as our hospital administrative data did not include important socio-demographic variables such as ethnicity, nor were there clinical parameters like symptom ratings and measures of cognitive function. Confounders could be checked for the subsample who provided such data in **Study I**.

Choice of measures

Choosing the Empowerment scale was at the time a natural choice as this instrument is founded on mental health users' own perceptions of empowerment, and it is validated for persons with severe mental illness and applied in mental health research (Rogers et al., 1997; Rogers et al., 2010). Also, the Swedish version has been psychometrically tested showing good internal consistency (Hansson & Björkman, 2005). While the Empowerment scale covers recovery-oriented phenomena such as thriving and having control over one's societal life, it does not specifically target interactions with health care. While the wider scope of the Empowerment scale is a highly relevant one, it is not optimal for the measurement of change in empowerment in the context of inpatient health care. Recent instruments that include an explicit focus on health care, not available at the time of our study initiation, would be more appropriate for future studies. One example is the Netherlands Empowerment List (Boevink, Kroon, Delespaul, & Van Os, 2016) which might have greater potential to evaluate benefits of future person-centered care interventions.

Rating satisfaction comes with some considerations as well. Early works on the measurement of satisfaction with care suggested that actual outcomes of care interventions might only explain a small percentage of patient-rated satisfaction. Instead, ratings might reflect a perception of improved health status (Kane, Maciejewski, & Finch, 1997). Other have suggested that satisfaction might not be an appropriate measurement of quality of care (at least not in an objective way) as patient ratings are affected by their subjective expectations of care and personal preferences (Sixma, Kerssens, Campen, & Peters, 1998). While qualitative data might better illustrate what aspects of care are causing dissatisfaction (Duggins & Shaw, 2006), ratings covering both the process and outcome of care could supply an assessment of the quality of care, and the UKU-ConSat was constructed to do that (Ahlfors et al., 2000). We took into account possible confounding variables such as age, legal status and severity of symptoms as suggested by a previous review (Miglietta, Belessiotis-Richards, Ruggeri, & Priebe, 2018), we however did not specifically measure depression which has been pinpointed as a confounder on its own. Patients' expectations of care are not covered by this instrument, but we have no reason to believe that patients would have lower expectations in the post-intervention period.

We used the Remission sub-scale of the PANSS interview (RSS) to shorten interview time by concentrating on the core symptoms of schizophrenia (Kay et al., 1987). In doing so we have no data pertaining to psychotic symptoms beyond the sub-scale selection, and the general symptoms often associated with psychotic disorders, e.g. depression (Kay et al., 1987).

Choice of qualitative analysis

Our aims in the two qualitative studies were to explore staff experiences from the PCPC project (**Study III**) as well as patient and next-of-kin experiences of inpatient care after the intervention (**Study IV**) We chose to conduct thematic analyses as this method 1) provides a sound structure for finding and reporting themes or patterns, and 2) allows for analysis of texts covering broad areas (not dependent on narrowing the scope to explore a one defined phenomenon or aspect)(Braun & Clarke, 2006). This was suitable as we wanted to report a comprehensive description of all aspects of the interviews. This broad scope was pursued at the cost of a more in-depth examination of each aspect in the material, giving a rich, yet "superficial" account of the material. Looking ahead it would be possible to return to the staff and next-of-kin interviews to look more closely at a narrowed scope. The interviews with service users provided less rich descriptions and a deeper analysis approach would thus be less applicable. Conducting more in-depth analyses would provide another type of insights that could more profoundly tell us something about how PCC is understood, practiced, or related.

On trustworthiness and reflexivity

I would argue that all research is to some extent affected by the researchers involved as their preunderstanding will affect the formation of research questions, choice of method and analysis, and interpretation of results. This is of course most explicit in qualitative research where the researcher as a person is integrated in the analytical process, balancing the subjective input with the demands of an objective analysis (Graneheim & Lundman, 2004) in which the personal bias is impossible to completely sidestep. While several measures were taken to pursue trustworthiness in the qualitative studies, as described previously, no formal strategies such as audit trail or triangulation were employed. An informal member checking took place as staff was invited to discuss finding from **Study III** when preliminary findings were presented on the wards. Overall, staff agreed with the presented findings; no objections emerged, and analyses were finalized.

The sampling strategy for **Study III** does not align with Krueger's (2014) suggestion that randomized sampling and homogeneous groups are preferable to allow for generalization of findings (external validity). It however contributed to internal validity as the strategic sampling ensured a heterogenic sample, increasing the possibilities of finding different experiences. Further, the generalizability of qualitative findings is not straightforward. Reflexivity again plays a major role in combination of well-described context and participants to allow the reader to judge whether findings are transferable to other settings (Graneheim & Lundman, 2004; Malterud, 2001). An important reflection on the overall positive experiences reflected in **Study III** is that the sample might have consisted of staff generally more positive to PCPC, which could be a result of the sampling strategy in which staff members less interested or supportive of PCPC would not have volunteered for participation. The sampling for **Study IV** was limited by the practical decision (and in accordance with our ethical approval) to recruit from the **Study I** sample, and the sample size turned out small. This might affect the result as a larger sample would most likely have contributed additional aspects and experiences of the care delivery. The material however included a wide range of experiences which provided insight into the uneven "real life" delivery of PCC following the PCPC intervention. Some participants declined due to time or travel restraints. Future studies could consider using online interviews to increase participation. Studies reporting on online interviews through digital services are overall positive as targeted populations are generally positive to the time effectiveness, and the distant but still visual connection these applications supply (Deakin & Wakefield, 2014; Gray, Wong-Wylie, Rempel, & Cook, 2020). Interview quality is comparable to the face-to-face set up (Greenspan, Gordon, Whitcomb, & Lauterbach, 2021; Halliday, Mill, Johnson, & Lee, 2021). There are however considerations to be made relating to digital literacy, technical preparations, and limitations related to the interaction by the digital interface (Adams ‐ Hutcheson & Longhurst, 2017; Falter et al., 2022; Greenspan et al., 2021).

UNDERSTANDING THE FINDINGS

The status quo of empowerment

Empowerment is a central feature of PCC, but the somewhat higher level of empowerment found in the post-intervention sample was not statistically significant **(Study I)**, and thus considered unchanged. The lack of change in empowerment could be due to the scope of the Empowerment scale, as discussed in the methodological considerations above. Other interpretations could be that PCPC could not affect patient empowerment, or that it could but was insufficiently implemented to demonstrate change at the group level. Findings from **Study III** indicate that patients changed their behavior and became more active or demanding, which staff related to patients being included in the work with care plans and getting more information about their care. Similar experiences have been reported from medical wards after the implementation of the GPCC model of PCC; well-informed patients aware of their influence and capability, was suggested to have higher engagement in self-care (Wolf et al., 2017). Other studies describe patients as being more independent with PCC in place, while showing less self-esteem and becoming passive in units where PCC were not in place (Fridberg, Wallin, & Tistad, 2021). These are indications that the Gothenburg model of PCC impacts on empowerment and I will return to the empowerment model described in the introduction to look more closely at how this can be understood in the PCPC project. As a reminder, the model describes six interacting components; meaningful goals, self-efficacy, knowledge, competence, action and impact, which, affected by the social context, contributes to empowerment (Cattaneo & Chapman, 2010). Staff interviews (**Study III**) illustrate efforts to engage patients in SDM and participation by enhancing information, preparing them for meetings, and co-creating care plans or "letting them" do practical tasks themselves (instead of taking over). These examples target the self-efficacy (partially), knowledge, competence and action components. There is less evidence from the staff interviews regarding goals and how the impact component was handled in terms of how patients' attempts to co-decide or take action was received. Patients taking a more active role was however described in positive terms, indicating positive feedback from at least some staff. Some patients and next-of-kin described being invited and encouraged to participate, but others experienced that decisions were taken without their influence; next-of-kin felt shut out, and patients felt told what to do. So, while PCPC seem to have the potential of increasing empowerment by addressing the components, the heterogenic delivery described in **Study IV** suggests insufficient implementation. Negative impact on attempts to accomplish a goal could decrease empowerment (Cattaneo & Chapman, 2010), which could further explain our finding of status quo. While some patients might have experienced greater empowerment, some patients might have been disempowered by being encouraged to engage by some staff but then having negative impact from other, e.g. being told what to do at the care planning meeting instead of having a true say.

The social context also needs some exploration as it holds major influence over the empowerment process, especially to the impact component (Cattaneo & Chapman, 2010). Cattaneo and Chapman (2010) note that barriers for empowerment involve power dynamics, which often become clear when the impact is evaluated. The effects of such power dynamics is touched upon by Davidson et al. (2017) as they described how the starting point for many psychiatric patients entering the recovery-oriented process involves dealing with self-stigma and the legacy of being told what to do. They suggest that great trust must exist for patients with a long experience of psychiatric care to engage in sincere co-planning. A relevant question is then how staff can put in the time and effort needed to show the individual patient that the inclusion of him/her in the care planning process is a genuine attempt to transfer power and promote that patient's own agenda. This is especially challenging considering the acute, sometimes hectic or chaotic, psychosis inpatient setting. **Study IV** gave some examples of staff being too busy or distant from patients and psychiatrists not engaging in PCC, although there were also reflections of staff "being there" for the patients. **Study III** describes not all staff engaging in PCPC or explicitly not wanting to work in a PCC manner which suggest the social context (in terms of the care environment) does not systematically work in favor of patient empowerment. Previous research shows that professionals regard patients limited decision-making ability a hinder for SDM (Beitinger et al., 2014) while patients describe the SDM situation as a struggle to be recognized as a competent and equal partner (Dahlqvist Jönsson et al., 2015).

There is here an important tension between a patient's need to be trusted as a capable partner and the care professional's complicated trust in the patient's ability. Such tensions need further exploration in future studies.

Improving satisfaction with care

The finding of increased patient satisfaction (**Study I**) following the intervention supported our hypothesis. While it might be contributed to factors outside our intervention there are indications from the qualitative studies aligning with previous research which supports the suggestion that PCPC improved patients' satisfaction with care. A recent review of PCC outcomes found that good work environment was a defining factor for greater patient satisfaction (van Diepen, Fors, Ekman, & Hensing, 2020). Ward atmosphere has also been reported to improve satisfaction in inpatient psychiatry (Middelboe, Schjodt, Byrsting, & Gjerris, 2001). Evaluations by psychosis inpatients further suggest a strong association between satisfaction with care and perceptions of the care environment (Røssberg, Melle, Opjordsmoen, & Friis, 2006). Røssberg et al. (2006) found that high levels of patient involvement and practical orientation, along with low levels of angry/aggressive behavior and staff control were the most influential factors. Similar findings are reported from qualitative studies showing that fear of violence, lack of autonomy, patient-staff communication and ward routines impact on satisfaction with care in inpatients with psychotic illness (Duggins & Shaw, 2006). The **Study III** sub-theme *A better care environment* shows how the ward was perceived calmer, with less aggression and a higher level of equality between patients and staff. The sub-themes *Improved relations* and *Person-centeredness put into practice* further illustrate how staff prioritized time with patients, making sure they had information and were involved in care planning and other practical tasks, leading to more and better relations. Listening to patients and letting them make decisions when possible (**Study III**), further aligns with respecting autonomy, and adapting routines to allow flexibility aligns with decreasing staff control in favor of patient preferences. Participants in **Study IV** make some references to increased participation, and overall staff was regarded as being nice, but several accounts also suggest that many features remain discouraging. The care milieu was at times described as messy or scary, and having to share a room prevented the feelings of having a safe space for oneself. There were also several accounts of patients and next-of-kin being run over in decisions and denied opportunity to influence the care. These accounts reflect the perspectives of a small number of patients and next-of-kin and cannot be considered representative for the overall care experience, but they provide important input on sources of dissatisfaction present after the intervention.

Other aspects related to higher satisfaction include less severe psychotic symptoms (Vermeulen, Schirmbeck, van Tricht, de Haan, & investigators, 2018) and higher illness insight (Bø et al., 2016). There was no difference between our samples regarding severity of psychotic symptoms as measured by the RSS (Opler et al., 2007). Insight is assessed in one of RSS items and thus included in the overall assessment. Involuntary admission has repeatedly been related to lower satisfaction in both psychosis and general psychiatric inpatient settings (Bø et al., 2016; Strauss et al., 2013; Svensson & Hansson, 1994) along with experienced or perceived coercion (Katsakou et al., 2010; Strauss et al., 2013; Woodward, Berry, & Bucci, 2017). Proportions with involuntarily admittance did not differ in the two samples but there was no measure of coercive procedures (such as forced medication, restraint or seclusion) or perceived coercion.

SDM has been shown to be a predictor of patient satisfaction across medical (non-psychiatric), psychiatric, and psychosis settings (Adams & Drake, 2006) (Malm et al., 2003; Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007), including psychosis inpatient care (Hamann et al., 2020). As described previously staff worked by several means to involve patients in decision-making but some patients still described being left out of decision-making. The increased satisfaction, if related to PCPC, but unchanged empowerment might be explained by a component in SDM that has also been related to satisfaction, namely the staff-patient relationship. Better therapeutic relationship has been suggested a predictor for satisfaction (Kim, Kim, & Boren, 2008; Middelboe et al., 2001) and shown to have a strong association with satisfaction (Miglietta et al., 2018; Sweeney et al., 2014). Building relations is a central feature of PCC and **Study III** shows how staff worked on relationships with the patients in several ways, from adopting an open approach with small talk in the corridor and assisting with everyday tasks to improve routines for formal talks between contact persons (or psychiatrist) and the patients. Although not explicitly describing relationships, participants in **Study IV** were generally satisfied with staffs' approach in the sense that they were perceived as kind and nice.

Prolonged length of hospital stay

The prolonged LoS found post-intervention (**Study II**) was contrary to our hypothesis as well as findings of reduced duration in non-psychiatric inpatient settings (Ekman et al., 2012; Olsson, Karlsson, Berg, Kärrholm, & Hansson, 2014). The previous studies had a greater focus on discharge planning than our study which is one possible explanation for the different findings. The processes of recovery and discharge might also differ between medical wards and the psychosis wards, with longer and less structured processes in the latter. Previous studies show that LoS is multifactorial. Patients' symptom severity, duration of untreated psychosis (Ajnakina et al., 2020; Piccinelli, Bortolaso, Bolla, & Cioffi, 2016), involuntary admission status and social or cognitive functioning (Beck et al., 2016), or medical comorbidity (Douzenis et al., 2012; Rodrigues-Silva & Ribeiro, 2020) all contribute. These factors are mainly beyond the scope of our intervention and while we can be sure they impacted on the LoS we have no measure of how much they affected the difference between the samples. The findings of longer LoS could however in part be an effect of PCPC implementation. Participants in **Study III** described that PCC is about seeing the needs of each individual, and they expressed further that many unmet needs became apparent when they listened to the patients' own narratives. Acknowledging these unmet needs could result in prolonged LoS when staff would work with the patient to attend to those needs. **Study IV** touches on this aspect briefly as some statements reflected that the ward had too few beds and next-of-kin wished that patients had the opportunity to stay longer. Another way in which PCC might contribute to prolonged LoS is through SDM. SDM can result in delayed initiation of treatment or changes in psychotropic medication, both of which are associated with prolonged LoS (Nielsen, Milting, Brandt-Christensen, & Ebdrup, 2020). The qualitative data (**Study III** and **IV**) gives a mixed picture of how much SDM actually occurred.

Failure to reduce involuntary care

Our hypothesis regarding LoIS was also contradicted as LoIS was longer in the post-intervention sample (**Study II**). As ~80% of all consumed hospital days, across both samples, were involuntary, and involuntary admission is one factor prolonging LoS, these two outcomes, and the understanding of them, are highly overlapping. There are few studies reporting on LoIS or causes for prolonged LoIS (Iversen, Høyer, & Sexton, 2009). The one study reporting on LoIS in a psychosis setting found no difference in LoIS (or coercion) between hospitalized patients with psychosis who attended an ACT team or a regular outpatient service (Øhlenschlæger et al., 2008). From previous studies we know several factors that predict involuntary admission, which might also influence LoIS. Lack of insight, lack of treatment adherence, previous involuntary admission, no relationship or job, and being dependent on social welfare were identified in a recent review (Walker et al., 2019). The listed factors indicate complex health situations and unsuccessful health care partnerships which suggests that this group might warrant comprehensive efforts to gain from PCC as it might take time to establish partnerships and there are many health care needs to attend to. Again, we do not know how much these factors contribute to the differences between samples, but it is possible that the post-intervention sample included more patients with such complexity. There are no statements from **Study III** or **IV** that specifically address the duration of involuntary care.

The ratio of involuntary care/hospitalization episode was marginally, and not significantly, lower post-intervention. Even if more complex or more severely ill patients account for the prolonged care episodes, why did the ratio not decrease? One explanation might be that psychiatrists were already ending involuntary care as soon as possible, so that there was no room for improvement. Should that not be the case, and there in fact is room for earlier ending of involuntary care, which Iversen et al. (2009) suggest, then the intervention was unsuccessful in doing so. It could have failed impact on patients' ability to recover faster and be able to partner up. It could also have failed to reach psychiatrist views on when a patient should be released from the involuntary care (in favor for voluntary inpatient care) or their ability to form such trusting relationships that earlier ending was perceived as safe.

Psychiatrists were involved in the PCPC educational intervention, and some statements referred by psychiatrists in **Study III** suggest a high degree of person-centered thinking. However, there was evidence of limited uptake of PCC among psychiatrists in general in both **Study III** and **Study IV**. Skepticism towards PCC and unwillingness to engage by physicians have been reported in previous studies (Naldemirci et al., 2017). Turn-over among the psychiatrists might contribute to disengagement. Another reason could be the organization of psychiatrists as separate from the ward staff. This means that psychiatrists are not organized to attend weekly meetings regarding workplace issues, and thereby less involved in the everyday change projects in PCPC.

Experiencing PCPC

The result of **Study III** suggested a good uptake of PCC into staffs' thinking and actions, with concrete examples of changes related to increased person-centeredness in everyday care on the wards, changes that could improve conditions for both patients and staff. Several participants described a more positive and fun work situation, along with smoother workflow, aligning with previous findings of improvements in staff satisfaction and perception of work quality in previous studies (Cook, Phillips, & Sadler, 2005; Ross, Tod, & Clarke, 2015). Participants in **Study III** related such changes to improved contact with patients. Being more engaged in patients was also related to the job becoming more fun, but for some it took an emotional toll, which has been shown also in non-psychiatric settings (Fridberg et al., 2021), leading to exhaustion and disappointment on behalf of the patient. Patients were described as being more grateful, hopeful and calm following the intervention, but also more engaged and demanded to receive proper information. Participants also related these outcomes to better contact between patients and staff, with staff making efforts and changing routines to for example, give patients opportunity to have questions answered, being listened to and de-escalating potentially dangerous situations.

Overall **Study IV** gives several examples of truly person-centered and health promoting encounters, along with examples of situations very far from PCC. Participants describe staff having a nice approach, and there were examples of patients and next-of-kin being recognized as individual human beings, being updated with information and invited to participate, and staff taking responsibility for decisions when needed. These examples align with the descriptions from staff in **Study III** and are all attributes of PCC (Håkansson Eklund et al., 2019). On the other hand, there were many examples of both patients and next-of-kin who experienced that they were not involved in decision-making, not being believed or trusted as sources of information, and being subjected to coercive or demeaning communication. Such experiences align instead with the repressive care PCC was meant to overcome (Staniszewska et al., 2019). Some participants' experiences of ward atmosphere (aggressive atmosphere, disturbing behavior of fellow patients) also nuanced the image of an improved care environment described by staff in **Study III**. Experiences of involuntary care were mainly negatively reflected with comparisons to punishment or imprisonment, indicating that patients and staff did not find a common understanding. Negative experiences involving medication included examples of patients or next-of-kin not having a say in decisions and not being believed regarding side-effects. These examples suggest that a patriarchal care structure remains and contribute to shed light on the epistemic injustice[12] persons with psychosis might face (Carel & Kidd, 2014; Sanati & Kyratsous, 2015). I believe this is an important aspect that needs further clinical attention. If staff take interpretative precedence, unaware of such prejudice, PCC will be seriously hampered, reducing potential for SDM and improved empowerment.

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[12] Epistemic injustice refers to the wrongdoing towards a person in his/her capacity as a knower as described by Miranda Fricker (2007). Fricker goes on to describe two types of epistemic injustice. Testimonial injustice occurs when a person's testimony is given less credibility due to prejudice. Hermeneutical injustice has to do with a collective interpretative void which put the person at disadvantage when trying to understand/explain a certain situation. In the psychosis setting patients might not be trusted due to prejudice concerning their capacity (testimonial injustice), and they may lack vocabulary to express experiences as patients suffering from psychosis have had few arenas to reflect and develop common language and understandings (hermeneutical injustice).

Facilitators and barriers for PCC

The description of facilitators and barriers are of specific interest when trying to understand how PCC can be implemented in the psychosis inpatient setting. In **Study III** staff explicitly describe such features, and in both qualitative studies statements touched upon potential facilitators or barriers described in previous research.

The complexity of the concept PCC was perceived by staff as a barrier for implementation; it led to a heterogenic understanding of what PCC meant and how it could translate into practice. Similar findings are reported from a range of settings (Fridberg et al., 2021; Naldemirci et al., 2017). Fridberg et al. (2021) discuss how not understanding an innovation hampers the ability to implement it. The participatory approach with the creation of many change projects might further have added to heterogenic understanding as well as the different levels of engagement reported in **Study III.** Similar findings have been reported from participatory approaches to PCC previously (Fridberg et al., 2021; Vikström et al., 2015). Staff not wanting to adopt a more person-centered way hampered the implementation, and psychiatrists not cooperating or engaging was considered especially problematic. Psychiatrists were identified as having the most power by participants in **Study IV,** as in previous studies of psychosis care environments (Stock, 2021). Having a powerful position and not engaging to reform the care practice could seriously hamper the success of the implementation. The power structure built around physicians has been identified as difficult to change in diverse medical settings (Moore et al., 2017; Naldemirci et al., 2017), and a special focus on psychiatrists might be warranted in future interventions.

Constraints in time and resources are commonly reported barriers for PCC implementation (Fridberg et al., 2021; Moore et al., 2017), and **Study III** described how everyday practice took precedence over change work, affected also by staff turnover. Additional resources might be needed during an implementation phase to assist staff.

The physical environment as described in **Study IV** is to be considered a barrier as it failed to assure personal privacy, feelings of safety, and spaces for private conversations or visits. Lack of private spaces have been put forward as a barrier for building relationships in medical settings (Moore et al., 2017), and a safe environment is considered important for recovery (Muir-Cochrane, Oster, Grotto, Gerace, & Jones, 2013; Schroder, Wilde Larsson, & Ahlstrom, 2007). Staff made no mention of the physical environment in **Study III**, and the projects initiated in connection with the PCC intervention was not focused on improving the physical aspects of the environment. A critical revision focusing on the physical environment involving patients and next-of-kin might be an important prerequisite for such change.

The starting point for PCC is the narrative and **Study III** participants pinpointed the conversation with patients as the outset. Disturbances in communication is a previously recognized barrier (Fridberg et al., 2021), including the use of interpreters. Results in **Study III** suggested that good communication was complicated when interpreters were needed. Having staff knowledgeable in different languages is thus a potential facilitator to manage good communication. While staff (**Study III)** did not experience that psychosis per se was a hinder for PCC, statements in **Study IV** elucidate that when having acute psychosis, it can be difficult to receive information, and having a dialogue is complicated. This is important to acknowledge as an initial barrier for establishing a partnership. Staff at the inpatient wards are experienced regarding these difficulties and reflections in **Study III** suggested that (some) staff worked to overcome such initial difficulties by continuously trying to involve patients throughout the care episode.

Some of the formal supportive features in PCPC were explicitly described as facilitators by staff, aligning with suggestions from previous implementations (Britten et al., 2020). The appraisal of the PCPC resource person, the steering group, and the care plan monitoring aligns with previous findings suggesting a need to provide practical support, continuous supervision and feedback to facilitate sustainable PCC (Chenoweth et al., 2015; Kirkley et al., 2011).

During the implementation phase of PCPC, the initial work on various change projects shifted to mainly focus on establishing a routine for co-creating a care plan with patients. This united focus on a practical feature, i.e. the care plan, was considered a facilitator in **Study III**. This highlights the trade-off to be made between a more structured routine-based implementation, with risks of losing the underpinning philosophy of PCC (O'Donovan, 2007), and an emphasis on the PCC principles as guidance for a practice, with risks of being ambiguous and difficult to translate into unified practice.

The contact person could be considered a facilitator, based on the statements in **Study IV**; both patients and next-of-kin related that having a specified staff member they could turn to helped them to feel comfortable. The most important thing for the contact person was according to participants not to have all the answers but to be someone who cares. From a staff perspective the contact person is the primary initiator of the partnership. PCPC ward projects involved routines to ensure conditions for listening to the patient's narrative upon admittance and to stimulate conversations between the contact person and the patient throughout the care episode. The contact person thus has an important role with potential of defining the partnership. Previous studies on person-centered care in community mental health settings suggest that a strong therapeutical relationship is a prerequisite for a person-centered care planning, and that such a relationship needs calibrating, continuity and involve a real connection (Hamovitch, Choy-Brown, & Stanhope, 2018). Further, without these attributes of the relationship participants might not bother to engage. The contact person could thus be a gatekeeper for patients' engagement in the PCC process. Practicing person-centered care planning was also found to facilitate the therapeutical relationship, suggesting that the practical and relational aspects of PCC are intertwined (Hamovitch et al., 2018). Some hindrances for building a relation with the contact person were described in **Study IV**. One pertained to scheduling; contact persons were not always available when needed. There were also relational aspects; the appointed staff member might not match the patient (personal chemistry), or might not be actively pursuing the contact person tasks resulting in patients not knowing who their appointed contact person was. Supporting staff in their roles as contact persons might constitute an essential element in the development towards a more systematic delivery of PCC.

CONCLUSIONS

This thesis contributes to the understanding of how PCC can be incorporated in inpatient psychosis care and what outcomes it might achieve by showing that a participatory educational intervention for staff was overall well received by staff (**Study III**), potentially improved patients' satisfaction with care, but was not related to an increased level of patient empowerment (**Study I**). It might have contributed to prolonged hospitalization episodes but could not be related to reduced proportion of involuntary care days (**Study II**). Patient and next-of-kin narratives suggested emerging person-centeredness, but the biomedical orientation and hierarchal organization of care remained evident (**Study IV**).

The discussion of these findings suggests that while PCPC was successful in enhancing person-centered thinking and actions in staff, not all were committed to the project and organizational or practical features obstructed implementation. The findings in **Study I, II** and **IV** might be explained by such insufficient implementation.

Facilitators and barriers align with reports from other settings, suggesting that the psychosis inpatient setting faces challenges similar to those of other medical specialties, including difficult-to-change hierarchies and implementation-related factors. The epistemic injustice potentially affecting patients with psychosis is however an important area for clinicians to acknowledge along with the communicative difficulties in acute psychosis.

FUTURE DIRECTIONS

PCC needs to be further explored within psychosis inpatient settings, especially focusing on how staffs' understanding, attitudes and practical work can be more systematically embedded into the care. This should involve all mental health professionals. Our findings point to specific hinders and organizational barriers which could be addressed in future studies. A specific feature for the acute psychosis care that needs further studying is the tension between patients' need to be acknowledged as worthy partners and staff members' struggle to see patients capability also during psychotic states.

Length of involuntary care in the context of PCC interventions is largely unexplored. Its role in perceived coercion, impact on therapeutic relations and the building of partnerships needs to be addressed along with its impact on long-term outcomes.

Despite the discussed difficulties in adopting robust research methods in complex interventions in real-life settings, such research is much needed to provide evidence of efficacy and effectiveness to guide future implementation of PCC. Patient involvement is further warranted to ensure that interventions and measures are directed towards relevant endpoints.

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